Autism, Aging, and Dementia:
A Consensus Report of the Autism/Dementia Work Group of the 2nd International Summit on Intellectual Disabilities and Dementia

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INTERNATIONAL SUMMIT II
ON INTELLECTUAL DISABILITY & DEMENTIA

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

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 Autism/Dementia Work Group include:

*(1) There is limited information available regarding the **demographics** and 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 (GI) 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 cases.*

*(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 revealed nuance. While their mean age at death closely mirrors that of the general population, exceptions exist for those 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 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 between 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 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 well-being, 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 and 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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Autism, Aging, and Dementia

1.0 Introduction

The aim of this report is to synthesize what is known about the nature of autism[1] (or 'autism spectrum disorder') and inherent later-age neuropathologies, such as dementia, and to explore the genesis of such neuropathologies and their effects on the lifespan and lived experience of older adults with autism. This stems from discussions undertaken prior to, during, and after the 2nd International Summit on Intellectual Disability and Dementia, held in Toronto, Canada, on October 24-25, 2023. One of the topics considered at the Summit regarded autism and the participants queried whether autism posed risk for any specific form of neurodegenerative disorder expressed as dementia, whether dementia expression in autistic adults was out-of-norm from the general population, and whether its expression was distinct from other neurodiverse or neuroatypical conditions. In this report, we use an international perspective, cover contributory information on aging, and consider factors that may have bearing on whether there is distinctness with respect to the risk and occurrence of dementia associated with autism.

A word about the literature related to autism and associated conditions. How research is done and who is researched is evolving with respect to autism. Earlier studies generally included more narrow definitions of autism as well as focused primarily, if not exclusively, on childhood. More recent work has broadly included various aspects of the spectrum, expanded to examine lifespan issues, and moved away from focusing more narrowly on autistic adults with co-occurring intellectual disability (ID). When attempting to examine the situations of aging autistic adults, we acknowledged that complications of life experiences must be considered in addition to the degree that autistic features have migrated from or to other forms of behavioral neurodivergence.

When examining the associations with aging-associated dementia, the co-occurrence of ID, epilepsy, other health conditions, and the cascading effects of medication, must all be considered. The life opportunities and lived experiences of adults (i.e., schooling, living arrangements, employment experiences, availability of support), as well as the adverse effects of social isolation and systemic discrimination over a lifetime should be considered. Therefore, who we consider autistic (earlier studies have focused on a group with higher rates of co-occurring conditions that are associated with dementia) and how their brain health is related to their environments and opportunities, is very much evolving. What we see now or what we saw in earlier research is impacted by various cohort effects. We also need to be cognizant of what research tells us about when and what population was studied. What was the prevailing characteristic and of what aspect of autism is it representative? Also, needing consideration is that the data may not reflect what will happen to autistic people growing up now, who are not yet older or of other cohort effects. This includes where the study was undertaken, what was the prevailing attitude toward autism, what educational opportunities were available, what social and financial supports were available, and how did autistic adults view themselves. Also, a consideration is a transition on how autism was (and is now) diagnosed, who is diagnosed, and who is diagnosing, also

[1] Terminology used to describe autism has varied. Two distinct perspectives included "person-first "language (e.g., "adult with autism") versus "identity-first "language (e.g., "autistic adult") (Canadian Academy of Health Sciences, 2020; Edelson et al., 2021). Supporters of person-first language feel that it is important to emphasize the person rather than the disorder or disability, and promote the use of terms such as, "person with autism" or "a person with ASD." Surveys in Australia (Bury et al., 2023), the Netherlands (Buijsman et al., 2023), and the United Kingdom (Keating et al., 2023) have supported language preferences depending upon the autism-related stakeholder group. In one study, Taboas et al. (2023), surveyed autism stakeholders in the United States and overwhelmingly autistic adults preferred identity-first language terms to refer to themselves or others with autism. Professionals and academics who work with the autism community tended to support and use person-first language. There are other terms in different languages in which self-definition, professionals and community terminology also vary. In this report, the term 'autism' is employed to be equivalent to 'autism spectrum disorders' (which include autism, Asperger's syndrome, and atypical autism or pervasive developmental disorder not otherwise specified, Rett's syndrome, and Heller syndrome). In this report, we have opted to use identity-first language.

makes summarizing research challenging. Lastly, we recognize the diversity of adults affected by autism, its degrees of impact, and confluence with other neurodevelopmental conditions.

In preparing this report, we drew from a broad range of studies and other sources, not all of which were explicit as to the factors noted above. We have tried to note the context of the studies, but also recognize that without standardization it is often impossible to extract such factors. Thus, what we present is an amalgamation of work reporting certain factors which may (or may not) lead us to better understand the possible relationship of autism and aging-associated dementia. We also recognize that the life situations of autistic adults may vary considerably and may be determined or influenced by co-occurring conditions. It is our intent to present what the literature and clinical practice offers and where appropriate draw conclusions, and if uncertainty prevails, offer what is known and leave the outcomes to interpretation.

This report is parsed into two main areas, beginning with an introductory segment that includes fundamentals on definitional issues, prevalence and occurrence, the hypothetical basis of gut health and autism, a summary of previous efforts at synthesis, and an analytic segment, in which we examine various potential contributions to aging-related neuropathologies, such as dementia, in autistic adults. This latter segment also contains commentary on peri- and post-diagnostic supports. We conclude with a commentary and recommendations for further queries and actions. In this report, we take a worldwide perspective and examine work emanating from many countries.

1.1 Autism

The National Institute for Health and Care Excellence (NICE, 2021) describes autism as a lifelong neurodevelopmental condition, with core features including persistent difficulties in social interaction and communication, as well as the presence of stereotypic (rigid and repetitive) behaviors, resistance to change, or restricted interests. While the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; APA, 2015) classifies autism as a disorder, many autistic people prefer terms such as neurological "difference" or "condition" to remove the negative associations with the word "disorder" (Canadian Academy of Health Sciences, 2022). In the United Kingdom, the Guideline Development Group (2012) recognized that different individuals and groups prefer various terms for autism, including autistic spectrum condition, autistic spectrum difference, and neurodiversity. These preferences are reflected in government documents.

Autism is a spectrum. This implies that while all individuals on the spectrum will encounter some of the differences mentioned above, the extent to which each autistic person experiences these differences and the level of support they require will vary. Autism may manifest in individuals in diverse ways at different life stages, often alongside coexisting conditions such as intellectual disability. The features of autism can range from mild to severe and may fluctuate over time or in response to changes in circumstances. Much remains unknown, specifically regarding the aging of individuals with autism, their health outcomes, and factors that might mitigate lifelong neurodiversity (Perkins & Berkman, 2012). Although research on brain changes with age has been limited, a small comparative study demonstrated structural changes, revealing reduced bilateral hippocampal volumes in middle-aged autistic adults (Braden et al., 2017). Another study indicated that autistic adults displayed age-related cortical thinning, most significantly in the left temporal lobe (Braden et al., 2019). However, there is limited information on brain changes in older autistic individuals. Mortality rates seem to be elevated 2- to 5-fold in studies involving middle-aged adult samples, with most deaths associated with epilepsy or accidents (Gillberg et al., 2010). Premature mortality is also markedly increased due to various medical conditions (Hirvikoski et al., 2016). It remains unclear whether being autistic is a risk or if premature mortality is better accounted for by the presence of co-occurring conditions such as epilepsy, intellectual disability (Happe & Charlton, 2010), or mental health issues (Newell et al., 2023), along with inequitable healthcare. Nevertheless, autism is believed to be a complex, neurobiologically determined, and heterogenous neurodevelopmental disorder (Murphy et al., 2016).

1.2 Prevalence

Globally, Salari et al. (2022) using a systematic review and meta-analysis of some 74 studies (N= 30,212,757 participants) reported that the earlier age (<27) worldwide prevalence of autism was 0.6% (95% confidence interval: 0.4–1%). Regional analyses indicated that the prevalence of autism in Asia, America, Europe, Africa, and Australia was 0.4% (95% CI: 0.1–1), 1% (95% CI: 0.8–1.1), 0.5% (95% CI: 0.2–1), 1% (95% CI: 0.3–3.1), 1.7% (95% CI: 0.5–6.1), respectively. No data were included on adults past their late twenties. In another global review, Zeidan et al. (2022) synthesized estimates of the prevalence of autism worldwide and noted a global autism prevalence that ranges within and across regions, with a median prevalence of 100/10,000 (range: 1.09/10,000 to 436.0/10,000) or about 1%. The median male-to-female ratio was 4.2. The median percentage of autism cases with co-occurring intellectual disability was 33.0%. Lyall et al. (2017) reported estimates show that 1.5% of the population in developed countries are autistic. Elsabbagh et al. (2012) in their review reported that the median prevalence estimate of autism was 62/10,000 and reported the limitations and reliability of existing data sets, particularly those from low-income countries.

In the U.S., Dietz et al. (2020), utilizing a statistical model based on estimates of children, estimated that the national prevalence of adults aged 18–84 years living with autism was approximately 2.21% (95% simulation interval 1.95%, 2.45%), equating to around 5.4 million adults. They also highlighted that exact figures for national and state populations of adults living with autism in the U.S. are unavailable due to the absence of surveillance systems. Sacco et al. (2022) reported that European member state estimates, primarily drawn from younger age individuals with autism, were 0.8% based on register-based studies and 1.4% based on population. They observed that there is still a gap in research and awareness regarding autistic adults, and many teenagers and adults remain undiagnosed, suggesting a potential underestimation of prevalence among older age groups. Estimates for the United Kingdom provided by O'Nions et al. (2023) indicate that rates of diagnosed autism in children/young people were much higher than in adults/older adults. They found that only 0.02% of adults aged 70+ (1 in 6000) were diagnosed compared to 2.94% of 10- to 14-year-olds (1 in 34). Age-related inequalities were evident in new diagnoses (incidence): approximately 1 in 250 5- to 9-year-olds had a newly recorded autism diagnosis in 2018, vs. approximately 1 in 4000 20- to 49-year-olds, and approximately 1 in 18,000 people aged 50+. Liu et al. (2023) merged the Swedish Total Population Register and the National Patient Register of some 4.2 million adults aged 35+ and found 5,291 middle-age and older autistic adults, accounting for 0.001% of the 35+ population.

In Canada, it was estimated that 1.5% (or one in 66) children and youth aged 5-17 years had a diagnosis of autism based on administrative data derived in 2015 from six provinces and one territory (Public Health Agency of Canada, 2018). The estimated prevalence ranged between 0.8% and 1.8% across jurisdictions. Autism was four times more prevalent among males than females. Jurisdictions that tracked prevalence of autism over time, found an increase of three to four-fold among children 5-14 years of age between 2003 and 2015. Loomes et al. (2017) undertook a meta-analysis of prevalence studies of autistic children undertaken in the United Kingdom and found that the true male-to-female ratio is not 4:1, as is often assumed; but closer to 3:1. The authors posited that there appears to be a diagnostic sex bias, meaning that girls who meet criteria for autism are at disproportionate risk of not receiving a clinical diagnosis.

A more recent estimate of autism prevalence among Canadian children aged 1-17 years is 2.0% (one in 50) ranging from 0.8% to 4.1% across jurisdictions (Public Health Agency of Canada, 2022). This estimate is based on data from a pan-Canadian survey completed by parents. The prevalence of autism varied by age, and it was the highest at 2.5% among children 5-11 years of age. Among autistic children, there were almost four times more boys than girls (a sex ratio of 3.9). The survey did not include adults, so currently, there is no estimate of autism prevalence among Canadian adults at the national level.

As noted by O'Nions et al. (2023), imperfections in domestic datasets and "substantial age-related differences in the proportions of people diagnosed suggest an urgent need to improve access to adult autism diagnostic services." An Irish survey of unhoused adults, conducted by Boilson et al. (2023), highlighted a substantial number of autistic adults without stable housing, potentially contributing to undercounts of prevalence for adults. This issue was also addressed in a UK study (Churchard et al. , 2019) and by Brugha et al. (2011), who observed that autistic adults "living in the community are socially disadvantaged and tend to be unrecognized." In the U.S., Zahorodny et al. (2023) conducted a prevalence investigation of teenagers with autism and concluded that approximately 25% of the potential population were undiagnosed, further supporting the belief of a gross undercount among aging autistic adults.

While estimates providing an indication of the prevalence of autism exist in most populations, these estimates are predominantly based on studies and analyses involving younger individuals. Little to no prevalence studies exist that offer a sound indication of the epidemiology of adults diagnosed with autism. As reported by Gerhardt and Lainer (2011), approximately 70% of currently identified individuals with autism are less than 14 years old. The rationale for variations by age includes a greater focus on diagnosis at a younger age (due to early recognition and documentation for special education services), increased integration within the workforce among post-school age adults, adverse longevity factors (mortality), and a lack of diagnostic urgency in older age. Also, noteworthy is the finding of Shaw et al. (2022) that there are early identification disparities due to ethnicity, such that in the U.S. African-heritage and Spanish-language heritage children without ID were less likely to be identified with autism than were European-heritage children. All these factors may influence prevalence determinations with increasing age. Piven et al. (2011) have projected that by 2030 there will be approximately 700,000 older autistic adults with a formal diagnosis in the U.S..

A factor to consider when defining the nature and extent of the older population of autistic adults (and projecting the potential expression of dementia) is the lived experience of adults born prior to or proximate to the midpoint of the 20th century. As Krantz et al. (2023) have aptly noted, these autistic adults were born before autism was recognized as an official diagnosis in the various diagnostic manuals (e.g., the 1980 Diagnostic and Statistical Manual III; DSM-III) and interventions and behavioral therapies were available for autistic individuals.[2] It is likely, therefore, that many current older adults were not beneficiaries of special attention and services, and exposure to special education efforts, all of which may have shaped their developmental and aging trajectory. This life situation may also affect any efforts to assess prevalence of autism in older age groups from this generation (Brugha et al., 2011). Krantz et al. cautioned that current older autistic adults with concurrent conditions, that may have been shaped by various aging-related neurological factors and potentially influence rates of dementia observed in this age group, may not auger what younger-older adults and children in current and subsequent generations may experience as life and health trajectories and consequently shape their social and biological aging.

> ***In summary***, little formative information is available on the demographics and older age factors of autistic adults. Those available are mainly prevalence studies on cognitive decline. Estimates of aging population vary but are mostly extensions of estimates of epidemiological studies of individuals in early age or school age populations. What is known is that autism is found in about 2% of adults, with an approximate 3:1 ratio of males to females with aging, and inherent differential prevalence is not associated with 'race' or ethnicity. Therefore, this prevalence highlights that during the transition to aging, the lifetime experience of autism may play a role in veiled and perhaps early symptoms of

[2] For a trajectory of the diagnostics associated with autism and its implications, see: IACC (2023). IACC Statement regarding scientific, practice and policy implications of changes in the diagnostic criteria for autism spectrum disorder. https://iacc.hhs.gov/publications/general/2014/statement-changes-in-diagnostic-criteria.shtml

mild neurocognitive disorders and dementia, emphasizing the need to offer treatment for this population. The available literature may not distinguish aging, autism, and comorbidities such as intellectual disability, which could determine whether certain groups could have an increased risk for cognitive decline. These groups may not have been scrutinized in epidemiological studies of intellectual disability cohorts. The expression of the population of autistic adults is pyramidal, with the bulk within the early three decades and then progressively lessening with middle-age and what would be considered the retirement-age populations. This lessening effect appears to be due to a variable 'moderating' of certain symptoms, earlier mortality, minimal clinical contacts, diagnostic uncertainties, societal blending, and difficulties with ascertainment.

1.3 Nutrition, Microbiota, and Gut Health in Autism

This section is included as contemporary work is making significant advances on examining the relationship of gut issues and autism, and we are interested in determining whether any of these issues might show a relationship to cognitive impairment in later age and possible transition to dementia (Panpalli Ates & Yilmaz Can, 2020; Zhou et al., 2021). Autism originally was thought to be a static, inheritable neurodevelopmental disorder. However, research now indicates that the etiology of autism arises from a complex interaction between genetic susceptibility and environmental exposures (Frye et al., 2019). One theory is that a dynamic system of metabolic and immune anomalies involving many organ systems, including the brain, and environmental exposure may influence the neurology behind the brain in autism. The initial detailed observation and inquiry of autistic adults and related conditions and the histories of their caregivers and families pointed to connections between the gut and some cases of autism. Although the mechanism of the connections is not clear yet, many autistic adults have a history of previous antibiotic exposure or hospitalization, GI symptoms, abnormal food cravings, and unique intestinal bacterial populations. These factors have been proposed to relate to variable symptom severity (MacFabe, 2013).

GI symptoms (including constipation, diarrhea, recurrent abdominal pain/bloating and gastroesophageal reflux) are frequent among autistic adults, who often present alterations in intestinal motility and dysfunction of the epithelial barrier ("leaky gut") (Dargenio et al., 2023). Holingue et al. (2018) examined the rate of such GI issues among autistic adults via a review of numerous studies. They found that the prevalence range for constipation was 4.3-45.5% (median 22%), for diarrhea 2.3-75.6% (median 13.0%), and for any or more than one symptom 4.2-96.8% (median 46.8%). GI symptoms were found to differ significantly by age of individuals, primary goal of study, study design, study sample, and who reported symptoms ($p<0.05$). They reported the difficulties experienced by workers in obtaining valid data due to various methodological challenges, including age of subjects, primary goal of study, study design, study sample, and who reported symptoms.

With the rapid growth of microbiome research during the last fifteen years (Clavell et al., 2022), more studies were conducted to better understand the role of the gut macrobiota[3] (Hou et al., 2022) in health and in disorders such as autism that show symptoms of gut microbiota dysbiosis or imbalance. The gut microbiome's link to psychiatric disorders including autism has been studied (Bastiaanssen et al., 2019). Research also included factors that affect the microbiome (individual factors beginning in the womb and environmental factors). Besides the gene, factors include diet and other lifestyle behaviors (smoking and alcohol), delivery

[3] The *macrobiota* is defined as the macroscopic living organisms of an area. The *microbiome* is the collection of all microbes, such as bacteria, fungi, viruses, and their genes, that naturally live on our bodies and inside us. The human microbiota consists of the 10-100 trillion symbiotic microbial cells harbored by each person, primarily bacteria in the gut; the human microbiome consists of the genes these cells harbor [see: Hou et al., (2022). Microbiota in health and diseases. *Signal Transduction and Targeted Therapy*, 7, 135. https://doi.org/10.1038/ s41392-022-00974-4; Turnbaugh et al., (2007). The human microbiome project. *Nature,* 449(7164), 804-810. doi: 10.1038/nature06244.]

method, sex, race, stress, medications (antibiotics and psychotropics), illnesses, nutritional status, and inflammation (Bastiaanssen et al., 2019; Srikantha & Mohajeri, 2019). Interventions to help the gut microbiome include probiotics, prebiotics, synbiotics, and fecal transplant (Abdellatif et al., 2020; Bastiaanssen et al., 2019). Studies on dysbiosis and gut-related symptoms in autism focus more on children than on adults. Understanding the etiology and pathology in childhood contributes to quality of life throughout the life course. When the disorder has no satisfactory or effective treatment available (such as in autism), avoiding symptom triggers. mitigating symptoms, and providing holistic person-centered care are realistic goals.

The complex partnership of the gut microbiota with the host at the endocrine, neural, immune, and metabolic levels has received greater attention in relation to health and diseases (Watson, 2023). Evidence shows that alteration in level of gut microbes and their metabolites are not only linked to GI problems but also to autism (Mehra et al., 2022). The co-occurring GI problems that many children with autism experience point to a possible link between the gut microbiome and autism. A wide range of GI symptoms are found in these children, such as constipation, diarrhea, bloating, abdominal pain, reflux, vomiting, gaseousness, foul smelling stools, and food allergies (Alharthi et al., 2022; Alhazmi et al. 2019; Wasilewska & Klukowski, 2015). Some researchers use the gut-brain axis (GBA) to understand the interplay between the gut and the brain in the causes and symptoms of autism. GBA indicates the reciprocal relationship between the central nervous system and GI system, including the intestinal nervous system (Lewandowska-Pietruszka et al., 2023).

The gut and the brain cross talk and influence each other. The communication system ensures the proper maintenance of GI homeostasis and may have multiple effects on affect, motivation, and higher cognitive functions (Carabotti et al., 2015). Signals from gut-microbiota to brain and from brain to gut-microbiota go by means of neural, endocrine, immune, and humoral pathways. In clinical practice, evidence of microbiota-GBA interactions comes from the association of dysbiosis with central nervous system (CNS) disorders (i.e., autism, anxiety-depressive behaviors) and functional GI disorders such as irritable bowel syndrome (Carabotti et al., 2015). Metabolites and molecules such as short chain fatty acids (SCFAs) (acetate, propionate, and butyrate) and neurotransmitters (serotonin, and gamma amino butyric acid or GABA) produced along the metabolic pathways affect the CNS and the brain. The colonic macrobiota digests the non-digestible carbohydrate such as dietary fiber, forming the SCFAs which are fuel sources and can regulate motility, secretion, and gut-brain signaling (Margolis et al., 2021).

A systematic review by Srikantha and Mohajeri (2019) reviewed several epidemiological, and experimental human and in vivo studies for the involvement of different microbes in the autism pathology, such as *clostridia* spp. That is, the correlation between changes in distinct bacterial populations and several bacterial metabolites, and the behavioral changes related to autism warrant further investigations. The authors noted that elevated abundance of Clostridium spp in autistic individuals correlated with the severity of autistic behavior. The mechanism via the gut brain axis needs to be clarified (Srikantha & Mohajeri, 2019). A good concept to remember is that the diversity of the microbes is important as it improves their ability to stop pathogens. Using an ecological approach in their study, Spragge et al. (2023) concluded that ecological diversity, as well as community, is important for colonization resistance (Spragge et al., 2023). Thus, examining the effects and potential applications of the gut microbiota on autism pathology and symptom alleviation and GBA should be in the context of the macrobiota composition, their community, and ecology.

A comprehensive systematic review of the current studies on gut macrobiota and autism (Lewandowska-Pietruszka et al., 2023) concluded that the altered composition of the gut microbiota in children with autism and its correlation with GI symptoms and core behavioral characteristics need further investigation. Interventions, particularly probiotics and microbiota transfer therapy, show promise in ameliorating both the GI and behavioral symptoms. Targeting the gut microbiome could be a viable avenue to improve the quality of life of individuals with autism over their lifespan. However, their specific mechanisms of action and long-term

effects should be further studied. Limitations include variability in methodologies, study populations, and interventions, small sample sizes, and the lack of standardized protocols. Thus, definitive conclusions or universal recommendations cannot be established at this time. It does mean that the field needs large-scale, controlled studies to confirm the potential benefits of microbiota-based interventions for individuals with autism.

That said, questions still arise as to the relationship of GI issues and potentially declining cognitive health with aging. Dicks and Hurn (2021) reported that the gut microbiome is diverse, ever changing and highly responsive to external stimuli. Thus, research may not fully decipher the connection between gut microbiota and mental health, although some have noted a relationship (Appleton, 2018). However, better understanding of gut microbiome and the GBA, improves chances of developing new therapeutics, probiotics and psychobiotics to treat GI disorders such as inflammatory bowel disease and irritable bowel syndrome, improve cognitive functions and prevent or treat mental disorders (Dicks et al., 2021). It has been noted that disturbances along the brain-gut-microbiota axis may significantly contribute to the pathogenesis of neurodegenerative disorders, such as Alzheimer's disease (Bou Zerdan et al., 2022; Kowalski & Mulak, 2019). Alterations in the gut microbiota composition have been reported to induce increased permeability of the gut barrier and immune activation leading to systemic inflammation, which in turn may impair the blood-brain barrier and promote neuroinflammation, neural injury, and ultimately neurodegeneration (Kowalski & Mulak, 2019). Gut microbiota metabolites, including short-chain fatty acids, pro-inflammatory factors, and neurotransmitters were noted by Bou Zerdan et al. (2022) to affect Alzheimer's disease pathogenesis and associated cognitive decline potentially also. Zuou et al. (2021) concluded that Alzheimer's disease patients have gut microbiota alterations related to cognition, and differential taxa between Alzheimer's disease patients with and without neuropsychiatric symptoms (NPS) associated differently with NPS domains, which helps further understand the pathogenesis of Alzheimer's disease. However, the question remains as to whether these processes may heighten the risk for Alzheimer's disease in autistic adults?

> ***In summary,*** our evolving understanding of autism is beginning to challenge the traditional notion of this condition as being a static, inheritable neurodevelopmental disorder. Current research is exploring the complex interplay between genetic susceptibility and environmental exposures, proposing a dynamic system of metabolic and immune anomalies across organ systems, including the brain – which may influence cognitive functioning in later age. GI factors in autism, particularly antibiotic exposure, hospitalization history, and unique intestinal bacterial populations, are considerations, though the exact relationship remains unclear. Studies are beginning to reveal a prevalence range of diverse GI issues in autistic adults. Microbiome research is highlighting the gut microbiota's role in autism as well as in psychiatric disorders, reflecting the influence of factors like diet, lifestyle, and medications. The gut-brain axis emerges as a crucial focus, emphasizing bidirectional communication between the central nervous system and GI system. Individuals with autism experience a spectrum of GI symptoms (and which carry over to adults), pointing to a potential link with the gut microbiome. Comprehensive reviews underscore the promise of interventions like probiotics in ameliorating both GI and behavioral symptoms, although specific mechanisms and long-term effects still are awaiting large-scale, controlled studies to confirm the benefits of microbiota-based interventions for individuals with autism. Diverse microbial composition, its responsiveness to external stimuli, and ecological considerations underscore the complexity of the gut-brain connection, suggesting potential avenues for therapeutic development in treating GI disorders, improving cognitive functions, and potentially mitigating the onset of dementia.

1.4 Previous Collective Efforts Exploring Aging and Autism

Over the past few years, several working groups and scientific panels have convened to examine general issues associated with autistic adults and their aging (e.g., Autism Canada, 2017; Edelson et al., 2021; Janicki et al., 2008; Mason et al., 2022; Piven et al., 2011; Roestorf et al., 2019). These efforts have been complemented by academic reviews touching on the same subject (Happé & Charlton, 2012; Mukaetova-Ladinska et al., 2011; Perkins & Berkman, 2012). Some of these efforts were general and exploratory and some attempted to examine nuanced issues. For example, Mason et al. (2022) undertook a broad review of the literature on autism across the lifespan. They found that there was a 392% increase in research with autistic people since 2012, however, older adult research only accounted for 0.4% of these published studies. One prominent difficulty is the challenge in identifying papers relevant to older age autism research. However, in aggregate, these previous efforts in researching aging issues in autism showed that these endeavors are not without their difficulties, and none have produced a definitive statement on dementia and autism. Most, if not all, noted the absence of significant focal research in adult autism issues and barely raised older age neuropathologies. At the same time, on a singular level the extant research involvement in adult autism has increased, albeit very marginally.

Table 1: Reports and Key of Previous Efforts

Table on previous efforts to examine autism and aging is found in the Appendix, pages A-D.

To set a foundation and to examine what others have done prior to the 2nd International Summit on Intellectual Disability and Dementia, we have provided a summary of these various efforts in **Table 1** (see Appendix, pages A-D), noting key summative findings as to whether specific variables contribute to general aging differences among autistic adults and to what degree later-age onset neuropathologies were noted. The various groups, panels, and review authors have reported that in the realm of autism and aging, significant challenges exist due to sparse case identification, low representation of older adults in research studies, and a lack of focus on aging within the autism research community. The adverse health status and predictable trajectories of older individuals with autism remain largely unknown, but some studies of trajectories into older age have found that, for most individuals, body mass index, and prescription medication use increase throughout early adulthood. Limited information is available on the phenomenology, associated features, neurobiological changes, and specific medical, psychiatric, and social aspects related to aging in autism, as well as later life care or support issues or practices.

While there is a growing body of evidence on brain abnormalities in autism, these findings are predominantly confined to children and young adults, with practically no studies on older adults. The impact of aging processes on individuals with autism is not well-understood, and research on age-related changes in behavior, cognition, and neurobiology is scarce. The literature suggests that autism-related behavioral characteristics may vary across the lifespan, and comorbidities such as anxiety, depression, epilepsy, and ID can impact life experiences, clinical needs, cognitive and adaptive functioning, and quality of life (Overland et al., 2022). Suggested also is some effect from social determinants of health, particularly those that affect lifestyle.

These efforts have also noted that a lack of consensus exists on effective diagnostic approaches for later life assessments, referral procedures, and post-diagnostic support for autistic adults. To address these gaps, they proposed various remedies, including the initiation of prospective, longitudinal studies using both cross-sectional and longitudinal methods. Such studies, it has been generally reported, should focus on understanding typical and atypical aging in autism (given its heterogeneity) and evaluating the effectiveness of interventions for different sub-groups of older autistic adults (e.g., those with autism as a primary condition, and those with significant co-occurring conditions).

On a clinical level, the reports generally report that insufficient associated data on medical history, development, therapies, and educational backgrounds of autistic adults limit opportunities for reliable clinical and neurobiological correlations. The call for such longitudinal studies on autism and aging includes a requirement to collect biological samples and brain tissue, to parse on neurological factors that may show autism-related factors affecting brain aging. Such a bio-neurological focus would aid in gaining detailed insights into the progression of autism over the life course and to improve correlations between clinical phenotypes and neurobiological mechanisms. The current impediments to research involving brain tissue include the heterogeneity among autism spectrum disorders, differing clinical presentations, and diverse developmental trajectories.

The consensus among these reports is that the impact of aging processes on individuals with autism is not well-defined, and research on age-related changes in behavior, cognition, and neurobiology is scarce. Moreover, the variation of behavioral characteristics across the lifespan and the influence of comorbidities such as epilepsy, intellectual disability, anxiety, and depression on quality of life underscore the complexity of the issue. The absence of consensus on effective diagnostic approaches for later life assessments and the need for post-diagnostic support for autistic adults further complicate the landscape. Generally, there is agreement on the necessity for prospective, longitudinal studies using both cross-sectional and longitudinal methods to understand typical and atypical aging in autism in all its forms. There is also agreement on the need to evaluate the effectiveness of interventions for diverse sub-groups of older autistic adults (for example, those with high intellectual function versus those with concurrent intellectual disability, and those with stable lifestyles versus those whose living arrangements and lived-experience conditions are sketchy).

In summary, as recognized in preceding efforts, researching aging issues, including neuropathologies such as dementia, in autism is not without difficulties and none of the efforts undertaken to date have produced the definitive statement on aging and autism or the foundation for older age emergent neuropathologies (i.e., dementia). There is general recognition that the challenges in understanding the intersection of autism and aging are significant, marked by sparse case identification, a dearth of representation of older autistic adults in research studies, and a notable absence of emphasis on aging within the autism research community. The health status and predictable trajectories of older individuals with autism remain largely unexplored, lacking comprehensive insights into phenomenology, associated features, neurobiological changes, and specific medical, psychiatric, and social aspects related to aging in autism. Existing evidence on brain abnormalities in autism is predominantly centered on children and young adults, leaving a critical gap in knowledge concerning aging and potential risk factors or biomarkers for mild neurocognitive disorders and dementia.

2.0 Methodology

This report emanates from work associated with the 2nd International Summit on Intellectual Disabilities and Dementia, held in Toronto, Ontario, Canada on October 24-25, 2023 (see: https://www.the-ntg.org/key-past-events). Summit participants represented key researchers, academics, advocacy personnel, providers, and government officials concerned with lack of robust knowledge about different facets of life with dementia among adults with intellectual and related disabilities.

Participants were involved in collective discussions as well as subgroup teams. Prior to meeting in person at the Summit, participants worked in small groups to produce background documents on the three

main topics to be examined at the Summit (these included brain health, human rights and equity, and neurodiversity), including an extensive search of the relevant literature (published and 'grey').

Autism was examined as part of the discussions on neurodiversity. Summit participants contributing to the examination of autism and dementia led the open discussion during the comment period and then worked together after the Summit to produce this report. Participants were asked to examine subtopics related to previous efforts exploring autism and aging; diagnostic aspects, characteristics, and variation; risk factors with lifelong autism; autism and dementia; co-occurring conditions, risk, and dementia; other factors-mortality; other factors; pharmacological approaches; assessment for dementia; non-pharmacological interventions, autism and post-diagnostic supports; interventions and later life outcomes. The report drafts were shared with all Summit participants to obtain further insight and contributions, and to gain consensus on the findings and recommendations. The report also benefited from outside content experts who read and contributed during the post-Summit report generation period.

Specifically, Summit participants considered the following questions:

a) What were key findings from preceding efforts?

b) What is the connection between autism, ID, and dementia?

c) What about autism and ID might increase the risk for dementia?

d) What are the difficulties faced when trying to diagnose dementia in older autistic adults?

e) What are recommended non-pharmacological interventions and supports for older autistic adults who have been diagnosed with dementia?

f) What might be a research agenda stemming from the findings of this report?

3.0 Autism Diagnostic Aspects - Recognition and Assessment

Autism is a relatively contemporary diagnosis, first identified in case reports by Kanner (1943) and Asperger (1944). Given this and the fact that the diagnostic term is more common from the 1960s onwards, the first cohort of identified children are only now entering old age (Happé & Charlton, 2010). "Classic" symptoms of autism in children are not always present in adults on the spectrum, especially in those underdiagnosed as children (Lewis, 2018). Adults on the spectrum commonly exhibit symptoms related to social and communication difficulties, repetitive behaviors, sensory processing difficulties, and issues with executive function and theory of mind.

There are two major sets of autism diagnostic criteria commonly used. One is criteria in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (currently in its fifth edition – DSM-5; 2013). The DSM-5 requires professionals to assess the symptoms of autism and the impact these have on a person's life. Symptoms are identified in two 'domains' – social communication and social interaction, and restricted and repetitive behaviors. It requires a range of considerations, including co-occurring diagnosis. Diagnosticians are also asked to specify what level of support among three levels, whether the individual assessed has co-occurring intellectual disability, and if the individual also displays catatonia. This information can help clinicians in their diagnostic decision-making and identification of support needs. The other is the World

Health Organization's International Classification of Diseases (currently in its 11th edition – ICD-11; 2019/2021). The ICD-11 requires clinicians to specify the presence and extent of intellectual and language impairment, along with the impact on numerous areas of functioning.

Numerous authors/groups have produced guidelines for assessing individuals suspected of having symptoms of autism. Most of these guidelines focus on diagnosis in childhood; however, several guidelines have been issued for assessing and diagnosing adults (e.g., APA, 2013; AutismSA, 2023; Centers for Disease and Prevention [CDC], 2022; National Institute for Health and Care Excellence [NICE], 2021; Royal College of Psychiatrists, 2020; Whitehouse et al., 2018). The diagnostic criteria for autism in adults and children are generally the same, but the ways symptoms are assessed against the criteria will vary by age group. Hayes et al. (2018) in their review reported that guidelines varied in recommendations for use of diagnostic tools and assessment procedures and that although multidisciplinary assessment was identified as the 'ideal' assessment, some guidelines suggested that in practice a singular experienced healthcare professional was sufficient. They also noted that social factors in operational, interactional, and contextual areas added complexity to guidelines, but there were few concrete recommendations as to how these factors should be operationalized for best diagnostic outcomes. Although guidelines are available, practice often does not follow guidelines. There is no one test that can unequivocally ascertain the presence of autism. The ADOS-2 comes the closest and is the international gold standard (Curnow et al., 2023), but in the U.S. it is not necessarily the most prevalent assessment used due to its bias toward medical aspects. There is great variability in the testing protocols used outside of university center clinics and clinical judgment is still the most accepted means at which diagnosis is determined.

Timing with respect to diagnosis of autism is a factor. Most instances of determining the presence of autism occur in early childhood when the classic symptoms are most evident and education authorities are involved with documenting needs for specialized educational services. Later life determination may be less precise due to confabulation of symptoms and the effects of life factors. In aging, clinical determinations are even less evident, with many overt symptoms attributed to psychiatric conditions or organicity, such as dementia. Such 'diagnostic overshadowing' is prevalent in situations of disadvantage, isolation, or when adults are unhoused (Brown et al., 2019; Gupta & Gupta, 2023). The recognition of autism is also complicated by gender and culture. Most assessments of autism have been normed on males and do not pick up the subtle social variations that have been reported among high functioning females who may be diagnosed with social anxiety or ADHD and have their autism missed (Harmens et al., 2022). Similarly, autism is less likely to be recognized among minoritized groups who may not have access to clinical centers in which individuals are assessed for autism (Aylward et al., 2021).

Symptom trajectories are also a factor; witness situations which occur where children originally diagnosed show lessening of symptoms past school age (Baghdadli et al., 2018) and alternatively where adults absent symptoms in childhood have clinician-observed autism symptoms later in the lifespan (Ozonoff et al., 2018). Spinazzi, Velasco, et al. (2023) reported a mean 4.7-year gap between first noticing symptoms and receiving an autism diagnosis in school age children; with adults this gap is unknown. Elias and Lord (2022) remarked that the diagnoses of autism can shift across life and are associated with gradual changes in core features of autism beginning in childhood. They noted that in later age, adult diagnostic judgments are based on current functioning and do not rely entirely on historical information. Given this, it is noteworthy that Abu-Akel et al. (2019) described a bimodal distribution in autism prevalence [potentially linked to age at diagnosis], with the bulk occurring between ages 10 and 20, but with a small bump-up occurrence noted around age 40. The late-age factor is considered further in this report with respect to risk for Alzheimer's disease or neuropathologies linked to dementia.

There are also reports of a variable 'moderating' of specific symptoms of autism at certain periods of the lifespan. Hong et al. (2023) reported significant trajectories of age-related change in a USA cohort, with variations in patterns depending upon the symptom category. They noted that most autism symptoms improved through adulthood, while health worsened. They reported that an inverted U-shaped curve best describes change for repetitive behavior symptoms, activities of daily living, maladaptive behaviors, and social interaction. For these measures, improved functioning was evident from adolescence until midlife, then change leveled off with worsening functioning from later midlife into early older age. Given such variations, Keller et al. (2020) recommended periodic reassessments to determine the nature of prevalent symptoms and considering life issues that may affect behavioral changes as autistic adults grow older.

An autism evaluation in adulthood can be challenging. The Canadian Academy of Health Sciences (2020) has noted that research has not produced an assured or recommended autism diagnostic tool for adults (Baghdadli et al., 2017; Wigham et al., 2019) and suggested that extant diagnostic tools should be incorporated into the assessment process and tailored to the complexity of clinical presentation. However, with adults with average-to-above average intelligence, diagnosis of autism is obtained through a clinical interview using a scale, for example, the Autism Diagnostic Observation Schedule-2[4] (ADOS-2; Curnow et al., 2023; Lord et al., 2012) and a clinical assessment. Typically, a full evaluation includes a history presenting complaint, psychiatric history, family history, medical history, and a developmental history (Garland et al., 2013). Garland et al. (2013) noted that an evaluation must consider the core clinical features of autism, which would include (1) difficulties in social relationships (such as evidence of few or no sustained relationships, aloof, awkward interaction with others, egocentric, with limited empathy, and poor awareness of social norm); (2) problems in communication (such as stilted, pedantic use of language, monotonous voice or inappropriate volume, non-reciprocal, one-sided interaction, literal interpretation of what is heard, restricted affect and limited use of gestures, poor integration of gaze with content of speech, and uncomfortable posture and body language); (3) absorbing and narrow interests (such as circumscribed interest of limited practical or social value, obsessive pursuit of restricted interests, strict daily routine and schedule, deviation from daily structure causes distress); and (4) onset and duration (such as onset in childhood, lifelong condition, and pervasiveness across all activities of living).

Keller et al. (2020) also suggested that there is a need for a diagnostic revaluation over time during various transition periods in the lifespan. They reported that almost half of their Italian study sample of autistic adults (N=500) required revision of diagnosis—mostly due to changes of the clinical picture, nosographic reference parameters, cognitive functioning, and psychopathological co-occurrences – during various periods in the lifespan. They noted these modifications occurred in about a quarter of their sample. Such revaluations are particularly useful in detecting not only modifications of cognitive level of functioning but also the co-occurrence of a psychiatric disorder, which may be more problematic at a later age.

In contrast to diagnostic practices in play with respect to Alzheimer's disease and the growing reliance on biomarkers,[5] Hayes et al. (2018) reported that currently there is a lack of consensus on a definitive

[4] Module 4, in the Autism Diagnostic Observation Schedule 2 (ADOS-2), can be used with autistic older adults who have fluent language; it has been shown at least moderate power to distinguish autistic adults from those adults without autism (Royal College of Psychiatrists, 2020; Swetlik, Earp, & Franco, 2019). Given its medical focus, work has been undertaken to adapt procedures for the ADOS-2 to accommodate assessors to incorporate key principles including "nothing about us without us"; "difference not deficit"; "environment first"; "diagnosis matters," "language and mindsets matter"; and "a neurodevelopmental lens," to support the provision of neurodiversity affirming assessment practice (Curnow et al., 2023).

[5] Biomarkers are objective measures of biological or pathophysiological processes and are seen to be more effective confirmation of the presence of a disease or condition. According to the Biomarkers Definitions Working Group (2001), common applications of biomarkers include biomarkers which (I) can help diagnose a disease by identifying individuals with an abnormal biological process, (II) can classify disease severity, (III) can indicate prognosis, or (IV) can predict or monitor response to therapy.

biomarker for autism. Anderson (2015) commented that the heterogeneous and interactive nature of autism symptoms makes the identification of clinically useful biomarker tests problematic (Anderson, 2015). However, emerging work is exploring their use with early-age children, but due to heterogeneity of autism physiology, no definitive biomarker has yet been identified to be viable (Frye et al., 2019). Work with adults is emerging, for example, Kim et al. (2023) suggest that retinal photographs may be a viable objective screening tool for autism and possibly for symptom severity. However, biomarker research has yet to be integrated with clinical practice and none currently has enough evidence to support routine clinical use. As Frye et al. (2019) noted, "...any diagnostic biomarker developed needs to measure biological processes and most likely will need to be used in conjunction with other behavioral tests and clinically relevant information to perform adequately."

> ***In summary,*** the diagnostic landscape for autistic adults presents several challenges and complexities. The contemporary diagnosis of autism, initially described by Kanner (1943) and Asperger (1944), has evolved over the years, with the early cohorts of identified children now entering old age. While classic symptoms may not always persist into adulthood, autistic adults commonly exhibit challenges in social interaction, communication, repetitive behaviors, sensory processing, and executive function and may interact with diminishing capabilities when aging. Two major sets of diagnostic criteria, outlined in the DSM-5 and ICD-11, guide professionals in assessing these symptoms and their impact on individuals' lives. Guidelines for diagnosing adults vary, with some recommending multidisciplinary assessments, while others suggest reliance on a singular experienced healthcare professional. Evaluating autism in adulthood involves considering diverse aspects such as developmental history, psychiatric and medical history, and core clinical features. Unlike diagnostic practices for diseases like Alzheimer's, consensus on a definitive biomarker for autism remains elusive due to the heterogeneous and interactive nature of symptoms. Although researchers have explored biomarkers appropriate for young children, none have been validated for routine clinical use with adults, emphasizing the need for further research into integrated approaches combining biological measures and behavioral tests.

3.1 Characteristics and variations

Autism represents a diverse group of conditions, which are characterized by some degree of difficulty with social interaction and communication, as well as atypical patterns of activities and behaviors – such as difficulty with transition from one activity to another, a focus on details and unusual reactions to sensations (WHO, 2023). Adults on the spectrum commonly exhibit symptoms related to social and communication difficulties, repetitive behaviors, sensory processing difficulties, and issues with executive function and theory of mind (ARI, 2023).

There are differentials in characteristics depending on sex. Autism is found less frequently in females than males as several sex-differential genetic and hormonal factors may contribute (Werling & Geschwind, 2013) and symptoms may appear different in girls and women (OHSU, 2023). Females may often more effectively mask autistic features or experience more subtle social challenges (Rynkiewicz et al., 2016), and often are diagnosed later in life than males (Leedham et al., 2020)). Some of the symptoms include (a) difficulty with friends as a child or fewer, closer friendships, (b) sensitivity to textures and clothing, (c) social anxiety or confusion, (d) eating disorders, (f) higher rates of anxiety or depression, (g) difficulty understanding or following social rules, (h) intense special interests, and (i) mood disorders (OHSU, 2023). With respect to this, most commonly a sex ratio of 4:1 is cited. Intelligence level affects this sex ratio as well as males are substantially over-represented among high-functioning cases, but males and females are more equally represented among cases with severe intellectual disability (Werling & Geschwind, 2013). A question is to what degree does such

adaptive social functioning and gender roles contribute to 'masking' which may confound diagnoses of neurocognitive impairment associated with dementia?

Autism is strongly biased towards males, with ratios of 4:1 (male:female) for classic autism and as high as 11:1 in individuals with Asperger's (Baron-Cohen et al., 2011). Baron-Cohen et al. proposed that high male ratio stems from the 'extreme male brain' (EMB) theory, first proposed in 1997, as an extension of the Empathizing-Systemizing (E-S) theory of typical sex differences that proposes that females on average have a stronger drive to empathize while males on average have a stronger drive to systemize. The male bias is much more pronounced in autism, especially in the case of Asperger's. They note that this male bias could simply reflect the difficulty of diagnosing autism in females and though classic autism would not be missed in females, it could be if it presented as some other condition (such as anorexia or borderline personality disorder, both of which involve the exercise of excessive control over the environment or other people, and a certain degree of a self-centeredness). Equally, they posited, autism in females could be under-diagnosed if females are more motivated to learn to conform socially or have better imitation skills that allow them to "pretend to be normal." Beggiato et al. (2017) raised the question as to whether there is a potential gender bias in autism diagnostic instruments that leads to an underestimation of the prevalence of autistic females.

Hull et al. (2017) reported that differences found in male and female autism symptoms may offer some explanation for the differences in diagnostic rates between sexes/genders in autism. It may be that the greater task switching and cognitive flexibility abilities of females with autism may explain why they are able to develop compensatory or 'camouflaging' techniques to 'mask' their social and communication impairments. Ratto et al. (2018) found that although females and males were rated similarly on gold-standard autism diagnostic measures (such as the ADI-R[6]), females with higher IQs were less likely to meet criteria on the ADI-R and were also found to be significantly more impaired on parent reported autistic traits and adaptive skills. Ratto et al. noted that their findings suggested that some autistic females may be missed by current diagnostic procedures. Lehnhardt et al. (2015) also found higher processing speed in females than males in their adult diagnosis sample, suggesting that autistic females are better able to use explicit cognitive strategies to cope in complex social interactions. It is possible that other cognitive and behavioral abilities found in neurotypical females are also used by autistic females when camouflaging. Navarro-Pardo et al. (2021) questioned whether current instrumentation has a gender bias and concluded that specific or complementary diagnostic tools and procedures differentiated by gender should be refined to reduce any potential biases.

> ***In summary,*** the assessment of autism reveals notable differentials based on sex, with the condition being less frequently identified in females. Various genetic and hormonal factors contribute to this sex disparity, and symptoms may manifest differently in girls and women. Females may exhibit more subtle social challenges, masking autistic features, and presenting with characteristics such as difficulty with friendships, sensitivity to textures, social anxiety, eating disorders, and mood disorders. The sex ratio, commonly cited as 4:1, is influenced by intelligence levels, with males over-represented among high-functioning cases. Additionally, late-life onset of autism symptoms has been explored in

[6] Frigaux A, Evrard R, Lighezzolo-Alnot J. (2019). L'ADI-R et l'ADOS face au diagnostic différentiel des troubles du spectre autistique : intérêts, limites et ouvertures [ADI-R and ADOS and the differential diagnosis of autism spectrum disorders: Interests, limits and openings]. *Encephale,* 45(5), 441-448. French. doi: 10.1016/j.encep.2019.07.002. Epub 2019 Sep 5. PMID: 31495549. Rutter, M., LeCouteur, A., & Lord, C. (2003). Autism Diagnostic Interview–Revised (ADI-R). Western Psychological Services. https://www.wpspublish.com/adi-r-autism-diagnostic-interviewrevised.html?utm_term=adi%20r&utm_campaign=Search+%7C+Product+Family+Name&utm_source=adwords&utm_medium=ppc&hsa_net=adwords&hsa_tgt=kwd-323653837841&hsa_ad=628854246702&hsa_acc=6243382947&hsa_grp=145401091671&hsa_mt=b&hsa_cam=18635497850&hsa_kw=adi%20r&hsa_ver=3&hsa_src=g&gad_source=1&gclid=Cj0KCQjwwYSwBhD-cARIsAOyL0fjezYUBLGE1YYHSCPzSEzoS_teRbBL4se412fv37IcpBvUiD9cWqjIaAqzpEALw_wcB

relation to degenerative dementia, showing a significant association with early-onset dementia. Further research on the interplay between autism and late-life dementia could provide insights into shared neuroanatomic involvement between the two conditions.

3.2 Co-occurring autism and other neurodevelopmental disorders

The focus of this section is on the intersection of autism and other co-occurring cognitive impairments, and the issues related to ascertaining the impact of this intersection in later life. The question arises as to what degree do various co-occurring neurodevelopmental disorders occur in people with autism? Numerous genetic or genomic disorders can include autistic features in their clinical presentations. For example, people with certain genetic disorders, such as fragile X syndrome (FXS), Rett syndrome, Cornelia de Lange syndrome, tuberous sclerosis complex (TSC), and Down syndrome, are more likely to have comorbid autism (CDC, 2022). FXS is the most known genetic cause of inherited ID and the most known single-gene cause of autism. Dykens and Volkmar (1997) reported that 4% of people with autism have FXS. Kidd et al. (2014) reported that a spectrum of medical problems is commonly experienced by people with FXS, such as otitis media, seizures, and gastrointestinal problems. Kaufman et al., (2017) reported that behavioral manifestations in FXS among autistic adults are quite variable and include attention deficits, hyperactivity/ impulsivity, hyperarousal, anxiety, self-injurious behavior, and are extensified when FXS and autism coexists, versus when only FXS is present. Such comorbidity can stem from DNA mutations, triplet repeat expansions, or rare chromosomal abnormalities visible by high resolution karyotyping (Persico & Napolioni, 2013). There are many other genetic variants including deletion, insertion inversion, duplications, and complex recombination involving DNA segments and the effects of gene-environment.

It has been reported that there was a strong association of autism with hypermobile Ehlers Danlos syndrome (EDS). Autonomic dysfunction may further impair quality of life in autistic adults, particularly among those unable to adequately express their experience of autonomic symptoms (Owens et al., 2021). Casanova et al. (2020) outlined a symptom overlap between autism and Ehlers-Danlos syndromes/hypermobility spectrum (EDS/HSD) and reiterated certain features present in EDS/HSD, such as hypermobility, dysautonomia, chronic pain, and proprioceptive impairment, all of which contribute as sources for pain. They also noted early data regarding the presence of an EDS-like phenotype associated with the FMR1 gene. Additionally, she suggests that it is also possible that chronic collagen dysregulation and subsequent tissue injury may lead to chronic immune dysregulation, as evidenced by the mast cell-related disorders that are such a common comorbid feature in EDS/HSD. This lends itself to a relationship to “weathering” and allostatic load, which may add to cognitive decline in older age.

The relationship between ID, autism, and dementia is a multifaceted and increasingly critical area of research in the field of neurodevelopmental disorders. ID is a condition characterized by below average intellectual functioning (IQ<70) in conjunction with significant limitations in adaptive functioning (American Association on Intellectual and Developmental Disabilities [AAIDD], 2023). While ID is usually diagnosed early in life, autism is also present early in life, although in some individuals it may not be diagnosed until later in adulthood. ID may occur as an isolated phenomenon or accompanied by malformations, neurological signs, impairment of the special senses, seizures, and behavioral disturbances. ID is common in autism, although not as common as once thought. Recent estimates from the CDC suggest that 38% of children identified as autistic also had an ID (Maenner et al., 2020). The Centers for Disease Control and Prevention (CDC, 2009) reports 41% of individuals with autism also have an ID that can range from mild to profound. Kats et al. (2013) set out to investigate the prevalence of clinically relevant behaviors and medical problems in a sample of adults aged 30 to 59 in the U.S. with autism and ID, in comparison to those with ID only. They observed the rate of support needed to manage self-injurious, disruptive, and destructive behavior in subjects with autism and ID ranged

from 40 to 60%. Similarly, the rate estimates of self-injurious, disruptive, and destructive behavior were almost double in adults with autism and ID relative to those with only ID.

Are there other notable co-conditions that may contribute to cognitive decline with aging? As late-onset seizures are often indicative of brain neuropathies (DiFrancesco et al., 2022), studies showing the presence of epilepsy can provide value to this query. Lee et al. (2015) noted that autism and epilepsies are often comorbid with varying degrees of developmental delay, learning disorders (Vidyadharan & Tharayil, 2019), ID, and behavior problems and there exists a clinical overlap in adults presenting with epilepsy and autism. They cited that there are genetic causes of both disorders, with several biological pathways involved in both disease processes, including gene transcription regulation, cellular growth, synaptic channel function, and maintenance of synaptic structure. Tidmarsh and Volkmar (2003) noted the co-incidence of various disorders in autism such as epilepsy, as well as tuberous sclerosis complex, cerebral palsy, and Down syndrome. They reported rates of epilepsy in autism ranging from 5% to 38.3%, with increasing rates in adolescents and adults (with about one-third with seizures). Also, they reported that the presence of ID has a potential predictive aspect for the development of seizures in persons with autism. The risk of epilepsy is also higher in Rett's syndrome, usually between 75% to 90% (Minshew, Sweeney & Bauman, 1997). Bauman (2010) noted that the high prevalence of seizures among autistic adults emphasizes the neurological dimension of autism.

The question arises as to whether late-onset seizures (those after age 60) among older autistic adults signal the potential emergence of dementia? In an analysis of seizures and age among autistic adults, Bishop et al. (2021) found, from an analysis of U.S. Medicaid claim data in the state of Wisconsin, that while epilepsy prevalence was impacted by age, there were no clear age-related trends across age categories in autistic adults *without* ID. For autistic adults *with* ID [data were absent if this group contained adults with DS] there was increasing prevalence with increasing age. The authors noted that the lack of an association between age and epilepsy prevalence in autistic adults without ID could be due to cohort effects, as older autistic adults without ID are likely very different from younger autistic adults without ID (Rubenstein & Bishop, 2019). Although the prevalence of seizures over the lifespan is higher than norm for autistic individuals, and the cumulative effects can lead to neurological issues in adulthood (Bolton et al., 2011), data are unavailable as to a direct association of late-onset seizures and dementia. As Reyes et al. (2023) have noted, whether seizures result in accelerated brain and cognitive aging has been an ongoing debate in the literature, there is evidence of cognitive deterioration regardless of the age of onset.

Although there is no *population-based data* on autism prevalence in persons with DS, there are various reported *estimates* based on population samples. Capone et al. (2005), Oxelgren et al. (2017), and Warner et al. (2014) provided estimates that ranged from 7 to 42%. Richards et al. (2015) undertook a systematic review and reported that the comorbidity may occur in some 16% of people and Baio et al. (2018) estimated co-occurrence rate of autism and DS in the U.S. general population at 2%. Dimachkie Nunnally et al. (2021), reported that individuals with DS are diagnosed with autism at a higher rate than individuals in the general population. The connection between these conditions may lie in both shared genetic factors and the presence of specific neuropathological changes. The primary contributing factor to this increased risk is thought to be the presence of excess amyloid-beta protein in the brain, a hallmark of Alzheimer's disease and other mechanisms (Antonarakis et al., 2020). Notably, as individuals with Down syndrome exhibit a heightened risk of developing dementia as they age, the question is whether DS and autism together in an individual raises the risk for expressing dementia in older age among adults with this comorbidity?

> ***In summary,*** when examining the co-occurring neurodevelopmental disorders associated with autism, it becomes evident that numerous genetic or genomic disorders, such as fragile X syndrome, tuberous sclerosis complex, and DS, can present with autistic features. These disorders often result from DNA mutations, triplet repeat expansions, or chromosomal abnormalities. The interplay between ID, autism, and dementia is a complex area of research, with ID commonly occurring in individuals with

autism. The co-occurrence of epilepsy in autism is notable, with increased rates found in those individuals with ID. The relationship between DS and autism is characterized by varying estimates, with a reported co-occurrence rate of 2% in the general U.S. population. Individuals with DS are at a notably increased risk of developing dementia, primarily attributed to the accumulation of amyloid-beta protein, a hallmark of Alzheimer's disease. Overall, the connection between these conditions may stem from shared genetic factors and specific neuropathological changes, contributing to the complex landscape of co-existing disorders in individuals with autism. What these interesting findings mean for the occurrence of dementia in autistic individuals remains to be established.

3.3 Health and related factors

What are identifiable risk factors for health issues and possibly later-age neuropathologies among autistic adults? Numerous studies explored comorbidities in autistic adults, revealing a diverse range of health issues and challenges (Brondino et al., 2019; Cawthorpe, 2017; Miot et al., 2019; Vohra et al., 2017). The prevalence of seizures among these individuals ranges from 20% to 35%, emphasizing the neurological dimension of autism and risk proffered by concurrent epilepsy (Wise et al., 2017). Gastrointestinal disorders (GI), estimated between 9% and 70%, underscore the complex nature of health challenges in this population and add to health-related risk. In one study, Vohra et al. (2017) reported that in a sample of 1,772 autistic adults, a substantial prevalence of psychiatric comorbidity (81%) was observed, as well as epilepsy (22%), infections (22%), skin disorders (21%), and hearing impairments (18%). Developmental disorders were prevalent in 70% of autistic adults, with lower rates of non-psychiatric comorbidities compared to the general population. Notably, autistic adults showed lower prevalence rates of cancer, cardiovascular disorders, musculoskeletal disorders, and respiratory disorders. Overall, autistic adults and ID displayed higher rates of medical comorbidities, and those taking psychotropic medications were more likely to have medical conditions (Brondino et al., 2019). The number of medical comorbidities positively correlated with age and severity of autism. However, none (with the exception for seizures) correlated with risk for Alzheimer's disease, or most other dementias. Hong et al. (2023) noted that studies of health trajectories into older age have found that, for most individuals, body mass index and prescription medication use increased throughout early adulthood.

Findings have also revealed a wide range of physical health (medical) comorbidities, such as constipation, epilepsy, mental and neurological diseases, and cardiovascular risk factors (Miot et al., 2019). Noteworthy was the finding of the range of comorbidities, including GI disorders, mental, and neurological diseases. Chronic kidney disease was prevalent in 25% of the autism-ID sample, elevating cardiovascular risk factors. Constipation, epilepsy, and chronic kidney disease were the most frequent chronic health conditions. With respect to mental health comorbidities, Rydzewska et al. (2018) reported that mental health conditions were present in 33% of all adults with reported autism (range 23%–37% depending on age group; 27%–37% for men and 30%–40% for women). Vohra et al. (2017) found significantly higher rates of psychiatric comorbidity (81%), noting that some 70% of autistic adults had developmental disorders, followed by schizophrenia (17%), mood disorders (14%), and anxiety (12%). With respect to serious mental illnesses, Jonas et al. (2022) found that some non-autistic adults with schizophrenia often experience accelerated cognitive deterioration that results in dementia. It is unknown what the actual transition rate is among autistic adults so affected.

Bishop and Rubenstein (2019) compared autistic adults without an ID with those with an ID and noted that although there were many similarities between those individuals with and without co-occurring ID, middle-aged and older autistic adults had a greater prevalence of epilepsy and lower prevalence of depression and anxiety compared to those without co-occurring ID. They suggest that autistic adults have a high prevalence of physical and mental health conditions in midlife and old age, regardless of ID status. However, none of these health comorbidities were associated with elevated risk for dementia associated with Alzheimer's disease or other forms of dementia, such as vascular dementia.

With respect to later life outcomes, genetic or familial risk factors have been noted, some of which may contribute to health risk factors contributing to progressive health issues contributing to cognitive decline. Xie et al. (2019) in a population-based cohort study of 567,436 Swedish participants, found that positive family history was associated with increased risk of autism. Autism with ID exhibited a weaker familial association with other mental disorder diagnoses but a stronger familial association with some neurological diagnoses as compared with autism without ID. This suggests that family history of mental and neurological disorders is associated with autism risk, and the familial component of autism etiology may differ by presence or absence of co-occurring ID.

Hand et al. (2022) undertook a cross-sectional retrospective cohort study of U.S. 2016–2017 Medicare data to compare the prevalence of physical and mental health conditions in a national sample of autistic older adults (N = 4685) to a matched population comparison (N = 46,850) cohort. Autistic older adults had significantly greater odds of nearly all physical health conditions, including epilepsy (odds ratio = 18.9; 95% confidence interval = 17.2–20.7), Parkinson's disease (odds ratio = 6.1; 95% confidence interval = 5.3–7.0), and gastrointestinal conditions (odds ratio = 5.2; 95% confidence interval = 4.9–5.5). Most mental health conditions were more common among autistic older adults, including schizophrenia and psychotic disorders (odds ratio = 25.3; 95% confidence interval = 22.4–28.7), attention deficit disorders (odds ratio = 24.4; 95% confidence interval = 16.2–31.0), personality disorders (odds ratio = 24.1; 95% confidence interval = 17.8–32.5), and suicidality or self-inflicted injury (odds ratio = 11.1; 95% confidence interval = 8.9–13.8). Health conditions commonly associated with advanced age in the general population (e.g., osteoporosis, cognitive disorders, heart disease, cancer, cerebrovascular disease, osteoarthritis) were also significantly more common among autistic older adults.

Ward et al. (2023) conducted a cross-sectional, convenience-sampling study via a survey of autistic and non-autistic adults (n = 2305, mean age = 41.6). There were significantly elevated rates of non-communicable conditions across all organ systems in autistic people, including gastrointestinal, neurological, endocrine, visual, ear/nose/throat, skin, liver and kidney, and hematological conditions. This confirmed previous findings by showing highly significant differences in rates of neurological and gastrointestinal symptoms. In addition, they established in the largest sample to date that EDS [see page 15] was more likely to occur among autistic females compared to non-autistic females. Notably, they also found a higher prevalence of Celiac disease among autistic individuals compared to non-autistic individuals.

With respect to sex differences, males with autism are less likely to have certain disorders, while females exhibit a higher likelihood of specific conditions, including ID (Cawthorpe, 2017). Contrary to general population trends, female sex predicted all conditions within the autism population, challenging conventional assumptions. Notably, mental health conditions were prevalent in 33% of all adults with reported autism, varying across age groups and sex. The prevalence of comorbidities such as deafness/hearing loss, blindness/sight loss, ID, mental health conditions, and physical disabilities was substantial, with autism significantly predicting these conditions (Rydzewska et al., 2018).

> ***In summary***, the synthesis of multiple studies of comorbidities in autistic adults reveals a complex and varied landscape of associated health conditions. Seizures are prevalent, emphasizing the neurological aspect of autism, alongside gastrointestinal disorders, psychiatric comorbidities, infections, skin disorders, and hearing impairments. Developmental disorders affect a sizable portion of autistic adults, with lower rates of non-psychiatric comorbidities compared to the general population. Genetic or familial risk factors are implicated in later life outcomes, potentially contributing to progressive health issues and cognitive decline. Autism with ID shows varying familial associations compared to autism without ID, suggesting a nuanced relationship between family history and autism risk. Mental health conditions also appear more prevalent among autistic older adults, including schizophrenia, attention deficit disorders, personality disorders, and suicidality. Moreover, health conditions typically

associated with advanced age in the general population were more common among autistic older adults. Studies also suggest a higher prevalence of cardiovascular risk factors, diabetes, dyslipidemia, heart disease, and, to a lesser extent, Parkinson's disease among autistic adults. Overall, these studies underscore the multifaceted nature of health and condition comorbidities among autistic adults, highlighting the need for tailored interventions and healthcare approaches that consider the diverse health challenges faced by individuals within this population. Understanding the intricate web of comorbidities in autistic adults is crucial for comprehensive healthcare planning. These findings shed light on the diverse health challenges faced by this population and provide a foundation for further research exploring the intricate relationship between comorbidities and the risk of dementia in autistic adults (see section 4.1 on *Co-occurring Conditions, Risk, & Dementia*, p. 21).

4.0 Autism and Dementia

Dementia is a term that generally characterizes behavioral declines associated with some form of brain trauma or brain neuropathology in later life. It is primarily evidenced by a decline in cognitive and functional abilities, losses in memory and reasoning, and changes in carrying out our daily living activities. Its roots are in various neurodegenerative disorders, including Alzheimer's disease. Alzheimer Disease International (2024) notes that in high income countries, only 20-50% of dementia cases are recognized and documented in primary care, and that this 'treatment gap' is much greater in low- and middle-income countries. The Alzheimer's Association in the U.S. notes that about 10.7% of adults, age 65+ and older, have been diagnosed with Alzheimer's disease (Alzheimer's Association, 2023), a major contributor to dementia. About ID, there is a recognized elevated risk for Alzheimer's disease among adults with Down syndrome (National Institute on Aging, 2023).

General ID studies show both normative prevalence of dementia among adults with various ID (absent Down syndrome) (Janicki & Dalton, 2000; McGlinchey et al., 2019; Zigman et al., 2004) and elevated prevalence (Strydom et al., 2009; Shooshtari et al., 2017; Takenoshita et al., 2023). The rates of dementia among autistic adults are generally affected upward with the coincidence of Down syndrome or other ID. It has been reported that some individuals with autism may also be at an increased risk of developing dementia. For example, in a recent case-control study in the U.S., the 5-year prevalence of dementia among autistic adults who were *under the age of 65 years* was 4.04%, which was 2.6 times higher than the reported prevalence for the general population and among those autistic adults and co-occurring ID, the prevalence of dementia was higher at 5.22% (Vivanti et al., 2021). Males with autism have been found to be at a greater risk for dementia than females with autism (Barnard-Brak et al., 2019). Rhodes et al. (2020) reported that *age of onset* of cognitive symptoms appears to occur significantly earlier in the adults with likely autism [X_{age}=71] (than in a control group of adults unlikely to have autism [X_{age}=76]). Vivanti et al. (2021) found that for those adult age less than 65, the mean age at dementia diagnosis was 49.5 years for those with autism only, 47.5 years for those with autism and ID, 51.7 years for those with only an ID and 53.8 years for others (not having an ID or autism).

Rhodes et al. (2020) suggested that it is possible that lifelong subclinical autism may manifest only when neurological function is compromised by the development of even the mildest of cognitive pathologic insults in older adulthood. Further, that pathological overlap in neuroanatomical structures and systems in autism and dementia may create earlier behavioral burdens in the presence of degenerative disease, as evidenced by age of onset of cognitive impairment and presence of behavioral symptoms. Rhodes et al. (2020)

and Vivanti et al. (2021) did not specify the type of dementia in their findings. In reports related to other neurodiverse conditions, the difference between age of 'onset' and diagnosis in Down syndrome, for example, ranged between 3 and 5 years (Janicki & Dalton, 2000; Strydom et al., 2013).

Autism alone or with ID in some adults may eventually manifest dementia as the result of a neurodegenerative disorder. Cummings et al. (2024) noted that neurodegenerative disorders (NDDs) include Alzheimer's disease (AD), Parkinson disease (PD), dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), progressive supranuclear palsy (PSP), corticobasal syndrome, multiple system atrophy, amyotrophic lateral sclerosis, chronic traumatic encephalopathy, and traumatic encephalopathy syndrome (TES), and Huntington disease (HD). Most of these conditions are age related and become symptomatic in late life or late middle age. Arvio & Bjelogrlic-Laakso (2021) screened some 230 adults with ID and other co-occurring conditions, including autism. They observed that autistic adults with ID had 'high dementia sign' scores on the Present Psychiatric State Learning Disability Scale (Cooper et al., 1997), but without the earlier age correspondence seen in adults with DS. They posited that there may be varied clinical and etiological factors which contribute to finding these 'high dementia sign' scores. One, is that diagnostic outcomes with autistic adults may be driven by multiple genetic and environmental factors. They questioned whether some adults may have had some yet undetected syndrome associated with early dementia. Second, the presence of self-destructive and aggressive behaviors in some autistic adults with ID may impair successful differential diagnoses as behavioral symptoms observed may stem from unrecognized psychosocial/environmental factors or a psychotic disorder. They also questioned whether autistic adults with ID who have been on multiple antipsychotic and other neuropsychiatric medications since childhood or early adolescence may have altered behavior that reflects a state of diminished cognitive capacity.

Autism co-occurs with other disorders, such as anxiety (Nimmo-Smith et al., 2020), attention deficit hyperactivity disorder (ADHD; Rasnani et al., 2023), depression (Hollocks et al., 2019), and obsessive-compulsive disorder (OCD) – each of which alone present cognitive, emotional, and behavioral challenges. Many of these conditions are associated with cognitive difficulties and neurocognitive disorders among aging neurotypical individuals, thus dementia symptoms may be masked in adults with autism . A small portion of adults with autism are also diagnosed with DS (Bradbury, 2021); knowing this might lead to assumptions about elevated risk for AD in this subgroup. Studies have also presented mixed results with some questioning whether autistic adults (absent the presence of DS) do present an elevated risk for dementia. Work by brain scientists indicates that there may be some structural differences in the brains of autistic adults that are at variance from those of neurotypical age peers and which may result in dementia. For example, Walsh et al. (2022) found that there was a significant group by time interaction for long-term visual memory, such that middle-age and older adults with autism declined faster than matched neurotypical adults. Others (Alves et al., 2023; Pagni et al., 2022) have also noted brain changes that signal symptoms associated with dementia. However, while dementia may be a factor, studies are absent that indicate classic risk for late onset Alzheimer's disease (LOAD). Torenvliet et al. (2023) reported that autistic individuals diagnosed in adulthood, without ID, do not seem at risk for accelerated cognitive decline.

The literature on autism and dementia has been limited. Some studies have pointed to earlier onset of dementia among autistic adults; others are equivocal. For example, Vivanti et al. (2021) found that early-onset dementia (diagnosis at <65 years of age) occurred 2.6 times more frequently in autistic adults with and without co-occurring ID than in the general population of Medicaid beneficiaries. Another study (Croen et al., 2015) reported a higher prevalence of dementia in autistic adults (2.3% vs. 0.5% in the general population control group). One review noted that compared to the general population, autistic adults might develop earlier cognitive decline and dementia with cognitive functions such as memory and executive functions most affected (Toloza Ramirez et al., 2020). Another report (Miot et al., 2019) reported that autistic adults have high rates of severe psychiatric disorders and medical conditions (such as diabetes, hypertension, and seizures), which in neurotypical adults are linked to increased risk of dementia and can also impact their quality of life,

their health, and prognosis. In contrast, Torenvliet et al. (2023) reported that specifically, autistic individuals diagnosed in adulthood, without ID, do not seem at risk for accelerated cognitive decline. Several studies have noted signal behaviors associated with suspicions of the presence of dementia which include degeneration of frontotemporal functioning, severity of expressed behavioral and psychological symptoms of dementia (BPSD) and increased stereotypical behaviors and increased compulsivity.

Other studies have noted that autistic adults are perhaps protected from age-related cognitive impairment (Oberman et al., 2014) given their cortex begins as relatively "hyperplastic." Another theory proposed that lifelong subclinical autistic symptoms might emerge once neurologic function is compromised in older age (Rhodus et al., 2020). Although some studies indicate possible associations between dementia and symptoms of autism, there is a need for further research investigating the interplay between these entities. These difficulties stem from the overlapping behavioral and cognitive symptoms of these conditions and may include communication deficits, limited verbal expression, and atypical presentation of dementia-related symptoms. We are aware that often autistic adults have been treated since childhood or early adolescence with multiple antipsychotics and or other classes of psychotropic drugs. Such psychoactive drug treatment has a role in treating persistent challenging behaviors, but its effects on developing brains are largely unknown. Another factor is when the symptoms of dementia are observed at an unusually early age (Hof et al., 1991), this could be due to repeated trauma to the head (such as head-banging) resulting in a type of 'dementia pugilistica' (Arvio & Bjelogrlic-Laakso, 2021).

One of the biggest challenges in being able to determine the rate at which people with autism will develop mild neurocognitive disorder (MCI) or dementia is that autistic adults are a heterogeneous population, with varying levels of IQ or coincident neurodevelopmental conditions, and later-age cognitive decline is caused by a host of different underlying factors. This is unlike that for adults with trisomy 21 DS who appear to have a unitary cause (i.e., Alzheimer's disease) and an identifiable rate (Antonarakis et al., 2020; Wilcox & Griffin, 2013).

> ***In summary,*** the relationship between dementia and autism is complex, with limited research exploring this connection, particularly in older adults. Dementia, characterized by cognitive and functional decline, is known to be elevated among individuals with ID, notably those with DS. In autistic adults, the prevalence of dementia is generally influenced by co-occurring ID or DS. Recent studies indicate that autistic adults may have an increased risk of developing dementia, with a 2.6 times higher prevalence of early-onset dementia compared to the general population. Notably, males with autism are found to be at a greater risk for dementia than females. The literature suggests mixed findings on the specific risk for dementia in autistic adults, and studies have pointed to earlier onset of dementia in subsets of this population. Some studies propose that autistic adults might be protected from age-related cognitive impairment, while others note potential associations between dementia and autism symptoms. Signal behaviors associated with suspicions of dementia in autistic adults include degeneration of frontotemporal functioning, severity of expressed behavioral and psychological symptoms, increased stereotypical behaviors, and heightened compulsivity. Challenges in understanding this interplay arise from overlapping behavioral and cognitive symptoms, communication deficits, limited verbal expression, and atypical presentation of dementia-related symptoms. Further research is needed to unravel the intricate relationship between autism and dementia in older adults, considering the unique challenges posed by overlapping symptoms.

4.1 Co-occurring conditions, risk, & dementia

To what degree is there proof that autism is linked to select types of dementia? Vivanti et al (2021) reported that it is currently unclear whether individuals with autism, compared to the general population, are at a higher risk of being diagnosed with early-onset forms of dementia. To study this question, Vivanti et al. (2021) examined the U.S. nationwide prevalence and incidence of dementia in a sample of autistic adults aged

30-64 years who were enrolled in Medicaid (a government insurer of behavioral health services in the U.S.). Medicaid claims data, which include information on the diagnoses that beneficiaries receive, suggested that the autistic adults under age 65 were approximately 2.6 times more likely to be diagnosed with early-onset dementia compared to the general population. However, contrary to what some autism or Alzheimer's websites[7] note the study did not establish a relationship specifically with Alzheimer's disease. It is possible that the aggregate information on dementia provided by Vivanti et al. may be more reflective of non-Alzheimer's dementia (as shown by studies linking autism with behavioral variant frontotemporal dementia – Hodges, 2023; Midorikawa & Kawamura, 2012; Rhodus et al., 2020).

Vivanti et al. (2021) noted that the risk factors associated with the increased prevalence of dementia in the general population, including older age, depression, the presence of additional psychiatric conditions, and cardiovascular disease risk factors, were similarly associated with an increased risk of dementia in individuals with autism (both with and without co-occurring ID), as well as in those with ID only.

The findings are of interest as there has been speculation that there may be a bio-neurological relationship between autism and some form of dementia. Zauderer (2023) has noted that both conditions involve changes in the brain. In autism, there are often structural differences in the brain that affect how it processes information, whereas in dementia, there is damage to the brain that impairs function. A similarity is that both conditions can affect memory and communication. In autism, some individuals may have difficulty with social cues and nonverbal communication, making it hard to form relationships and interact with others. In dementia, some individuals may experience memory loss and difficulty communicating, leading to a loss of connection with others in their immediate environment. Zauderer reported that some studies (e.g., Nadeem et al., 2021) have suggested that there may be a genetic link between autism and dementia. Specifically, researchers have found that some of the genes that are associated with autism are also associated with an increased risk of developing some form of dementia later in life. This connection between autism and dementia remains unproven but has been noted as a connection.

While genetics may play a role in the development of both autism and some dementias, there is also evidence to suggest that lifestyle factors can impact an individual's risk for these conditions (Zauderer, 2023). One area where lifestyle factors may be particularly important is diet. Research has shown that certain nutrients, such as omega-3 fatty acids and antioxidants, may have a protective effect on the brain. Some studies have suggested that people who consume diets high in these nutrients may be at lower risk for dementia (Hartnett et al., 2023) and neuroatypical conditions, like autism (Mazza et al., 2007). Others cite particular diets as having a productive effect on cognitive health, such as the MIND diet's importance for cognitive resilience (e.g., Wagner et al., 2023). However, the science is still uncertain about the long-range preventive or ameliorative effects of nutrition in the expression of dementia (Yassine et al., 2022).

There may be a connection between ADHD, autism, and dementia. Although a meta-analysis estimated the current and lifetime prevalence of ADHD in autistic individuals as 38.5 % (95 % CI 34.0–43.2) and 40.2 % (95 % CI 34.9–45.7), respectively (Rong et al., 2021), no studies have examined the prevalence of the mix of these two conditions and dementia. Historically, studies of the association of only ADHD and dementia have been inclusive (Becker et al., 2023; Carr et al., 2024; Dobrosavljevic et al., 2021). Becker et al. (2023) investigated the associations between ADHD and neurodegenerative diseases/dementia. They concluded that the studies reviewed identified some evidence for a link between ADHD and subsequent development of neurodegenerative conditions (such as dementia), the magnitude of the direct effect of ADHD on neurodegeneration is yet to be determined. Carr et al. (2024) undertook a systematic review of whether or how ADHD may be a risk factor for neurocognitive disorders and found that ADHD may be a risk factor for certain neurocognitive disorders, although the evidence base is limited, and the absolute risk is small. Dobrosavljevic et al. (2021)

[7] See: app2vox (https://app2vox.com/resources/is-there-a-link-between-autism-and-alzheimers/); https://www.olgabogdashina.com/post/autism-and-dementia-1-prevalence; Medical News Today. (2024).

undertook a large population study from Swedish population-based registers to investigate the association between ADHD and mild cognitive impairment (MCI)/dementia. They found that ADHD is a potential risk factor for MCI and dementia, although the risk significantly attenuated after controlling for psychiatric disorders.

Studies attempted to look at whether there was sufficient evidence of a relationship between ADHD and dementia (Levine et al., 2023; Zhang et al., 2022). Levine et al. (2023) examined data from an Israeli national cohort drawn from some 109,218 members of a nonprofit Israeli health maintenance organization born between 1933 and 1952 and found that upon follow-up in old age, adult ADHD was found to be associated with an increased risk of dementia. Zhang et al. (2022) examined data from the Karolinska Institute in Sweden and identified a link between ADHD and dementia in the biological parents and kin of adults with ADHD. Their work revealed that parents of individuals with ADHD had an 55% increased risk of AD compared to the parents of persons without ADHD (HR 1.55, 95% CI 1.26–1.89). The strongest association was for early-onset AD and the associations weakened with decreasing genetic relatedness, indicating shared familial risk between ADHD and AD. Zhang et al. further reported that the exact cause of this association remains unknown but proposed three potential theories. One, that ADHD may increase the risk of other factors such as diabetes and head injuries, which in turn could elevate the risk of dementia. Two, that symptoms of ADHD in adults may resemble early signs of dementia. Three, that there may be shared genetic factors. Because of the high prevalence of ADHD in autistic adults and the growing knowledge of dementia risk of ADHD for some older age neurodegenerative condition, we may assume that autistic adults who also have been diagnosed with ADHD may be at elevated higher risk of some form of dementia. However, this supposition warrants further investigation to determine the extent of this connection.

The Lancet Commission (Livingston et al., 2020) identified several key risk factors for dementia in general, noting that growing body of evidence supports twelve potentially modifiable risk factors for dementia (these include: less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution). Together these twelve modifiable risk factors account for around 40% of worldwide dementias, which consequently could theoretically be prevented or delayed. The Commission report prescribes public and health policy and prevention initiatives to mitigate these risk factors and address lowering the incidence of dementia worldwide. These risk factors are being reiterated and increased. Hendriks et al. (2023) documented that having 2 *APOE* ε4 alleles, lower socioeconomic status, high CRP [C-reactive protein] levels, orthostatic hypotension, stroke, diabetes, heart disease, depression, hearing impairment, vitamin D deficiency, alcohol use disorder, social isolation, and lower physical frailty (handgrip strength) as risk factors.

From an individual risk reduction perspective in the general population, these may include mitigating hypertension by maintaining midlife systolic blood pressure control at 130 mm Hg or lower to delay or prevent dementia. Stopping smoking, even in later life, is known to ameliorate risk. The Commission recommends keeping cognitively, physically, and socially active in midlife and later life (although, it admits, that little evidence exists for any single specific activity protecting against dementia). Hearing loss can be mitigated using hearing aids, which can reduce the excess risk from hearing loss. Sustained exercise in midlife, and possibly later life, protects from dementia, perhaps through decreasing obesity, diabetes, and cardiovascular risk and lowering risk for cardiovascular dementia. Depression might be a risk for dementia, but also in later-life, dementia might lead to depression. Stress from being 'different' and consequent 'weathering' may also be a risk factor, oftentimes less susceptible to mitigation as it is externally generated (*see page 26*).

Even with risk factors gaining more attention, Weir (2023) reported that there is a paucity of research on the chronic physical health problems among autistic people as they age, with only a handful of studies assessing chronic health burden among those older than 35 years. There is history to the notion that autistic adults may be more likely to have specific health problems, including epilepsy/seizure disorders, sleep problems, and gastrointestinal conditions, along with immune system issues (Bishop-Fitzpatrick et al., 2019; Lord et

al., 2022; Miot et al., 2019; Tye et al., 2019,). Weir further noted that there may be more physical health problems than previously believed. In addition, many syndromes that include co-incident autism (e.g., Down syndrome, Fragile X, Rett syndrome etc.) also generate secondary conditions such as obesity, sleep disorders, seizures (regardless of the autism) which are risk factors.

Increasingly, studies correlate autism with cardiovascular as well as metabolic issues. A systematic review and meta-analysis found that autism was associated with greater risks of developing diabetes overall, increased risks of dyslipidemia, and heart disease; yet, showed no significantly associated increased risk of hypertension and stroke (Dhanasekara et al., 2023). Another study demonstrated that there is evidence of increased prevalence of Type 2 diabetes, hyperglycemia, hypertension, and dyslipidemia for those with autism, but the relationship is poorly understood (Chieh et al., 2021). Autistic adults are up to 3.4 times more likely to be diagnosed with obesity or diabetes and there is an increased risk of hypertension, particularly for males (Flygare Wallén et al., 2018).

As these risk factors also apply to autistic adults, exercise is another important lifestyle factor to consider. Regular physical activity has been linked to improved cognitive function and reduced risk of dementia (Mandolesi et al., 2018). Additionally, exercise has been shown to improve mood and reduce anxiety in individuals with autism (Hallett, 2019). Other lifestyle factors that may impact the risk of autism and dementia include sleep habits, stress levels, and social support. For example, poor sleep habits have been linked to increased risk of both conditions, while strong social support networks can help reduce stress and improve overall well-being (Stewart et al., 2020). Although behavior change is difficult and some associations might not be purely causal, individuals have the ability and potential to reduce their risk of dementia. While more research is needed to fully understand the impact of lifestyle factors on the development of dementia in autistic adults, making healthy choices can have a positive effect on brain health.

With respect to autism, modifiable risk factors with practical applications can include maintaining health and not being overweight, avoiding injury, exercising, and controlling for cardiovascular health. When examining the potential contribution of co-occurring physical health conditions, little data are extant that link prevalent health risk factors to autism (see section above on co-occurring health factors) and this calls for a program of research examining these factors. Certainly, environmental issues within the control of the individual, such as use of tobacco products or abuse of beverage alcohol or non-prescription drugs and minimizing exposure to stress ('weathering'), maintaining recommended weight, and controlling for hypertension can be seen as minimizing risk for dementia in later life. None of the factors noted as co-occurring conditions or genetic predispositions may be seen as specifically contributing to the development of Alzheimer's disease, which prevalence for older adults remains below norm generally in autistic adults. Although Vivanti et al. (2021) reported that there was an earlier expression of dementia in autistic adults under 65, data are absent that show that there is a prevalence of dementia above the norm for 65-year-olds and older in the general population. Nothing is known about prevalence of other dementias among autistic adults after age 65. It is uncertain whether this is due to earlier mortality, under-recognition, or no clear line to systemic dementia derivation among autistic adults (or more importantly, the lack of research on this topic).

In summary, the association between autism and select types of dementia remains a complex and largely unexplored area. While it has been observed that autistic adults under the age of 65 were approximately 2.6 times more likely to be diagnosed with early-onset dementia compared to the general population, these data did not establish a link with Alzheimer's disease. Instead, the findings may be more reflective of various dementias. Speculation on a potential bio-neurological relationship between autism and dementia arises from the observation that both conditions involve changes in the brain, with structural differences in autism and brain damage in dementia affecting memory and communication. Some studies suggest a genetic link between autism and dementia, while others propose lifestyle factors, such as diet and exercise, as potential influencers. The Lancet Commission identified

modifiable risk factors for dementia, applicable to both autism and the general population, including maintaining cardiovascular health, stopping smoking, staying physically and socially active, and managing mental well-being. However, specific data on the prevalence of Alzheimer's disease in older autistic adults are lacking, and current assumptions suggest that autistic adults may not show above-normal rates of Alzheimer's dementia in later life. Overall, the interplay between autism and dementia, especially in older adults, remains an area requiring further investigation to understand the potential connections and risks.

4.2 Other factors

4.2.1 Mortality.

Bernard-Brak et al. (2019) analyzed a database of 1,754 adults in the U.S. who had autism listed as one of the causes of deaths from the National Vital Statistics System with data from 1999 to 2015. They found a mean age at death for autistic adults at 68 years. They noted that autistic females had a higher mean age at death than autistic males, consistent with the trend in the sex differences in the general population. They also reported that results of their study indicated that autistic adults were, in fact, less likely than the general population to have Alzheimer's disease or a form of dementia as a cause of death. However, when it was present, autistic males were significantly more likely to have acquired Alzheimer's disease or a form of dementia as compared to autistic females. Krantz et al. (2023) undertook a review the Medicare-enrolment data in the U.S. and found that the median age of death was 72 years (IQR=69-78) for autistic adults, compared to 75 years (IQR=70-83) for non-autistic older adults. Among autistic older adults, those with ID had 1.57 times greater rate of mortality (95% CI=1.41-1.76) than those without, and males had 1.27 times greater rate of mortality (95% CI=1.12-1.43) than females. They suggest that when autistic people live to the age of 65, they may live to a more similar age as non-autistic peers. Lunsky et al. (2022) examined sex differences and premature mortality data in the province of Ontario in Canada and found that autistic males and females were more likely to die prematurely than non-autistic males (adjusted risk ratio, RR 3.13, 95%CI 2.58-3.79) and non-autistic females (adjusted RR 3.12, 95%CI 2.35-4.13) without developmental disabilities, but were less likely to die prematurely than adults with other developmental disabilities (males: adjusted RR 0.66, 95%CI 0.55-0.79; females: adjusted RR 0.55, 95%CI 0.43-0.71). Hwang et al. (2019) examined mortality rates for autistic individuals (age 5-64) in Australia and reported a rate of 2.06 times that of the general population. They noted that concurrent ID, epilepsy, mental health conditions, and chronic physical health conditions were associated with a higher risk of death for autistic adults, whereas demographic variables such as sex and socioeconomic status were not.

Hirvikoski et al. (2016) undertook a review of Sweden's National Patient Registry and the Causes of Death Register, which details how each Swedish resident died, and found autistic adults are more than twice as likely as their age peers in the general population to die prematurely. The mean age of death in the general population was 70.2 years (s.d. = 24.2, median = 80), whereas the corresponding figure for the entire autism group was 53.9 years (s.d. = 24.8, median = 55), for low-functioning autistic adults was 39.5 years (s.d. = 21.6, median = 40) and for high-functioning autistic adults was 58.4 years (s.d. = 24.0, median = 63) respectively. Hirvikoski et al. (2016) also found that mortality rates were higher among autistic adults who also have ID than among those who have autism alone. They also uncovered sex differences in the causes of death, with autistic females more likely dying of endocrine disorders (such as diabetes) or birth defects such as congenital heart malformations, whereas autistic males more likely dying from nervous and circulatory system disorders, such as epilepsy or heart disease. The most common cause of death among people with *severe* autism was epilepsy. By contrast, the most probable cause of death among people with *mild* autism was circulatory diseases.

Catala-Lopez et al. (2022) found, following an international review, that autistic persons had higher mortality rates than the general population and when causes of death were examined, autism was associated with higher mortality due to unnatural causes (e.g., injury, poisoning, and other). There was also an increased

risk of mortality from natural causes of death (ego, neurologic, respiratory system, and cancer). Their data indicated that for the most part longevity is abridged by earlier mortality, some attributed to lifestyle and social situations, rather than any inherent genetic factors.

> ***In summary,*** the *mortality patterns* among autistic adults reveal nuanced insights, drawing from numerous studies. Reviews noted that the mean age at death for most autistic adults was not too far from that of the general population, with exceptions for those with significant comorbidities. There are notable differences between low and high-functioning individuals. Mortality rates were higher among those with both autism and ID. There are also differences related to sex, with females with autism having a higher mean age at death than males, aligning with general population trends. Surprisingly, individuals with autism were less likely than the general population to have Alzheimer's disease or dementia as a cause of death. However, males with autism tended to have a higher likelihood of dementia, compared to females, showing up on death certificates. Sex differences also emerged in causes of death, with women more prone to endocrine disorders and birth defects, while men faced higher risks from nervous and circulatory system disorders. Epilepsy was a prevalent cause of death in severe autism, contrasting with circulatory diseases in mild autism. Overall, studies attributed higher mortality rates in autism to the shortened lifespan to lifestyle and social factors rather than intrinsic genetic elements. The collective findings highlight the need for further research studies to produce a comprehensive understanding of mortality factors within the autism population.

Environmental stress. As more research adds to the evidence on risk factors (Hendriks et al., 2023), it is evident that there is a greater influence of social determinants, individual behaviors, the physical and cultural environment, and biological systems. The intersectionality of these health determinants is gaining more recognition as focus is increased on understanding and addressing minority health and health disparities. In the U.S., the National Institute of Minority Health, and Health Disparities (NIMHD, 2023) is one governmental agency that is examining this, and its research framework adaptations acknowledge these lifespan factors. NIMHD includes adults with disabilities in the list of populations that experience health disparities.

Aviderez and Barksdale (2022) adapting a research framework for mental health disparities, drew attention to allostatic load, inflammatory response, telomere attrition within the biological domain of influence. Within the sociocultural environment they acknowledge the effects of stigma, bias, microaggressions, and more. McEwen (2004) proposed the mechanism of allostatic load to explain brain pathophysiology. Geronimus et al. (2006) described the relationship between the allostatic load and 'weathering'. Allostatic load refers to the physiological response of the body to cumulative burden of chronic stress and life events. Under such a burden, the body responds with primary inflammatory mediators, such as catecholamines, glucocorticoids, and cytokines (Juster et al., 2010; McEwen & Seeman, 1999).

Using the lens of race, Geronimus et al. (2006) further explained that socially structured factors contribute to repeated stress process activation which can accumulate and increase disease vulnerability across the life course. She explained this phenomenon in which individuals' social and psychological experiences produce physiological dysregulation and accelerated aging, and terms this intersectionality of these biopsychosocial mechanisms as 'weathering.' This 'weathering hypothesis' views the elevated rates of illness and disability seen among Black Americans as a physiological response to the structural barriers, daily slights, and other threats. Using biological and sociocultural environmental factors, the same phenomenon can be used to examine issues as experienced by autistic adults. Studies have acknowledged that the pathophysiology of autism involves several modifications at the genetic and at the immune level, such as with the increase of inflammatory cytokines and abnormal immune response on several levels (i.e., allostatic load biomarkers) (Lima et al., 2020).

The intersectionality of the biological system with the sociocultural environment is a lens that can be considered for people with autism. Mason, Ronald et al. (2021) suggest that the accelerated aging that is experienced by some autistic adults may be a result of allostatic load stemming from multiple stressors such as bullying, victimization, and stigma. This in conjunction with McEwen and Karatsoreos' (2015; 2020) proposal and research on immune system issues as well as a more recent article (McEwen & Karatsoreos, 2022) on circadian disruption of sleep with allostatic load consequences easily connects known physical conditions and biological stressors that may contribute as health risk factors specific to autism.

> ***In summary,*** as research sheds light on risk factors, the influence of social determinants, individual behaviors, environmental factors, and biological systems on health outcomes becomes evident. The intersectionality of these determinants, particularly in understanding and addressing health disparities, gains prominence. Governmental agencies are actively examining health disparities among populations, including adults with disabilities. Adapting research frameworks for mental health disparities, scholars highlight biological factors like allostatic load and inflammatory response, alongside sociocultural factors like stigma and bias. Allostatic load, a physiological response to chronic stress, is proposed as a mechanism contributing to physiological dysregulation and accelerated aging in autistic adults, akin to the 'weathering hypothesis' in explaining health disparities among some ethnic or racial minority groups. The intersectionality of biological and sociocultural factors offers a lens to understand the health challenges faced by autistic adults, including accelerated aging attributed to multiple stressors and immune system dysregulation. Circadian disruption of sleep, coupled with allostatic load consequences, further complicates the health risks specific to autism. Overall, a comprehensive understanding of the chronic physical health challenges in aging autistic adults requires consideration of both biological and sociocultural factors.

4.2.2 Intellectual disability and dementia risk.

The differences in co-occurring health conditions in autistic adults with and without co-occurring ID are less studied but may provide some clues as to who is at greatest risk for developing dementia and other neurological disorders. Studies have shown a higher prevalence of cardiovascular risk factors (i.e., overweight and obesity, diabetes, hyperlipidemia) particularly in those people with autism and a co-occurring ID (Cashin et al., 2016). Bishop-Fitzpatrick and Rubenstein (2019) found higher prevalence of most health conditions including cardiovascular disease, motor problems, hypothyroidism, and neurological disorders with diabetes, dyslipidemia and heart disease cited as higher risk. They used 2012-2015 Medicaid data for 143 adults residing in the U.S. with a recorded diagnosis of autism who were between 40 and 88 years of age and compared physical and mental health conditions for those with and without ID. Although there was an increased odds of neurological disorders including dementia (aOR 2.00, 95% confidence interval [CI]: 1.0, 4.1), none of the observed differences in physical and mental health conditions was statistically significant. They reported that an association with dementia may be explained or influenced by those comorbidities rather than being a direct result of autism.

Vivanti et al. (2022) drew upon multi-year Medicaid claims data in the U.S. population and looked for the incidence of neurodegenerative conditions, such as autism, among adults aged 30-to-64. Their results showed that the 5-year prevalence of dementia was 4.04% among adults with autism only, and 5.22% for those with autism and co-occurring ID (not including DS). Esbensen et al. (2010) examined functional differences of autistic adults and coincident ID with those of age-peer adults with ID associated with DS. They reported that autistic adults and ID were less residentially independent and had less social contact with friends, had more limited functional abilities and literacy, exhibited more behavior problems, and had more unmet service needs, compared to adults with DS. This finding speaks to the complexity of contributions to the functionality of autistic adults and ID and potential effects of lifetime cognitive impairment.

Although the association for risk of dementia in autistic adults absent ID is less clear-cut than in the case of concomitant ID, research suggests that genetic and neurobiological factors shared between autism and certain forms of dementia, such as frontotemporal dementia, may contribute to some risk for dementia. Starkstein et al. (2015) reported findings from two studies that suggest a relationship between autism and Parkinson's disease; however, they could only speculate on the underlying explanation for this observed relationship but postulated several potentials such as exposure to neuroleptic medication, and pathogenetic mechanisms, amongst possibilities. Dementia has been increasingly more recognized to be a common feature in people with Parkinson's disease, especially in old age (Emre et al., 2007). It has been reported that Parkinson's disease, Parkinson's disease dementia and dementia with Lewy bodies share clinical, pathological, genetic, and biochemical signatures (Walker et al., 2019).

> ***In summary,*** the relationship between ID and dementia in individuals with autism is a complex and less-explored area. Studies suggest a higher prevalence of cardiovascular risk factors in people with autism, particularly those with co-occurring ID, including overweight, obesity, diabetes, and hyperlipidemia. Studies using U.S. Medicaid data for autistic adults, found increased odds of neurological disorders, including dementia, in those adults with ID. However, none of the observed differences in physical and mental health conditions were statistically significant. The association with dementia may be influenced by comorbidities rather than being a direct result of autism. While the link between autism and dementia is less clear-cut without concomitant ID, research indicates shared genetic and neurobiological factors, particularly with forms like frontotemporal dementia. It has been suggested that there exists a potential relationship between autism and Parkinson's disease, highlighting the need for further investigation into underlying explanations, including medication exposure and pathogenetic mechanisms. The recognition of dementia as a common feature in Parkinson's disease adds complexity to understanding the interplay between autism, ID, and different forms of dementia.

4.2.3 Down syndrome and dementia risk.

The association of DS and autism has been noted in the clinical and research literature (e.g., Hamner et al., 2020; Richards et al., 2015; Spinazzi, Santoro et al., 2023). Channell et al. (2015) have cautioned that prevalence estimates of autism in DS are highly varied, and that this variation is partly due to the difficulty of screening for and diagnosing comorbid autism in individuals with a syndrome that carries its own set of social communicative and behavioral difficulties that are not well documented. A meta-analysis undertaken by Richards et al. (2015) suggested that about 16–18% of individuals with DS have been diagnosed with autism, and Spinazzi, Santoro et al. (2023) reported that estimates from individual studies using differing ascertainment criteria ranging from 5 to 39%. Spinazzi, Santoro et al. also reported that of the child-age individuals with DS and autism in a cohort they studied, 91% had Trisomy 21 variant DS and 5.6% had Mosaic variant DS, and that individuals with DS and autism had twice the odds of being male. They also reported that a history of epilepsy and/or infantile spasms was more associated with DS at significantly higher odds of being diagnosed with autism, and that individuals with DS and autism had significantly higher odds of a diagnosis of gastroesophageal reflux and constipation, consistent with findings in idiopathic autism.

Further, as noted by Sultan, Juneja, and Bhaskar (2020), school age individuals with DS and autism have been described to show an increased frequency of developmental regression along with the greater potential for neurological afflictions such as seizures, dysfunctional swallowing, severe hypotonia, and weaker motor skill, congenital cardiac defects, gastrointestinal tract aberrance, ophthalmological disorders, pneumonia, and sleep disturbances. Dimachkie Nunnally et al. (2021) reported that individuals with DS and autism tend to have lower cognitive abilities when compared to those with DS-only and that there are differences in expressive and receptive language abilities with individuals with DS and autism have lower expressive and receptive language abilities than those with only DS. Baumer and Capone (2023) suggested that younger adults with DS or autism, and especially those with both DS and co-occurring autism commonly display behavioral

and psychiatric symptoms that can impact quality of life and places increased burden on caregivers, and this has the potential of also impacting caregiving in older age.

As virtually all adults with DS show neuropathological changes of Alzheimer disease by age 40 years (Lott & Head, 2021), the question arises to what degree does DS pose a risk for dementia in autistic adults who also have DS? Studies have noted the relationship between Down syndrome and high risk for dementia. Hithersay et al. (2019) found that dementia was associated with mortality in 70% of older adults with DS. APOE ε4 carriers and/or people with multiple comorbid health conditions were at increased risk of dementia and death. The answer to the question is elusive, as there is a dearth of studies specifically examining this question. Channell et al. (2015) commented on the difficulty of screening for and diagnosing comorbid autism in individuals with Down syndrome due to commonality of social communicative and behavioral difficulties However, it was uncertain what proportion of those adults with ID may have also had DS and the study excluded adults coded as having DS.

> ***In summary***, studies note that approximately 16–18% of individuals with DS are diagnosed with autism. Individuals with DS and autism exhibit a higher likelihood of certain health issues, such as epilepsy, infantile spasms, gastroesophageal reflux, and constipation. Notably, as adults with DS are known to show neuropathological changes related to Alzheimer's disease by age 40, the question arises regarding the risk of dementia in adults with DS and autism. There are virtually no dedicated older age or dementia studies regarding this mixed population. One study offered some insight into the risk as it was found that autistic adults with a co-occurring ID are 2.5 times more likely to be diagnosed with early-onset dementia compared to the general population. However, since DS was not included explicitly in the analysis, it is possible that some adults with ID also had DS but were not coded as such. Overall, while the coexistence of DS and autism is noted, we suggest that if there is an elevated risk for Alzheimer's in adults with both conditions it is primarily attributed to co-occurring DS rather than autism.

4.2.4 Mental health conditions and dementia risk.

The Lancet Commission (2022) highlighted that all neurodevelopmental disorders, including autism, have co-occurring conditions; these include physiological conditions (as previously noted), mental health disorders (such as anxiety, depression, ADHD), repetitive and challenging behaviors (such as self-injury, aggression) and sleep issues. Symptoms of mental health disorders may be expressed in atypical ways. This coupled with a lack of appropriate assessment tools and diagnostic criteria along with communication barriers and proxy informants lends itself easily to the risk of diagnostic overshadowing (Kindahl et al., 2023).

It appears that the rate of psychological medication prescription is significantly higher in medical situations with autistic patients than with patients absent autism. The most common medications prescribed for autistic adults were antipsychotics and antidepressants (Birch et al., 2017). Both older age and psychiatric comorbidity were associated with higher prevalence of psychopharmacotherapy and psychotropic polypharmacy. Adverse long-term effects are an issue as psychotropic medications are known to increase the risk of obesity, cardiovascular disease such as hypertension, hyperlipidemia, and diabetes (Robert & Duff, 2021).

Recognition of the presence of autism in adulthood can represent a diagnostic challenge, mainly since comorbidity with psychiatric and/or neurological conditions could veil neurodevelopmental disorders' manifestations (Bertelli et al., 2010). Crawford and colleagues (2014) surveyed the caregivers of 140 subjects in the U.S. with late-life cognitive impairment from the University of Kentucky Alzheimer's Disease Center Longitudinal Cohort and found that autism symptoms were associated with late-life degenerative dementia. Autism symptoms were more common in those with early vs. late onset dementia (Crawford et al., 2014). There is also some evidence of greater risk for various dementias among adults with mental disorders, which may be

co-occurring conditions for some autistic adults (although this association does not imply causal factors). Richmond-Rakerd et al. (2022) found, from analyzing New Zealand Integrated Data Infrastructure's systems data, that adults in general with a mental disorder were at increased risk of developing subsequent dementia (relative risk [RR], 4.24; 95% CI, 4.07-4.42; hazard ratio, 6.49; 95% CI, 6.25-6.73) and among individuals with eventual dementia, those with a mental disorder developed dementia a mean of 5.60 years (95% CI, 5.31-5.90) earlier than those without a mental disorder. It is unknown to what degree this mirrors the situation of autistic adults with mental disorders.

There is also evidence supporting the link between autism and dementia and cognitive decline based on self-reported data. For example, Klein et al. (2022) reported that in a sample of middle and older age autistic adults in the U.S. without ID (N = 210), who were recruited through Simons Powering Autism Research (SPARK), high rates of cognitive decline were reported, with 30% of the sample screened positive for cognitive decline using the dementia screener, AD8 Dementia Screening Interview (Chen et al., 2018; Galvin et al., 2005). Roestorf et al. (2022) also reported that some two-thirds of autistic adults reported experiencing at least one co-occurring mental health condition, and over a third met the criteria for three or more co-occurring mental health conditions. They noted that mental and physical health difficulties were related to autistic traits and difficulties in everyday life and were consistent predictors of poor quality of life. Likewise, Steward et al. (2021) noted that autistic adults reported significantly elevated rates of psychiatric diagnoses compared to the neurotypical group. This included significantly higher self-reported symptoms of current depression and anxiety, but few differences in individual physical health conditions and no differences in total co-occurring physical diagnoses between groups.

With older age, Lever and Geurts (2016) found that when compared to other psychiatric patients, levels of symptoms and psychological distress were high over the lifespan for autistic adults in a Netherlands sample. They reported that some 79% met criteria for a psychiatric disorder at least once in their lives, with depression and anxiety the most common. However, looking at older adults, they found this group less often met criteria for a psychiatric diagnosis and they concluded that despite marked psychological distress, psychiatric problems were also less prevalent in older aged individuals with autism. Conceptually, it is recognized that many autistic adults may not have severe mental illness[8] (or 'psychiatric conditions') but may experience social disturbance conditions or clinically relevant behaviors that are linked to depression, anxiety, and social phobias. Kats et al. (2013) investigated the prevalence of clinically relevant behaviors and medical problems in a U.S. sample of adults aged 30 to 59 with autism and ID, in comparison to those just with ID. They found that estimates of self-injurious, disruptive, and destructive behavior were almost double in autistic adults and ID relative to those with ID only. Otherwise, McGuire et al. (2022) found that in an Irish sample of older autistic adults some half had some level of ID. Among the autism group, they reported reduced functional independence, increased psychiatric comorbidity, more psychotropic prescribing, and more behavioral presentations than the older population generally or those with ID only.

Longitudinal research has shown that autistic adults without ID did not show any differences in cognitive declines with age compared to non-autistic adults (Torenvliet et al., 2023), however, this suggests that some of the increased risk for dementia may be specific to the subgroup of autistic individuals with ID. Oberman and Pascual-Leone (2014) remarked that some autistic adults may have a dysfunction in brain plasticity, which is essential to the establishment and maintenance of brain circuitry; however, too much plasticity may lead to instability of structural connections and compromise of functional systems necessary for cognition and behavior. They undertook a multiple linear regression using age and diagnosis as predictor variables in order to evaluate strength of the relationship between age, diagnosis or an interaction of the two factors and the

[8] Serious mental illness (SMI) commonly refers to a diagnosis of psychotic disorders, bipolar disorder, and either major depression with psychotic symptoms or treatment-resistant depression. SMI can also include anxiety disorders, eating disorders, and personality disorders, if the degree of functional impairment is severe. SMIs are long-term illnesses involving substantial functional impairment over multiple symptom domains (Evans et al., 2016).

degree of modulation in cortical excitability by transcranial magnetic stimulation as an index of cortical plasticity and found that across the age-span autistic adults show a consistently increased modulation of cortical excitability as compared to typically developing individuals, such that the general slope of decline across the age span is matched across both groups. Their contention is that an individual's risk of age-related cognitive decline (and risk for manifesting symptoms of dementia) depends on the individual's starting point and slopes of change in plasticity efficiency over the lifespan. They suggest that autistic adults might be relatively protected from age-related cognitive decline and the risk of dementia.

> ***In summary,*** the review of numerous studies underscores the intricate relationship between autism, cognitive health, and cognitive decline in adulthood. Recognizing autism in adults poses diagnostic challenges due to potential comorbidities with psychiatric or neurological conditions that may mask neurodevelopmental disorder manifestations. It has been shown that there is a significant association between autism symptoms and late-life degenerative dementia, with a higher prevalence in early-onset cases and that adults with mental disorders, including some with autism, can face an increased risk of subsequent dementia, occurring earlier than in those without mental disorders. It was also noted that there are elevated rates of cognitive decline in middle and older age autistic adults without ID, indicating a potential link between autism and cognitive deterioration. Longitudinal research has suggested that autistic adults without ID exhibit similar cognitive declines with age compared to non-autistic adults, raising the possibility that increased dementia risk may be specific to the subgroup with ID. Generally, findings suggest that older adults with elevated autistic traits may be at greater risk of poorer mental, but not physical, health in later life and that mental health difficulties in autism persisted into older age and did not improve over time. The exploration of brain plasticity appears to support the notion that individuals with autism might be relatively protected from age-related cognitive decline and dementia due to consistently increased cortical excitability. This synthesis of findings highlights the need for further research to unravel the complex relationships among autism, cognitive decline, and potential protective factors like brain plasticity.

4.2.5 Behavioral and psychological symptoms of dementia and dementia risk.

Behavioral and psychological symptoms of dementia (BPSDs) are another factor in identifying potential increasing cognitive impairment in autistic adults. BPSDs are non-cognitive symptoms commonly associated with Alzheimer's disease. Fernández et al. (2010) in a study of Spanish Alzheimer's patients, reported that the most prevalent symptoms were lack of concentration (56%), tremors (56%), depression (44%), lack of cooperation (36%), and delusions (32%). Patients with higher BPSD scores showed a significantly higher prevalence of psychotic symptoms (delusions, hallucinations, and delirium) and tremors, while emotional symptoms (tearfulness and apathy) predominated in patients with lower BPSD scores. Cheney et al. (2023) reported that people with autism experience fewer close relationships, higher levels of social isolation, and significantly more mental health problems, with estimates of up to 72% of individuals meeting criteria for at least one comorbid mental health diagnosis, often in the realm of mood and anxiety disorders. It is unknown to what degree BPSDs manifest in autistic adults with dementia.

One consideration is the co-occurrence of Down syndrome, which poses an elevated risk for Alzheimer's disease. Dekker et al. (2018) reported that changes in anxiety, sleep disturbances, apathy, and depressive symptoms possibly serve as 'alarm signals' of the onset of Alzheimer's disease in DS and conversion to dementia. Adults with DS and Alzheimer's disease tend to show increased verbal aggression, destructive behavior, or physical aggression against other people. If autistic adults also have Down syndrome this may be an additional signal that MCI or early Alzheimer's disease is present.

> ***In summary***, autistic individuals, experiencing higher levels of social isolation and mental health issues, often meet criteria for comorbid mood and anxiety disorders. However, the manifestation of BPSDs in autistic adults with dementia remains unclear. Co-occurrence of DS, which elevates

the risk for Alzheimer's, may further complicate the picture. Changes in anxiety, sleep disturbances, apathy, and depressive symptoms in Down syndrome individuals may signal the onset of Alzheimer's and conversion to dementia, marked by increased aggression or destructive behavior. For autistic adults with Down syndrome, heightened verbal or physical aggression may serve as additional signals of mild cognitive impairment or early Alzheimer's disease. Understanding and recognizing these behavioral and psychological symptoms is crucial for timely intervention and support in this vulnerable population. This is an area that warrants in-depth research.

4.2.6 Autism and frontotemporal dementia.

Frontotemporal dementia (FTD) is a highly heritable group of neurodegenerative disorders, with around 30% of affected adults having a strong family history (Greaves & Rohrer, 2019). FTD is probably the most common form of dementia experienced in people under the age of 60, with an estimated lifetime risk of 1 in 742 (Greaves & Rohrer, 2019). Behavioral variant FTD (bvFTD) is the most common diagnosis within this type of dementia and is characterized by changes in personality, while the language variant (known as primary progressive aphasia or PPA) is typically associated with progressive speech production or comprehension difficulties. Age at symptom onset is variable in each of the various forms of FTD, with intrafamilial variability (even within the same generation) of at least a decade in some families. Familial heritability is expressed as a greater risk of psychiatric disorders, including schizophrenia and autism. Midorikawa (2015) noted that in certain cases, older adults with undiagnosed autism, who developed maladaptive behaviors after negative life events, were considered as having a behavioral variant of frontotemporal dementia (bvFTD). Midorikawa and Kawamura (2012) examined three patients who showed symptoms of bv-FTD and demonstrated signs of autism using the diagnostic criteria for bv-FTD, and their caregivers retrospectively provided data to calculate the Autism-Spectrum Quotient, Japanese version. They compared these data with those obtained from three adults, absent autism, with Alzheimer's disease. All three patients met the criteria for bv-FTD and had a higher Autism-Spectrum Quotient score than did comparable Alzheimer's disease subjects. It is possible that some senile persons with frontotemporal lobar degeneration-like maladaptive behavior may also have subclinical autism. With respect to signals of presymptomatic expression bv-FTD, Greaves and Rohrer (2019) have noted that neuropsychometric measures are abnormal in presymptomatic carriers around 5 years prior to expected symptom onset.

Interestingly, the question of onset of autism in later age was noted by Crawford et al. (2014). They reported that some studies have suggested that late-life onset of autism symptoms can develop in frontotemporal dementia but have not been linked to the development of other dementias or MCI. To characterize late-life autism symptoms in mild neurocognitive disorders and dementia, they surveyed the caregivers of 140 subjects with late-life cognitive impairment using the Gilliam Autism Rating Scale (GARS-2, 2006; Montgomery et al., 2008). Those adults with the highest autism index ratings reported significantly younger age at onset of decline than those who scored in the 'Unlikely' range (n=49): 68.2±9.3 vs 74.9±7.9 ($p < 0.01$). This remains true when the respondents were restricted to just those cases with dementia (n=13 and n=33): 67.7±9.4 vs. 74.0±8.8 ($p < 0.05$). These data demonstrate that autism symptoms are associated with late-life degenerative dementia and that such symptoms are more prevalent in those with early vs. late onset dementia. Crawford et al. suggested that further work examining the interplay between autism and late life dementia could help identify key areas of shared neuroanatomic involvement between autism and late life dementia. Hodges (2023) reported that the syndrome of behavioral variant frontotemporal dementia (bvFTD) where changes in social cognition are prominent, has features that overlap considerably with those seen in people with autism. He showed that adults with bvFTD had impaired performance of a range of theory of mind tasks thus consolidating the clinical overlap between bvFTD and autism, although those with the former differ in that they progress to full blown dementia and eventual death.

Rhodus et al. (2020) investigated the hypothesis that subjects with *late-onset dementia* associated with autism-like behaviors will exhibit increased pathologic features in both the frontal and parietal association cortices. They undertook comprehensive neuropathologic evaluations including assessment of all common late-life dementia pathologies using both semi-quantitative rating scales and digital quantitative measures of global and regional pathological features. Between group analyses demonstrated no significant differences in age, education, sex, clinical diagnosis, or apoE4 status. High-autism vs. no-autism cases scored significantly higher on the Clinical Dementia Rating Scale[9] ($p<0.05$). Approximately 80% of cases had a primary pathologic diagnosis of Alzheimer's disease, with the remaining 20% of individuals demonstrating pathologic features consistent with Late (16%), cerebrovascular (2%), or Lewy body disease (2%). No cases had frontotemporal lobar degeneration (FTLD) as a primary or comorbid pathology. Quantitative measures of neurofibrillary tangles and tau burden were higher in the frontal lobes of high-autism subjects compared to the matched no-autism controls ($p<0.02$). They noted that their data were the first to link autism-like behaviors to increased levels of tau and neurofibrillary pathology in the frontal lobes at autopsy in subjects with late-life dementia. However, their data demonstrated that FTLD pathology is not a major contributor to such behaviors in a community-based cohort of late-life dementia.

The behavioral variant of frontotemporal dementia (bvFTD) is a frequent cause of *younger-onset* dementia (Ducharme et al., 2020). It has been noted that the diagnosis of bvFTD remains challenging because of the limited accuracy of neuroimaging in the early disease stages and the absence of molecular biomarkers, and therefore relies predominantly on clinical assessment. BvFTD shows significant symptomatic overlap with non-degenerative primary psychiatric disorders including autism and major depressive disorder, bipolar disorder, schizophrenia, and obsessive-compulsive disorder. Symptoms of particular interest include features that are strongly associated with other types of dementia and or with other FTLD-spectrum syndromes, falls, and dysphagia. Additionally, clinical histories should include symptoms of autism. Ducharme et al. provide a full explanation of the challenges of differentiating bvFTD for other similar neuropathologies in general but do not offer insights in application with autism. Several workers (e.g., Ducharme et al., 2020; Greaves & Rohrer, 2019) have reported the potential value of biomarkers with bvFTD once there is international consensus; however, while that may be useful in the future with autistic adults with risk for bvFTD, the level of certainty is not yet there.

Greaves and Rohrer (2019) reported that the C9orf72 mutation seems to be the most common worldwide cause of genetic FTD. Hodges (2022) found in a study screening for the mutation in phenocopy cases that the mutation to be rarely present. In contrast, another study involving 1,400 family members of FTD patients (with and without the mutation) showed that children from C9orf72 families had a significantly higher rate of autism. He asked, "Does late life autism simply mimic bvFTD, could autism be a risk factor for FTD or are they separate disorders with a shared genetic background?"

> ***In summary,*** the literature indicates a greater association (albeit not causality) of autism with FTD. This form of dementia encompasses a spectrum of neurodegenerative disorders with a significant hereditary component, affecting individuals predominantly under 60 years old. FTD onset varies, with some families showing intrafamilial variability spanning a decade. Familial heritability is linked to increased risk of psychiatric disorders like schizophrenia and autism. Studies suggest a potential overlap between bvFTD and autism, with some older adults with undiagnosed autism displaying maladaptive behaviors akin to bvFTD symptoms. Moreover, late-life onset of autism symptoms has been observed in dementia, particularly Alzheimer's disease. Neuropathological evaluations reveal increased tau and neurofibrillary pathology in the frontal lobes of individuals exhibiting autism-like behaviors in late-on-

[9] Morris, J.C. (1997). Clinical Dementia Rating: A reliable and valid diagnostic and staging measure for dementia of the Alzheimer type. *International Psychogeriatrics*, 9(S1), 173 - 176. https://doi.org/10.1017/S1041610297004870

set dementia. Although bvFTD diagnosis remains challenging due to symptomatic overlap with psychiatric disorders, biomarkers may offer future diagnostic clarity. The C9orf72 mutation is implicated in genetic FTD, with children from affected families showing a higher prevalence of autism. These findings prompt further exploration of the relationship between late-life autism and bvFTD, shedding light on potential diagnostic and therapeutic implications.

4.2.7 Other factors associated with dementia.

Other neuropathologies. Midorikawa (2012) has noted that there may be a relationship between developmental disorders and dementia, such as with Lewy bodies (DLB) and those with Parkinson's disease (PD). As the adults in these cases showed a tendency for having attention-deficit/ hyperactivity disorder (ADHD) at a younger age, he contended that a neurotransmitter pathway or language network in the brain is vulnerable in some subjects. Midorikawa also indicated that no studies have shown a causality of developmental disorders, such as autism, and dementia. To date, there has not been any published research linking the latter two diseases to autism, although Starkstein et al. (2015) raises many potentials given the overlapping phenomenology, neurobiology, and genetic such as involvement of the basal ganglia and frontal lobe dysfunction (Hollander et al., 2009; Mai et al., 2023). Additionally, lifestyle factors, including limited physical activity, social isolation, and suboptimal diet, may further increase the susceptibility to dementia in some autistic individuals. Factors specified as potentially contributing to expression of dementia among adults with autism include early-onset neurodevelopmental challenges. The cognitive and adaptive skills of individuals with autism often fall below age-appropriate levels, rendering them more vulnerable to the cognitive declines associated with dementia (Bishop-Fitzpatrick et al., 2017).

Rhodus et al. (2022) examined the neuropathologic features of late-life dementia in research volunteers with and without antemortem behaviors characteristic of autism spectrum disorders. They undertook antemortem cross-sectional assessments of autistic spectrum behaviors proximal to death in persons (N = 56) with diagnosis of mild cognitive impairment or dementia (via the Gilliam Autism Rating Scale, 2nd edition (GARS-2)[10], followed by postmortem quantitative and semiquantitative neuropathologic assessment. The GARS-2 was used as an antemortem screening tool to stratify participants into two groups: "Autism Possible/Very Likely" or "Autism Unlikely." Data were analyzed using nonparametric statistics comparing location and scale to evaluate between-group differences in pathologic features. Neurofibrillary tangles (NFT; $p = 0.028$) density and tau burden ($p = 0.032$) in the frontal region, the NFT density ($p = 0.048$) and neuritic plaque burden ($p = 0.042$), and the tau burden ($p = 0.032$) of the temporal region, were significantly different in scale between groups. Rhodus et al. noted that behaviors characteristic of autism were linked to increased pathologic tau burden in the frontal and temporal lobes in persons with late-life dementia.

Toloza Ramírez et al. (2020) suggested that cognitive impairment and behavioral disorders lead potentially to neurodegenerative diseases resulting in dementia in autistic adults – which affects the performance of activities of daily living (ADLs). Their systematic review of the articles noting the progression of cognitive impairment and dementia in adulthood lead them to believe that autistic adults develop early impairments mainly affecting cognitive functions such as memory and executive functions. Moderate to a profound ID also appeared to be associated with the development of dementia in autistic adults.

***Genetics*.** Genetic susceptibility is a consideration, as genetics plays a pivotal role in both autism and dementia. Recent research has unveiled shared genetic variants between autism and late-onset Alzheimer's disease (LOAD), potentially linking the two conditions at a molecular level (Nadeen et al., 2021). These genetic overlaps underscore the importance of understanding the genetic predispositions that may render autistic adults more susceptible to dementia. Neurobiology, such as chronic inflammation, oxidative stress, allostatic

[10] Volker et al. (2016). Factor structure, internal consistency, and screening sensitivity of the GARS-2 in a developmental disabilities sample. *Autism Research and Treatment,* 2016:8243079. doi: 10.1155/2016/8243079. Epub 2016 Feb 15.

load, and mitochondrial dysfunction, are processes implicated in both autism and various forms of dementia and might serve as common pathways contributing to cognitive decline (Mostafa & Al-Ayadhi, 2015; Swerdlow, 2018).

Life experiences. Further, life challenges in behavioral and functional adaptation, potentially linked to 'weathering' (Geronimus, 1992; Johnson & Gomez, 2023), are often encountered by autistic adults and can exacerbate their vulnerability to dementia. Some autistic adults may struggle with activities of daily living, social engagement, and adaptive functioning, making them more dependent on caregivers and susceptible to a decline in these abilities as they age (Trembath, 2019). Social-environmental factors may also be at play, as social isolation is a common issue faced by autistic adults due to communication difficulties and limited social skills. This isolation can lead to reduced access to healthcare services and preventive measures, potentially delaying the early detection and management of cognitive decline (Malik-Soni et al., 2022; Nicolaidis et al., 2019).

The synthesis of numerous studies reveals a complex relationship between autism and dementia, encompassing diverse factors such as behavioral manifestations, genetic susceptibility, shared neurobiological processes, and environmental influences. Midorikawa (2015) and Rhodus et al. (2020) suggest a potential link between autism and late-onset dementia, particularly frontotemporal dementia, supported by increased tau pathology in specific brain regions. Starkstein et al. (2015) explore shared phenomenology, neurobiology, and genetic factors, while genetic overlaps between autism and late-onset Alzheimer's disease are identified (Nadeem et al., 2021). Neurobiological processes, including chronic inflammation and mitochondrial dysfunction, are implicated in both conditions (Mostafa & Al-Ayadhi, 2015; Swerdlow, 2018). Furthermore, environmental factors such as lifestyle, limited physical activity, and social isolation may contribute to dementia susceptibility in autistic individuals. Notably, autistic adults, particularly those with ID, exhibit early impairments affecting cognitive functions, potentially leading to dementia (Toloza Ramírez et al., 2020). The intricate interplay of these factors emphasizes the need for comprehensive research to explain the mechanisms underlying the association between autism and dementia, with implications for early detection and tailored interventions.

> ***In summary,*** data do not show an evident, *above norm*, risk for Alzheimer's disease associated with autism; but some studies do show some uptick of other forms of dementia (such as behavioral variant frontotemporal) among autistic adults. Our understanding of the risk factors for dementia among autistic adults is still evolving; but it is evident that a complex interplay of genetic, neurobiological, and environmental factors contributes to this vulnerability. Better understanding the precise mechanisms underlying these associations remains an ongoing challenge. Future research may elucidate the intricate relationships between genetic, neurobiological, and environmental factors that contribute to the elevated risk of dementia in individuals with ID and autism. Such insights are crucial for developing targeted prevention and intervention strategies, determining early identification via the use of biomarkers, as well as any new disease modifying treatments that may become apparent.

5.0 Pharmacological interventions/treatments

Rossignol and Frye (2014) examined the utility of the use of medications approved for Alzheimer's disease in autism spectrum disorder and noted that only two medications (risperidone and aripiprazole) are approved for use in the U.S. to *treat Alzheimer's symptoms* in autistic adults. These medications have been approved to treat irritability, which is not a core symptom of autism, but one that may be found in adults with

dementia of the Alzheimer's type. Several medications originally developed to treat existing Alzheimer's symptoms (but not the reduction of amyloid buildup in the brain) have been used for treating BPSD-like behaviors in autistic adults, but not because Alzheimer's disease has been diagnosed. To determine other use, Rossignol and Frye examined studies which examined the use of Alzheimer's medications with persons with autism, including donepezil (seven studies, two were double-blind, placebo-controlled [DBPC], five out of seven reported improvements), galantamine (four studies, two were DBPC, all reported improvements), rivastigmine (one study reporting improvements), tacrine (one study reporting improvements), and memantine (nine studies, one was DBPC, eight reported improvements).

Collectively, these studies showed improvements in expressive language and communication, receptive language, social interaction, irritability, hyperactivity, attention, eye contact, emotional lability, repetitive or self-stimulatory behaviors, motor planning, disruptive behaviors, obsessive-compulsive symptoms, lethargy, overall autistic behaviors, and increased REM sleep. Reported side effects included irritability, gastrointestinal problems, verbal or behavioral regression, headaches, irritability, rash, tremor, sedation, vomiting, and speech problems. Both galantamine and memantine were sufficiently robust and improved both core and associated symptoms of autism. It is unknown of the utility of these medications in treating BPSDs in adults diagnosed with Alzheimer's disease. Rossignol and Frye (2014) noted that given the lack of medications approved specifically to treat autism, further studies on novel medications, including Alzheimer's disease treatment medications, are needed. The controversial aspect relating to the anticholinergic effects of various classes of drugs remains little investigated, despite the knowledge that autistic people with ID are subject to numerous pharmacological treatments which exposes them to a greater risk of these effects (De Vreese et al., 2018; O'Dwyer et al., 2018).

Questions arise as to whether the emerging anti-amyloid drugs (e.g., Leqembi™ [lecanemab] approved for routine use in the China, Japan, and the U.S.) might also have utility for autistic adults who have been *diagnosed with Alzheimer's disease* (Cumming et al., 2023). One drug, Aduhelm™, had limited use in the U.S. prior to being withdrawn from the market (Biogen, 2024; Hassan & Christensen, 2024). When both drugs were available, prescribers were cautioned about prescribing them for patients with Down syndrome due to expectations of adverse effects associated with amyloid-related imaging abnormalities or ARIAs (Cummings et al., 2023) which may have limited access to a segment of autistic adults. This caution may be an issue when considering prescribing lecanemab or any other newly approved Alzheimer's disease modifying treatments for autistic adults *and co-occurring* Down syndrome (Hillerstrom et al., 2024). To be eligible for obtaining one of the anti-amyloid medications (in the U.S.), autistic adults must show clinical and biomarker evidence of mild cognitive impairment or mild dementia *caused by Alzheimer disease*, including positron emission tomography (PET) neuroimaging or cerebrospinal fluid analysis demonstrating amyloid burden, and magnetic resonance neuroimaging not suggesting a likely alternative cause for dementia (Watt, 2023).

However, whether Leqembi™ or similar drugs have utility with autistic patients and meet the criteria of diagnosed MCI or early-stage dementia associated with Alzheimer's disease has been specifically addressed by John Kruse MD, PhD, at the School of Medicine and Dentistry at the University of Rochester. When aducanumab was still available, he cited: "*So far, it's not even clear if aducanumab is beneficial in treating Alzheimer's. The research so far suggests that the drug is more effective at reducing the amount of beta-amyloid plaques in brains than it is in reducing symptoms of dementia. Although some research suggests that at least some individuals with autism have an excess of beta-amyloid plaque in their brains, the amount does not appear to be as excessive or as prevalent in autism as it does in Alzheimer's. So, yes, the new med might be helpful, but we're a long way from showing that it actually helps"* (Quora, 2023).

Aduhelm™, the first conditionally approved AD medication, was removed from use in the U.S. by Biogen in January 2024 (Robbins, 2024). However, Leqembi™, the second, remains and has been approved for general use with its costs covered in the U.S. for all enrollees in Medicare, and in Japan for adults enrolled in

its National Health Insurance program (Igarashi et al., 2023; Japan Times, 2023), but only for those adults with proven MCI or early clinical dementia stemming from Alzheimer's disease. Eisai, the pharmaceutical firm behind Legembi™, has submitted applications for approval of use of lecanemab in numerous countries and regions, including to the European Medicines Agency in the European Union (BioArtic, 2023). In Canada it is under review by Health Canada (Watt et al., 2023). In Israel, the application has been designated for priority review. In China the application was submitted to the National Medical Products Administration (NMPA) and recently approved for use (Biogen, 2024), and in Great Britain, lecanemab has been designated for the Innovative Licensing and Access Pathway (ILAP), which aims to reduce the time to market for innovative medicines (Biogen, 2023). A third medication, donanemab (Sims et al., 2023), was poised to be approved in early 2024 in the U.S., but its approval was delayed pending further review by an expert panel (Foster, 2024). Donanemab is also being reviewed for approval in other countries (McKie, 2023). In England, the Medicines & Healthcare Products Regulatory Agency (MHRA) will decide if lecanemab and donanemab are safe and effective, then the NICE will decide whether the cost for the medications will be covered (Jarvis, 2024).

These medications are designed for treating early-stage Alzheimer's disease, which may be appropriate for a small number of autistic adults who have been diagnosed with this form of dementia. Practitioners should be aware that when these disease modifying treatments (DMTs) become more prevalent in use, there will be a few steps that have to be undertaken before they can be prescribed (The Lancet Neurology, 2024). Among them are diagnostic elements which will include a clinical diagnostic assessment, biomarker confirmation of the presence of this disease, documented impairment of ADLs and IADLs due to Alzheimer's, financial support (as these medications are costly, unless covered by national health schemes), and an evaluation of risk, given potential side effects (such as ARIAs). Once prescribed, consideration must be given to the local availability of medical clinics or facilities that have the capability for employing medication infusion (currently this is the only available means of medication provision), patient tolerance for multiple sessions (usually fortnightly) of medication infusion, and tolerance of periodic magnetic resonance imaging (MRI) and other means of invasive surveillance (included blood tests, spinal taps, etc.). To benefit from these drug treatments, clinicians need to agree upon whether general use instruments defining the presence of MCI and early-stage dementia apply equally to autistic adults or should work be undertaken to develop adaptations that would apply specifically to autistic adults. Access to clinicians and MRI and PET scanners to validate the presence of brain neuropathy may also be problematic in some jurisdictions. A report released in England cited the dearth of dementia diagnostic capacity in general, and that would pose a significant impairment for autistic adults (Gregory, 2024).

The American experience with the general population has revealed significant obstacles in the initiation phases of medication accessibility and medical facility capabilities to administer the drugs (Schindler, 2024). These include limited facilities having the capacity of the preliminary diagnostic processes, medication administration, and significant follow-up; having significant clinicians who can diagnose Alzheimer's in autistic adults; resources to obtain required biomarkers; and geographic accessibility barriers. A problem that may be experienced by autistic adults is accessing dementia diagnostics to access the DMTs, as most prescribers rely on memory clinics or Alzheimer's disease research centers – which are in short supply geographically (The Lancet Neurology, 2024). One proposal proffered by Rand Health Care (Alzforum, 2024) is to shift such assessments to primary care practitioners (PCPs); however, it is doubtful that many PCPs will have the capacities or resources to accurately diagnose dementia in autistic adults. A further challenge for autistic adults is complying with the preliminary measures (biomarker via blood or CSF draw and PET scans) as well as sitting through a fortnightly infusion process. New work, showing a greater uptake of the DMTs via weekly injection (but not yet approved as an administrative vehicle), may mitigate some of the challenges of the current medication administration process and frequency (Eisai, 2023). Most importantly will be the receptivity and readiness of PCPs and other prescribers to take on autistic adults as patients when there is suspicion of neurocognitive impairment associated with Alzheimer's disease (Gerhardt et al., 2011).

In summary, some Alzheimer's medications have utility in autistic adults (e.g., risperidone and aripiprazole), for addressing Alzheimer's symptoms, and can be used to address behavioral issues (e.g., irritability). Other on-label medications (donepezil, galantamine, rivastigmine, tacrine, and memantine) have been noted to have produced improvements in various autism-related behaviors. Galantamine and memantine have been shown to be useful in core and associated symptoms of autism. Given the absence of approved autism-specific medications, there is a necessity for further research on novel medications, including those designed for treating Alzheimer's disease. As to the potential suitability of emerging anti-amyloid drugs for autistic adults diagnosed with Alzheimer's, prescribers need to be cautious about using anti-amyloid drugs when the adults also have DS due to concerns about potential adverse effects. For those absent DS or ID, autistic adults need to demonstrate clinical and biomarker evidence of mild cognitive impairment or early-stage dementia due to Alzheimer's. However, the effectiveness of these drugs with autistic patients has not been proven in clinical trials.

6.0 Assessment/diagnosis for dementia

When undertaking assessments or diagnostic workups for dementia in older autistic adults, particularly if an ID is present, clinicians may experience challenges due to the complex interplay of cognitive, communicative, and behavioral factors inherent to assessing autistic adults. To begin with is a determination of a diagnosis of autism. In adults, this is often more difficult than diagnosing autism in children. In adults, as some autistic symptoms can overlap with symptoms of mental health disorders, such as anxiety disorder or ADHD, some diagnostic complexities may be present (NIH, 2023). Once the presence of autism is confirmed, then the challenge is to identify the presence of MCI or dementia. The presence of select mental health symptoms may confound the process of identifying dementia symptoms. This section examines some nuanced factors in undertaking assessments and diagnostic workups.

***Communication*.** One of the primary challenges in assessing autistic adults with ID lies in communication. Some may have limited verbal abilities or use unconventional means of expression, complicating the elicitation of relevant information during cognitive assessments. The report from the Neuroatypical Conditions Expert Consultative Panel (Janicki et al., 2022a; 2022b) emphasized the importance of considering receptive and expressive language abilities when conducting assessments, suggesting the use of non-verbal strategies such as visual representations and demonstrations of tasks. Alternative and augmentative forms of communication, including visual aids and augmentative communication systems, may also be necessary due to limited verbal expression or unconventional communication methods like echolalia. Establishing rapport and maximizing engagement are essential to ensure valid assessments. Moreover, gathering ancillary information from family members or caregivers familiar with the individual's daily routines and behaviors is crucial for obtaining a comprehensive understanding of their functioning. Social communication accommodations must be tailored to each individual, emphasizing the importance of being concrete with instructions and conversations during assessments to facilitate accurate evaluations.

***Assessing when ID or other conditions are present*.** Standard dementia assessment tools may not be suitable for autistic adults with ID due to a lack of normative data for this population and the complicating factors of sensory sensitivities and anxiety commonly observed in autism (Janicki et al., 2022a; 2022b). Clinicians must rely on comprehensive evaluations that incorporate information from multiple sources, including family members and caregivers, to establish an accurate diagnosis. Tailored assessment approaches and tools specifically designed for this population are essential to effectively address these challenges. Moreover, the behav-

ioral symptoms of dementia can be misinterpreted or obscured by preexisting behaviors associated with autism and ID, a phenomenon known as "diagnostic overshadowing" (Hallyburton, 2022; Janicki et al., 2022a; 2022b). Agitation, withdrawal, and repetitive behaviors may be mistakenly attributed to the individual's baseline characteristics rather than being recognized as signs of dementia.

Another consideration is that a small portion of autistic adults are also diagnosed with Down syndrome; knowing this might lead to assumptions about elevated risk for Alzheimer's disease in this subgroup (Bradbury et al., 2012; Dimachkie Nunnally et al., 2021). Sensory sensitivities and anxiety, which are often prevalent in individuals with autism, can further complicate the assessment process. Bright lights, unfamiliar surroundings, or loud noises in clinical settings can overwhelm autistic adults, affecting their ability to engage in the assessment process. Sensory-friendly assessment environments can help reduce stressors and anxiety, ensuring more accurate evaluations. Defining and creating sensory-friendly assessment environments can aid in alleviating these challenges (Hazen et al., 2014). Another factor in assessment when ID is present is the use of informants. Obtaining ancillary information from family members or others who are familiar with the daily routines and lifestyle of the adult is helpful. Informants (whether family or staff caregivers) who know the person well, can help with determining whether the routine functioning of the individual that was observed in a clinical interview, is generally reflective of the adult's repertoire of behaviors (Taylor et al., 2024). Information from multiple contexts can help evaluate decline in abilities and understand the timeline of the changes in the individual's cognition.

Assessing when ID is not a factor. Undertaking assessments for dementia in high functioning autistic adults (without ID) may require clinicians to modify standardized assessment tools to accommodate autism-related behavioral characteristics (van Niekerk et al., 2011). Autism often co-occurs with other conditions like anxiety, ADHD, depression, and obsessive-compulsive disorder, complicating the assessment process due to cognitive, emotional, and behavioral challenges. As these conditions are associated with cognitive difficulties in aging neurotypical individuals, dementia symptoms may be obscured in autistic adults. It is essential to gather information from various contexts to evaluate decline in abilities accurately and understand the individual's cognitive expectations and timeline of changes.

Given the heterogeneity of autism, a one-size-fits-all screening approach is not suitable, and consideration should be given to cognitive comorbidities like ID or psychiatric conditions. Awareness of the individual's history, social functioning, and indicators of memory loss or diminished self-care is crucial during examinations. Building rapport, adapting instrumentation, and providing predictability during testing can enhance the assessment experience for autistic adults. Assessments should be conducted in familiar settings whenever possible, and premorbid assessment is essential for comparing current functioning to prior abilities. Attention should be given to factors like environmental changes, anxiety, gastrointestinal issues, and medication effects that may impact assessment outcomes. A comprehensive and multidisciplinary approach, incorporating input from family members, caregivers, and individuals themselves, is necessary to obtain a holistic view of cognitive and functional abilities. Longitudinal assessments and frequent monitoring are valuable for identifying subtle changes over time indicative of dementia onset or progression.

Assessing when a psychiatric disorder is a factor. Clinicians face challenges in assessing and diagnosing cognitive impairment in autistic adults, particularly when other cognitive, emotional, or psychiatric conditions co-occur (Bertelli et al., 2010). Cognitive impairment in autism is diverse, spanning from sensory perception issues to deficits in cognitive processing, learning, and memory. Al-Mazidi (2023) highlighted the lack of specific diagnostic criteria for cognitive impairment in autism, with potential causes including neurological, immune, and gastrointestinal dysfunction. Early intervention is crucial for addressing cognitive dysfunction in autism, yet its heterogeneity, combined with comorbid ID and other conditions, complicates the development of standardized diagnostic and therapeutic criteria.

The presence of co-occurring cognitive or psychiatric conditions further complicates the diagnosis of dementia in autistic adults (Lai & Baron-Cohen, 2015). Conditions such as anxiety, ADHD, depression, and obsessive-compulsive disorder pose additional challenges for diagnosing dementia, potentially masking its symptoms (Janicki et al., 2022a; 2022b). Novel approaches, like self-report measures such as the AD8 dementia screener (Klein et al., 2023), may offer valuable insights into cognitive decline in autistic adults. Moreover, studies like that by Groot et al. (2021) suggest that alternative cognitive assessment tools, such as the MoCA-NL (Powell, Klinger & Klinger, 2017), may be more sensitive in detecting cognitive impairments in older autistic adults compared to traditional tools like the MMSE (Folstein, Folstein, & McHugh, 1975). It has been reported when using the MoCA, age was significantly related to performance in autistic adults such that older autistic adults exhibited significantly lower performance compared to older adults with neurotypical development (Powell et al., 2017). These findings underscore the need for tailored assessment methods and ongoing research to enhance dementia diagnosis and management in autistic adults.

Assessment applications. Undertaking assessments considers a variety of purposes. One may be screening autistic adults for indications of MCI or dementia for services planning. Most individuals with autism with baseline typical intelligence can participate in standard screenings, but adults with concomitant ID (including Down syndrome) or other co-occurring features may require multiple visits and tailored assessments. Another may be related to annual or periodic medical or health assessments. Cordell et al. (2013) provided a framework for situations which may be part of annual medical interview, which would include (1) completing a pre-visit screen about the adult before the visit; (2) using tools for the initial cognitive assessments that are brief, validated, and easily administered by non-physician clinical staff; and (3) when further evaluation is indicated, scheduling a more detailed evaluation for a follow-up visit or via a referral to a specialist familiar with the pre-existing condition. Another is to validate the presence of dementia for disease modifying treatment purposes or for eligibility determinations. In each the nature of the assessment may differ as to the information collected and degree of precision.

The Neuroatypical Conditions Expert Consultative Panel (Janicki et al., 2022a; 2022b) provided a general perspective on the challenges inherent in examining adults with neuroatypical conditions, including autism. They noted that from an assessment applications perspective the challenges include: (1) most clinicians experience difficulties in discriminating current behavior and function from that which was pre-existing in some of the conditions, particularly those that include pre-existing cognitive deficits; (2) many of the conditions included problems with comprehension, oral communication, motor task performance impediments, recognition of assessment related visuals, and comfort in testing situations; (3) for conditions with pre-existing cognitive issues, the use of standardized dementia assessment measures is not indicated unless the measures are significantly adapted or specially designed; (4) for conditions with motor or sensory impairments, special adaptations related to compensating for the impairments is necessary to obtain valid scoring; and (5) practitioners should be aware of the nature of aging effects in these conditions, know the expectations for cognitive decline and risk of dementia (and of what type), and be familiar with testing adaptations that can facilitate the examination process to generate meaningful data. Overlaying these challenges is differentiating examining approaches when adults are high functioning or possess concurrent ID.

In summary, assessing dementia in older autistic adults, particularly those with ID, presents a significant clinical challenge due to the intricate interplay of cognitive, communicative, and behavioral factors inherent to these neurodevelopmental disorders. Diagnosing autism in adults is inherently complex, and the overlap of autistic symptoms with those of other mental health disorders further complicates the assessment process. Standard dementia assessment tools may not be suitable for individuals with autism and ID, requiring clinicians to rely on comprehensive evaluations that consider sensory sensitivities, anxiety, and unconventional communication methods. Communication difficulties, limited verbal abilities, and pre-existing behaviors associated with autism can obscure dementia symptoms, necessitating tailored assessment approaches. The challenges include discriminating current behavior

from pre-existing conditions, considering sensory sensitivities, and adapting assessments for valid results. Overcoming these complexities requires a multidisciplinary approach, incorporating input from various sources, such as family members and caregivers, to gain a comprehensive understanding of the individual's cognitive and functional abilities. Longitudinal assessments and frequent monitoring are crucial for identifying subtle changes that may indicate the onset or progression of dementia in autistic adults. That said, the following exploration of service concepts and frameworks represent literature from the Western world, and we note that other models may be prevalent in other countries, particularly in Asia, the Middle East, and Africa.

7.0 Non-pharmacological interventions, dementia supports, and later life outcomes

Important is the consideration to be given to the effect that different welfare models, which countries are grounded on, may have on the delivery, financing, and outcomes for individual citizens, including autistic adults and their families (cf. Alesina & Glaeser, 2006; Esping-Andersen, 1990; Heath, 2020). Although not the main focus of this report, it provides a powerful context for how social welfare services are organized. Primarily, we will see three different welfare models in the Western world: The *Anglo-American welfare model* (US and UK) which focuses on providing citizens with a minimum safeguard against poverty rather than redistributing benefits, and the market plays a significant role. The *Continental welfare model* (France and Germany) which ties rights to class, occupation, or status and families are key providers of welfare, with the state stepping in when families are unable to support themselves. The *Scandinavian welfare model* (Sweden, Denmark, Norway, and the Netherlands) which is characterized by universality, with the state aiming to ensure equality. The system is based on individual rights, with families playing a smaller role as welfare providers. Heath (2020) notes that the three normative purposes most cited provide a justification for the scope of welfare state activity are equality, community, or efficiency. These give rise to a corresponding set of models, which he refers to as the redistributive, the communitarian, and the public-economic models of the welfare state. These may underlie the following discourse on services and would reflect national economic and political foundations for the delivery of services to disadvantaged populations.

Fumagalli and Crippa (2020) noted that it is a public health priority to better understand the factors that might contribute to the intersection of autism and neurodegenerative dementia. They reported the importance of understanding the strengths and the needs of autistic adults who present with comorbid dementia, to develop long-term care resources and arrange appropriate intervention programs. They argue for the systematic study of potentially common etiopathological mechanisms that could increase knowledge about the pathological basis of autism and neurodegenerative dementia and that may lead to the development of targeted interventions. What follows is an exploration into various issues that may fall under the rubric of non-pharmacological interventions and post-diagnostic supports, covering those issues that relate to support for autistic adults and dementia, as well as useful to aiding persons and family members involved in direct support.

7.1 Respite, caregiving, and training

Support programs for aging autistic older adults are generally not well-formulated or available, but services for supporting older adults with ID can offer some direction for how these can be adapted for autistic older adults (Canadian Academy of Health Sciences, 2020). In general, autonomous living services would mirror – those that governments organize for their older population – but with adaptations for specialized personalized supports. On a broader scale, these might include developing autism-friendly seniors' living models

and engaging in proactive long-term planning assistance for self-sustaining finances, housing, and healthcare decisions. On a narrower scale, these would be directed toward supporting existing primary caregivers. However, questions arise as to how these might support care for autistic older adults with dementia.

There is a dearth of studies that focus on the caregivers (or carers) of autistic adults with dementia. Those that address caregiving focus on caregiving factors when families are providing care at home for adults or older autistic adults. Writers have noted that some autistic adults approach their senior years living with minimal support, while others may need substantial assistance, requiring support and assistance at home or when living in supervised housing, particularly if there is a coincident condition present (Kartoz et al., 2022). Aside from basic activities for daily living (ADLs, e.g., bathing, cooking, dressing), they may need help with transportation, accessing healthcare, and managing financial and legal responsibilities. When living with family, these essentials are aided by family caregivers; if in supported or assisted living, an agency might provide for these needs. There are also autistic adults who are living autonomously or are unhoused, and are not receiving any supports (Stone et al., 2023). The literature is for the most part silent on dementia-related supports for this group, except for noting the social care challenges experienced by communities when confronted with unhoused adults. What can be learned from the research on caregiving for autistic adults can be translated to providing care when dementia becomes an issue.

7.1.1 Respite and home-based supports.

It has been suggested that about 80% of autistic adults live at home and receive support from a family caregiver and that many unpaid caregivers require assistance when continuing to care for autistic adults either living within or in the community (Autism Speaks, 2023). Duker et al. (2022) in a study of caregivers of autistic adults (but absent dementia) found seven key themes as challenges: (1) finding a primary care provider; (2) patient-provider communication; (3) anxiety due to unpredictability, an overstimulating sensory environment, and waiting time; (4) participation of consumers in the healthcare process; (5) stigma and assumptions about autism; (6) caregiver experiences; and (7) the impact of culture and ethnicity on care. Bagatell et al., (2023) via a similar effort isolated three themes reported by caregivers: (1) managing daily living needs, (2) obtaining services and supports, and (3) providing invisible supports.

With respect to caregiver health concerns, Warreman et al. (2023) found that caregivers of autistic adults reported more stress (OR 3.61, 95% CI 2.60–4.99), greater anxiety (OR 1.85, 95% CI 1.37–2.49), and depressive disorders (OR 1.83, 95% CI 1.17–2.86) than among "non-autism-caregivers." Warreman et al. concluded that such "autism-caregivers" had worse psychological health than non-autism-caregivers and speculated that "autism-caregiving" might be associated with an altered immune balance. They noted that there was inherent higher caregiver strain in autism-caregivers compared to other (non-autism) caregivers and called for increased supports to be made available to "autism-caregivers." Studies have also examined means of relieving stress and building capabilities for continued caregiving. For example, Romero-Martinez et al., (2017) studied a group of 17 parents (mean age of 52 years, 59% females) of autistic adults who had cared for their offspring (13 males and 4 females) for approximately 14 years and found that proper support and respite services can help caregivers cope with and reduce stress. They recommended that professionals interfacing with autistic adults and their caregivers should seek means to reduce barriers and augment pathways for effective service utilization.

Marsack and Hopp (2019) noted that the provision of care may be complicated for many aging parents of autistic adults due to their own social isolation and exclusion, as well as challenges associated with accessing support services. They also reported that parents often experience problems with their informal social support networks due to misunderstandings of autism by families, friends, and co-workers who did not know what to expect from an autistic adult. Further, aging parents of autistic adults often experience declining health, as well as shrinking informal social support systems, while caregiver burden remains constant or increases. With respect specifically to the health of family caregivers, Marsack and Hopp also found that when

the interaction between the health of the caregiver and the frequency of available social support was higher, caregiver difficulties experienced were significantly fewer. In another study, Marsack and Samuel (2017) reported the need to support aging parents of autistic adults through enhancing their informal social support networks.

Offering respite care services (one significant support) to provide temporary relief for caregivers has been noted as essential, as caring for individuals with complex needs can be physically and emotionally taxing. Respite, a time of relief from supervision and personal care, is often an essential service for caregivers of adults with significant behavioral or personal care needs, particularly if an autistic adult also has an ID. Graetz (2010) reported that respite may be hampered by a lack of available formal support for caregivers and limited opportunities for autistic family members in socialization, employment, and residential living, especially for those caring for adults most severely affected functionally. She also reported that in addition to respite, caregivers of autistic adults often have a need for information regarding financial planning, life-long planning, and learning about ways to advocate for their family members. Caregivers, she noted, often preferred informal support (e.g., a friend to talk to) to the formal support provided by professionals. Connecting such caregivers with support networks and resources, including informal ones, is helpful in addressing these needs. With respect to peer-to-peer approaches, Foley and Trollor (2015) cited the important function of support groups, a model used successfully in the dementia care system (Grässel et al., 2010).

Despite the need for respite care services and other supports for those caring for autistic adults with behavioral or health complexities, there are challenges and barriers present to obtaining needed supports and services (Gerhardt & Lainer, 2011; Mason, Ingham, et al., 2021). Challenges, such as the availability and affordability of services, have been well-documented in the literature and are found to pose difficulties for family caregivers (Marsack-Topolewski & Weisz, 2020). Coping strategies of caregivers in lifelong caregiving situations of autistic adults were examined by Marsack-Topolewski and Wilson (2021), who found that most parents used at least one coping strategy, with some sharing multiple strategies. These strategies were encompassed by several themes, including faith/spirituality, physical activity/fitness, self-focused coping, work, acceptance, reliance on social support, and barriers to coping.

> ***In summary,*** research addressing the caregiving needs of autistic adults with dementia is lacking, with most studies focusing on caregiving factors for autistic adults living at home or in supervised settings. The challenges faced by family caregivers, agencies, and the unhoused autistic population have not been extensively explored, particularly concerning dementia-related supports. Limited studies highlight the psychological strain experienced by caregivers of autistic adults, calling for increased support and respite services. Additionally, the provision of care is complicated for aging parents due to social isolation, declining health, and limited informal support networks. Caregivers of autistic adults with dementia face significant challenges, including healthcare access, stigma, psychological strain, their own declining health, and limited informal support networks. Studies emphasize the importance of respite care, social support networks, and coping strategies for caregivers. However, barriers to accessing these supports, such as availability and affordability, remain significant obstacles (Han et al., 2021). Further research is needed to better understand and address the unique caregiving needs of this population. Overall, there is a need for increased support and resources to alleviate caregiver burden and improve the well-being of both caregivers and autistic adults if dementia is present.

7.1.2 Environmental design.

A factor in facilitating caregiving into older age is the physical design of family homes or other types of dwellings. It has been noted that while the capacity and resilience of caregivers is a primary factor, how well-suited is the family home's built environment is equally important, particularly for older autistic adults (Graetz, 2010). Nagib and Williams (2017) reported that physical, social, and psychological challenges affect

the quality of life in the home and home modifications can aid in alleviating these challenges. Their work encompassed examining three housing types – detached houses, attached houses, and apartments – and how they accommodate autism-related needs. Although their study involved autistic children, many of their recommendations also apply to dementia-proofing housing for autistic adults with dementia. They noted that family home environmental assessments are one of the areas contributing to supportive caregiving and that there were several key areas where a home assessment has relevance and value. These include (a) checking for environmental factors (such as noise, bright light, cluttering, room temperature, and smell) which may cause distraction, restlessness, or the inability to sit and focus; (b) safety-related modifications (such as use of locks or alarms on doors and windows); and (c) organizing spaces and decluttering to mitigate distractions. They also considered the environmental and physical space challenges inherent when living in an apartment or attached home unit.

With respect to home assessment instruments, Ruiz-Rodrigo et al. (2023) reviewed seven home environment-related assessment tools that can be used in the identification of environment-related difficulties and home-based caregiving with autistic persons, and Struckmeyer et al. (2021) reviewed 33 distinct assessment instruments, including those evaluating the accessibility of home modifications, examining usability, addressing activities of daily living or functional activities, and addressing comfort and/or satisfaction. On a practical level, the '*Home Safety Checklist for Alzheimer's Disease*' (National Institute on Aging, 2017) in the U.S., '*Making your environment safe*' (Alzheimer Society of Canada, 2024), and '*Keeping safe at home*' (Alzheimer's Society, 2024), and '*Making home safe and comfortable for someone with dementia*' (Dementia UK, 2023) in the United Kingdom, and a practical environmental analysis instrument in use in Italy and noted by Alzheimer Trento ODV (Chiogna & Dalprà, 2009; De Vreese et al., 2012) are resources using a household model of design that have been cited as useful to identifying potential environmental hazards.

7.1.3 Caregiving.

Compound caregiving. Another area, unstudied, is the fact that many parents continue caring for their autistic adult, who is dependent upon them, for as long as physically possible (Palerino, 2023). However, as parents age, many also may have to provide care for another relative, such as a spouse, or parent. Marshak-Topolewski and Weisz (2020) studied such compound caregiving (i.e., providing care for multiple persons) on six dimensions of quality of life (enjoys life, life is meaningful, ability to concentrate, accepts bodily appearance, satisfied with self, and frequency of negative feelings) and found that such compound caregivers are often less able to concentrate and had fewer negative feelings than non-compound caregivers.

Partner caregiving. Another area germane to this report, yet unstudied, is spousal or partner caregiving among couples when one is autistic and is experiencing cognitive decline. A report of NIH Pre-Summit Workgroup on Caregiving and Intellectual/Developmental Disabilities (Heller et al., 2018) noted that most adults with developmental disabilities, which would include those with autism, and who are less functionally independent live with parents—many of whom provide lifelong caregiving. These caregivers are usually experienced with accessing long-term services and supports, including family supports and various models of residential supports (e.g., group homes, supported living); however, they may not always find that public services are adapted for dementia care (Research Institute, 2024).

This lifelong caregiving will contrast to the *assumed* caregiving in spousal/partner caregiving situations. In these situations, a different dynamic may predominate. Millar-Powell and Warburton (2020) examined adult 'coupling' relationships where one partner has autism and the other does not and found that relationship satisfaction was lower among the neurotypical partners than among those with autism They reported that 'caregiver burden' was comparatively high and negatively related to relationship satisfaction and that several key themes identified included caregiver burden, loneliness, and self-care within relationships. Much work in the general population has focused on the impact on marital relationships following the diagnosis of one partner with dementia in the general population (e.g., Colby et al., 2022; Williams, 2015).

Research is recently emerging with respect to couples with a neuroatypical condition, but necessarily involving dementia-related caregiving. Jacobs et al. (2023) undertook a review of existing work related to couples and noted that most extant work existed with respect to ID, and in particular Down syndrome, and identified diverse ways that care and support in relationships among partners, staff, and other family members was approached. They reported that support could act as a facilitator as well as a barrier to people and their relationships. While the lives of couples in general affected by aging-related conditions appeared to remain largely private, couples with ID had a high involvement of staff and family members in their lives. Jacobs et al. delved into the notions related to reciprocity in relationships and noted that reciprocity among people with intellectual disability is not always contingent upon equal exchange. They reported also, as a couple's abilities change, they might need others to take the initiative in creating possibilities for inclusion and participation. Also, with respect to dementia, they posited that in relation to couples with ID where one partner has dementia, this might translate into a risk that the partner without dementia is not recognized and supported in their caring role.

In what may be a sentinel study, Watchman et al. (2024) considered the experiences of couples with ID when one partner was living with dementia. Conducting in depth interviews with several couples with ID when one partner had dementia, they found that the starting point for most couples with ID will be different to that of couples in the population generally. The emotional impact of a dementia diagnosis, planning for the future and fear of separation was noted by couples with intellectual disability. Partners took on caring roles thus challenging views of being solely care-receivers. Their families spoke of the couples' commitment and longevity in relationships, whilst social care staff highlighted how their own information needs changed, recognizing the importance of ID and dementia-specific knowledge. Watchman (2024) reported that several dementia-related dynamics emerged from the discussions with the couples, included a need for assistance with caregiving, finding alternative housing for the adult affected by dementia (when care needs exceeded the partner's capacities), explaining the dementia diagnosis and its implications, providing counseling, assumed decision-making, and coping with BPSDs by the able partner. In such situations, families and staff who provide support needed to be sensitive to the previous experience and life story of each couple, have specific knowledge of how dementia can affect people with ID, and be sensitive to their perceptions of what they are experiencing. While no specific literature exists on caregiving for autism and dementia or autism/ID and dementia in these couple/partner caregiving situations, it is reasonable to assume that similar supports would be needed to be extended to care supports as with neurotypical couples or couples with ID, while also providing focused counsel on the special nature of decline and dementia related supports related to autism.

> ***In summary,*** research on spousal or partner caregiving for autistic individuals experiencing cognitive decline is lacking. Most adults with developmental disabilities, including autism, rely on lifelong caregiving primarily from parents. However, when it comes to spousal/partner caregiving, a different dynamic emerges, with potential challenges such as caregiver burden and loneliness. While research in the general population has explored the impact of dementia on marital relationships, studies on couples with neuroatypical conditions, particularly autism and dementia, are scarce. Existing literature on couples with ID, especially Down syndrome, highlights the importance of support in relationships but lacks specific focus on dementia-related caregiving. Recent studies examining couples with ID facing dementia reveal emotional impacts, challenges in planning for the future, and shifts in caregiving dynamics. These findings emphasize the need for tailored support and dementia-specific knowledge for couples with neuroatypical conditions facing cognitive decline. While no specific literature addresses autism and dementia caregiving in couple/partner situations, insights from existing research can inform support strategies tailored to the unique needs of these individuals and their caregivers.

7.1.4 Imparting knowledge.

Educating family members, life partners, and other carers about the specific needs of individuals with autism and dementia is vital. Education should cover effective communication strategies, behavioral management techniques, an understanding of the progression of dementia and interventions that support well-being while living with dementia such as physical activity, mental and social engagement, nutritional encouragement, sleep and stress management and health maintenance interventions such as vaccines and chronic disease management. With the presence of dementia, decisions on the extent of involvement will determine the nature of the support services put in place. In addition to specific training topics tailored to provide support to family members and caregivers, training designed to support caregiver health and wellness, as well as self-care is essential. This could be undertaken by an adaptation of the WHO Caregiver Skills Training Program for Developmental Disorders or Delays as applied for caregivers of autistic adults (Salomone et al., 2019).

Educational processes for family caregivers of autistic adults were examined by (Stone-Heaberlin et al., 2024) who reported perceptions of satisfaction and knowledge gained were lower for participants of virtually held classes regardless of class topic or instructor. The reported lower levels of acceptability for virtually based classes were consistent with instructor anecdotal feedback which noted that participants in virtual classes appeared less engaged, made fewer comments, and asked fewer questions. While virtually held classes may be logistically easier for some families, the authors posited that in-person classes may hold more value overall. Pacione (2022) reported that training on caregiver-mediated interventions, when presented via telehealth, is acceptable and feasible, and associated with similar positive outcomes as live face-to-face training. Telehealth innovations, which progressed during the COVID-19 pandemic, demonstrated advantages over in-person delivery of services in terms of safety, cost effectiveness, and increased accessibility. The author noted that caregiver skills training interventions for autism that were adapted or designed for telehealth delivery, were scalable, adaptable, caregiver-mediated, open-access, and delivered as part of a stepped care model. The author reported its utility in addressing the global treatment gap for families of children with autism and other neurodevelopmental disabilities.

> ***In summary,*** educating family members and caregivers about the specific needs of individuals with autism and dementia is crucial, encompassing communication strategies, behavioral management, understanding dementia progression, and interventions promoting well-being. Decision-making regarding caregiver involvement shapes support services. Training programs should address both caregiving skills and caregiver health. Research suggests that virtually held classes for caregivers of autistic adults yield lower satisfaction and knowledge gains compared to in-person classes. However, telehealth-based training on caregiver-mediated interventions is feasible and effective, providing scalability, adaptability, and accessibility, particularly beneficial during the COVID-19 pandemic. These telehealth interventions address the global treatment gap for families of autistic adults and other neurodevelopmental disabilities.

Commentary on respite, caregiving, and training. With respect to caregiving for older autistic adults, diverse support needs emerge during later-life years, ranging from minimal assistance to extensive caregiving, whether at home or in supervised housing. Caregivers grapple with a myriad of challenges, as studies have revealed hurdles in finding primary care providers, navigating patient-provider communication, managing anxiety, combating stigma, and contending with the cultural and ethnic dimensions of dementia related care. The mental health toll on these caregivers is substantial, with elevated levels of stress, anxiety, and depressive disorders compared to their non-autism counterparts. Recognizing the significance of respite care, which provides vital temporary relief for caregivers facing the physical and emotional strains of tending to those with complex needs, is important. Also, is the shift towards connecting caregivers with aging-related support networks and resources, prioritizing informal support networks over formal assistance from professionals. Aging parents of autistic adults confront a host of challenges, including social isolation, difficulties accessing support

services, declining health, and diminishing informal social support systems. The unique situation of compound caregivers, juggling care responsibilities for multiple relatives, introduces additional complexities, impacting concentration and overall quality of life. Professionals must grapple with service access challenges, acknowledging issues of availability and affordability that hinder family caregivers. Further, consideration of various welfare models' impacts on how nations frame service delivery, financing, and outcomes, may reflect distinct approaches to how services and support for autistic adults and aid families are provided. Lastly, the enduring commitment of many parents to care for their adult offspring with autism underscores the neglected domain of compound caregiving, a facet that remains understudied and significantly affects caregivers' quality of life.

7.2 Housing and dementia care planning

While we have focused on relief from dementia caregiving in living-at-home situations, there are other options. Generic options include memory care facilities and assisted living settings. Memory care facilities share many of the same features as assisted living, including apartment-style accommodations, common areas, and communal meals. However, memory care facilities provide a more specialized form of assisted living and generally are more secure for adults with dementia who wander (Russell, 2023). Options associated with the disability care community might include residing in supported living, such as dementia-capable apartments or group homes, which would offer staff support and supervision and specialized dementia care for adults. There is a rich body of research literature on these dementia care settings and their dynamics for adults with ID (e.g., Janicki, 2007, 2011; McCarron et al., 2013), as well as older adults (Kobayashi et al., 2008), but this literature does not extend specifically to dementia care housing for autistic adults. Information on group homes for autistic adults that may accommodate older autistic adults stems from the provider sector (e.g., Easter Seals, 2024; Golden Steps ABA, 2023; Research Institute, 2024; Zauderer, 2023).

One report from the United Kingdom addressed dementia-related residential care within the broader issue of 'residential services' and autism (Crompton et al., 2020). The authors noted the dearth of research relating to older autistic adults and residential care and reported on their efforts to conduct a multi-meeting effort to chart current best practice and identify key questions in residential care for older autistic adults (modeled on 'elder care'). Their effort cited a consensus on ten key topics for consideration in autism-related residential care, including (a) managing transitions into residential care; (b) training on autism for residential care staff; (c) recognizing and respecting autistic differences, and understanding autistic well-being; (d) supporting physical health; (e) attending to the sensory environment and sensory processing; (f) adhering to dementia care design principles, (g) creating a sense of community and belonging; (h) offering autonomy and choice; (i) ensuring the inclusion of advocacy; and (j) continually evaluating care quality. Acknowledging the lack of evidence-based knowledge in provision of out-of-home dementia care for older autistic adults. The findings of Crompton et al. recommended the undertaking of a longitudinal study of autistic old age and of transition into residential care is needed to provide key information about current practice and to identify points in time and place where the lives of older autistic people would benefit from appropriate adaptations.

As group homes have become a prevalent vehicle for *ad hoc* community care of singular adults affected by dementia, many are being adapted to make them 'dementia capable' (Iacono et al., 2013; Janicki et al., 2005; Kerr, 1997; De Vreese et al., 2012). In general, such small group residences, usually resembling private homes or apartments, provide lodging and supervised care for a small group of persons with special needs (Janicki, 2011). Within the past twenty years or so, group homes have also become viable alternatives for long-term care of older adults with ID affected by neuropathologies, such as dementia (Chaput, 2002; Janicki et al., 2002; McCarron et al., 2002, 2005), as well as from the population at-large (Funaki et al., 2005). They are staffed by employees who are skilled in working with people with dementia, and the program setting is adapted to accommodate the needs of people with dementia. These homes also provide for safety and care when adults transition to advanced dementia and need end-of-life care (Kobayashi et al., 2008). While the pathway patterns for admission of persons suspected of or affected by dementia may vary (Torr et al., 2010),

the accommodation for and receipt of dementia-related care is a common outcome. This may apply to any number of autistic adults who may wish to be housed in a small group home due to aging-related needs or progressive cognitive impairment and who may need supervised living.

Research is absent on reports of individual autistic adults and adjustments to small group home living. However, it is expected that environmental aspects will play heavily with respect to adaptation to such dementia care settings. Entailed would be influencing features such as characteristics of the living space, such as the number of residents per living area, the layout of the circulation system (for ambulation), the characteristics of the public spaces, the programmatic use of the common spaces and dining areas, and environmental adaptations to address sound and lighting (van Hoof et al., 2010). As the environment plays a significant role in how residents with autism will act and function, sensory accommodations are important (Tola et al., 2021). When housing autistic adults with dementia, accommodations should be made for control for sensory overload, socialization demands, and any other features within the home that may lead to perceptual discomfort or routines.

Another important feature in ensuring accommodations for autism in housing settings is environmental assessments. Several writers have reported that physical settings for individuals living with dementia should be examined for associations between designed features within the built environment and outcomes of interest (Black et al., 2022; Calkins et al., 2022; Mangeli et al., 2023a, 2023b; Tola et al., 2021). This would particularly apply for settings for autistic adults and living with dementia. In using environment assessments, writers have parsed such assessments into those that examine the social environment (i.e., therapeutic aspects, staff performance, person-centeredness, etc.) and those that examine the physical environment (i.e., built aspects, barrier-free designs, sensory adaptations, etc.) Housing programs need to reconsider the living environments based on the specific needs of people who function in an atypical way (Black et al., 2022; Tola et al., 2021).

Black et al. (2022) reported that design and construction, lighting, sound, aesthetics, temperature, and air quality are all factors when considering the built environment for autistic adults. They also noted that while in its preliminary stages, evidence demonstrating the impact that qualities of light, color, sound, and spatial planning have on the human sensorium is emerging. Mangili et al. (2023b) also cited scale (i.e., size) as a factor if housing transition is involved, and the minimization of losses in cognition (including visual memory, image recognition, the cognitive decline) and stabilization of global cognitive functioning, if the settings are designed for a small group. With specifics in mind, Tola et al. defined *spatial criteria* for the design of an autism-friendly built environment that would include a minimization of sensory stimuli (especially acoustic ones) within the environment. These setting characteristics would provide for a low arousal environment which would minimize stimuli and details is one of the main requirements linked to the altered sensory processing in autistic adults, particularly focused on low visual, acoustic, and smell stimuli. They also defined the setting as providing for adequate transition between spaces in which autistic adults are exposed to different sensory experiences (to avoid sensory overload and to support the tasks of processing and integrating sensory information). There should be quiet spaces that allow for retreat and prevent sensory overload and be designed following a well-defined set of spatial requirements to be comfortable and calming. Tola et al. also proposed that the built environment be *"intelligible,"* that is, it must have a simple spatial layout, facilitate orientation, and promote predictability (as a clear and simple spatial layout helps with navigating the space independently and with ease).

Another consideration is that the setting has visual relationships among all components of the space and thus can provide the residents with an overall view of the surroundings to help them navigate the space with ease. Lastly, Tola et al. reported that the settings should have predictability and routine so that the spatial structure can contribute enhanced predictability and mitigate unexpected situations which may be problematic for autistic adults living with dementia. This would be enhanced by visual aids (i.e., the use of specific

pictures, pictograms, colors, or small sentences) to indicate functions of different spaces to help the residents interact appropriately with their environment. For example, wayfinding via the use of signs to help the residents navigate the space independently and with ease. With all these factors in mind, there are several tools available for assessing housing settings for compliance with these environmental requirements (cf. Black et al., 2022; Tola et al. 2021)

Related to caregiving at home, but more importantly in out-of-home care settings is *dementia care planning.* Care settings for dementia can range from agency-overseen small dementia care group homes, assisted living, memory residential centers, and senior housing. Regardless of care setting, having a dementia care plan is something that will aid in planning and providing individualized services and supports. Providing a well-thought-out plan for organizing services and supports for an autistic adult living with dementia, whether at home, with mates, or in a dementia capable setting is important. Such plans need to account for the person's choices and needs, as well as their existing capabilities. Also considered must be duration and expectations of dementia in terms of the type of dementia, the person's co-incident conditions, and emotional and physical health, diet, and physical care needs. Such plans can reflect *formal planning* within care organizations or *informal planning* among caregivers related to how to best provide support for someone in their home. Many Alzheimer's or dementia support organizations (Alzheimer's Association, 2024; Alzheimer's Society, 2024) and governmental ministries (Singapore MoH, 2013) have provided useful guides for informal planning. Vinay and Biller-Andorno (2023) noted that national dementia care plans should cover informal planning, with particular attention to advanced dementia. National planning initiatives concerning caregivers' needs, including those of autistic adults, must include promoting shared decision-making, active family involvement in creating care plans and futures planning, and strategies and means for providing support to family caregivers of persons with dementia.

Such planning has been explored by various sectors, including one developed for use with adults with developmental disabilities, the *'Addressing Brain Health in Adults with Intellectual Disabilities and Developmental Disabilities Companion of the KAER Tool Kit for Primary Care Team*s' (GSA, 2024). Given that dementia care planning should consider the diagnosis of the autistic adult's type of dementia, current function, and abilities as well as anticipated trajectory (duration and nature of decline) a roadmap can be helpful when determining post-diagnostic supports and services. There are various formal planning kits or roadmaps available based upon clinical best-practices, as well as those which are used for assessing compliance with respect to regulatory requirements (NTG, 2023a; 2023b) for persons with ID, but none that specifically structure a dementia care plan for autistic adults. One, designed for adults with ID and related conditions, potentially can be adapted internationally for use in dementia care planning situations involving autistic adults (GSA, 2024).

> ***In summary,*** research has recognized the need for alternative living arrangements for older autistic adults, such as dementia-capable apartments or group homes. While existing literature primarily addresses dementia care for individuals with ID, there's a lack of research on similar housing options for autistic adults with dementia. Although guides for adults with developmental disabilities can offer insights, resources specifically tailored to autistic adults are lacking. Adapting group homes for dementia care may benefit autistic adults, but environmental factors must address sensory needs and discomfort. Dementia care planning, essential for all settings, must be individualized, considering diagnosis, function, and anticipated decline. Efforts to bridge this gap underscore the need for tailored support and staff training, sensory environment considerations, and ongoing care quality evaluation. Longitudinal studies are suggested to enhance understanding and identify optimal interventions. Additionally, dementia care planning is crucial, with existing toolkits potentially being able to serve as valuable resources for adapting plans to the unique needs of autistic adults with dementia.

7.3 Behavioral distress management

Addressing distressing behaviors requires a non-pharmacological approach, emphasizing positive behavioral support. Modifying the environment to reduce stressors, providing structured routines, and examination of the internal environment (pain, infection, thirst/hunger, GI disruption, etc.) can be effective. Most of the evidence suggests that a significant subgroup of autistic individuals demonstrates GI abnormalities and that GI issues can contribute to the clinical manifestations of autism-associated symptoms, including abnormal behavior, immune dysregulation, and metabolic dysfunction (Hsiao, 2014). Cited also is that significant chronic illnesses, stemming from infections during the COVID-19 pandemic, can have deleterious effects on tolerance of symptoms and may lead to post-traumatic stress disorder (PTSD) in some instances. Such reactive symptoms may lead to behavioral distress and may be misdiagnosed (LeBlanc, 2024).

Foley and Trollor (2015) noted that service provision for autistic individuals is dominated by pediatric services, while adult services are reported to be inadequate. Barriers to service access and appropriate care for autistic adults include inadequate training and awareness in health professionals, diagnostic overshadowing, lack of specific autism mental health services, and a lack of coordination and communication between agencies. This may be more acute as an issue when dementia is involved, and caregivers are challenged by BPSDs. Foley and Trollor (2015) undertook a survey of primary care physicians who reported that they would like more training in caring for autistic adults. They reported that a high degree (23%) of physicians reported never having any autism-specific training, highlighting the unmet need for training in developmental disabilities in undergraduate and postgraduate medical courses.

Post-diagnostic supports for mental health concerns were examined by Mills et al. (2023) to determine whether there were differences in the provision of non-pharmacological interventions based on the level of ID and the presence or absence of autism. In many countries, adults with a notable ID (with or without autism), receive mental health services from specialist ID professionals, but for those with autism and co-incident mild ID such services are often sourced from generic mental health services providers rather than specialist ID services. Mills et al. (2023) found that in the UK specialty providers tend to focus on assessment, diagnosis, and treatment of those with severe to moderate ID (with or absent autism), with the primary modalities being alternatives to pharmacological interventions, such as behavior management strategies and positive behavior support plans. Conversely, psychological treatments were generally the focus on adults with mild ID (and autism). Mills et al. were concerned that a focus on behavior support plans primarily overlooked specific features of autism that warranted a different focus. They concluded that as autistic adults with ID are at significantly higher risk of significant mental health comorbidities (such as schizophrenia and other non-mood psychotic disorders, mood/affective disorders, and anxiety disorders), the focus of non-pharmacological intervention using primarily positive behavior support plans was problematic. They noted, “considering the heterogeneous nature of autism and the additional complexity that ID and mental health comorbidities bring, it is somewhat simplistic to attempt to meet the needs of this population using positive behavior support plans alone.”

Several models have evolved that try to understand the needs of autistic people (e.g., strengths and needs frameworks) using thinking pattern profiles that might have more value. Tollerfield et al. (2021) noted that appreciating autistic neurodiversity is important when supporting autistic people who experience distress. Specifically, use of a profiling model can reveal less visible autistic differences, including strengths and abilities. From a clinical perspective of autism, as a multi-dimensional and inter-connected construct, there may be implications for planning support and building positive self-understanding. Thus, individually tailored adjustments and support strategies may be identified more easily after delineating variables found across four core aspects: sensory coherence, flexible thinking, perspective-taking, and regulation.

In summary, addressing distressing behaviors in autistic individuals necessitates a non-pharmacological approach, focusing on positive behavioral support strategies such as modifying environments, establishing structured routines, providing family and staff training, and addressing internal factors like pain or gastrointestinal disruptions. Research suggests a significant association between GI abnormalities and autism-associated symptoms, indicating the need for comprehensive care addressing physical and behavioral aspects. However, challenges persist in service provision for autistic adults, with pediatric services dominating and barriers including inadequate training and diagnostic overshadowing. Post-diagnostic mental health supports vary based on ID levels and the presence of autism, with concerns raised regarding the reliance on behavior support plans alone. Understanding autistic neurodiversity through profiling models is proposed to facilitate tailored support strategies, emphasizing individual strengths and needs across sensory coherence, flexible thinking, perspective-taking, and regulation. Efforts to improve care for autistic individuals require holistic approaches that encompass both physical and behavioral dimensions while acknowledging the complexity and diversity within the autistic population.

7.4 Health management

7.4.1 *Health care access equity.*

Autistic people experience significant health disparities and reduced life expectancy. Barriers to accessing healthcare are associated with adverse health outcomes. Autism training and healthcare professionals' knowledge about autism is variable, and heterogeneity among autistic people leads to additional educational and clinical complexities (Doherty, McCowan, & Shaw, 2023). Thus, autism remains nebulous for many practitioners, who are unclear about communication differences, access needs or life experiences common to autistic people. Malik-Soni et al. (2022) recognize that most autistic individuals do not have adequate access to the care required to address their diverse health needs. They note myriad reasons for this, including barriers to healthcare access in early developmental years (shortage/cost of services, physician awareness, and stigma) and barriers encountered with diagnosis (limited screening/diagnosis and unclear referral pathways). They also note problems inherent from the transition of health care responsibilities from pediatric health to adult medicine, often resulting in insufficient healthcare transition services and suboptimal physician awareness of healthcare needs. Similar barriers exist during adulthood (such as, shortage of services/limited insurance, communication difficulties with physicians, and limited awareness of healthcare needs of aging adults). A number of these factors may present as inhibitors for the communication of self-perceived decline or entry into MCI or early-stage dementia among autistic adults. Sonido et al. (2020) noted that for autistic adults, the challenges are twofold: they may face autism-specific effects of aging as well as other non-specific age-related effects experienced by the general population.

Inequity factors. Mason (2022) in examining the challenges accessing or maintaining adequate health care among older adults reported several factors, including *geographic density* (citing a 'urbanicity' [Vlahov & Galea, 2002] bias as a factor in healthcare inequity), with those adults living in rural areas less able to access appropriate healthcare. Living in rural areas can impede access to adequate healthcare, including long waits, service shortage, and travel time). Conversely, urban areas may have more health care resources, but also more competition for appointments and routine health care. Another factor, he noted, was *awareness of autism* among caregivers or autistic individuals (where lower socioeconomic families may be more unmindful and less likely to spot neurodevelopmental conditions), and the *dearth of research* into the healthcare needs of autistic adults. Malik-Soni et al. (2022) noted that many healthcare professionals report a lack of training about autism and lack confidence to manage the care of autistic patients.

A recent report on 'Autism in Canada' highlighted the inequities faced by underserved groups of autistic adults, including those from diverse ethno-cultural, linguistic, and gender communities (Canadian Academy of Health Sciences, 2022). As occurs in many countries, while each province and territory offers diagnostic

and support services for autism, there is significant variability in availability, leading to delays and disparities in service receipt. The report emphasized that certain autistic individuals, particularly those in rural and remote areas, equity-seeking groups, and adults, are particularly disadvantaged. In Canada, the responsibility for planning and delivering health and social services lies with the provinces and territories, often spanning multiple ministries. However, existing provincial legislation or plans for autism tend to focus primarily on childhood, leaving autistic adults underserved. Moreover, the presence of physical and mental health conditions can exacerbate challenges in daily activities. Regarding inequity, the report highlighted that many autistic adults lack access to essential healthcare services such as family doctors, dental care, and mental health services. Additionally, publicly-funded, locally-available, and culturally-responsive diagnostic and support services for autistic adults are virtually nonexistent in Canada. This dearth of support is compounded by a lack of professionals, therapists, and service providers with expertise in adult autism across the health, education, and social services sectors.

As reported by Hand et al. (2020), older autistic adults have a greater prevalence of nearly all physical health conditions, including epilepsy, Parkinson's disease, and gastrointestinal conditions, as well as mental health conditions, such as schizophrenia and psychotic disorders, attention deficit disorders, personality disorders, and suicidality or self-inflicted injury. As they age, they also have many common geriatric health conditions (e.g., osteoporosis, cognitive disorders, heart disease, cancer, cerebrovascular disease, osteoarthritis). The rate of occurrence of these conditions calls for greater involvement by the health care community, both in terms of early diagnosis, prophylaxis, and appropriate treatment. Yet, as noted by numerous authors, significant barriers exist to bring this to reality.

One study (Vogan et al., 2017) examined issues related to healthcare access for autistic adults and found that the family doctor was the most accessed source, and that the most common barrier was knowing where to find help and navigating the health system. Their study also found that some half of the study participants reported negative experiences with health professionals. Dern and Sappok (2016) spoke to barriers inherent in accessing health care, such as 'making appointments', 'waiting area', 'communication', and 'examination.' Shaw et al. (2023) working with autistic adults gleaned personal perceptions of barriers and interactions with health professionals, and found the adults reported a variety of barriers. The emerging themes included early barriers; communication mismatches; doubt (in oneself and from doctors); helplessness and fear; and healthcare avoidance and adverse health outcomes.

Psychological and physical processes. Shaw et al. (2023) reported that such *early barriers* included experiencing specific challenges interpreting internal bodily sensations to be able to decide if medical attention was needed; differences in pain thresholds/interpretation; with needing an appointment, challenges with contacting healthcare services to make one (such as challenges with making phone calls), when getting an appointment anxiety over lack of predictability (not knowing what to expect and sensory overstimulation) and needing to use public transportation to get to their doctor. These findings were echoed by Dern and Sappok (2016) and Mazurek et al. (2023) who also reported study participants describing barriers to obtaining services, including scheduling logistics, costs and inadequate insurance coverage, and transportation barriers.

Kartoz et al. (2022) also raised the challenges presented by not being able to explain what may be presenting health problems while at the medical appointment. Shaw et al. (2023) characterized this barrier as c*ommunity mismatches* – such 'mismatches' included anxiety and mistreatment in relation to communication with receptionists, struggling with idioms (such as being told to 'sit tight' for a referral letter), and experiencing misunderstandings when communicating with physicians and other healthcare staff. Weir et al. (2022) also reported that autistic adults are far less likely than non-autistic adults to report being able to describe their symptoms, understand what their healthcare professional means, or bring up a healthcare concern if not prompted by a healthcare professional. They are also over twice as likely as non-autistic adults to report not asking all the questions they would like when meeting with a healthcare professional.

Characteristically, some autistic adults may evidence '*doubt.'* Mason et al. (2023) noted this dynamic among some autistic adults who experience repeated adverse events, including rejection, victimization, and stigmatization and who described others being critical and negatively judging them, such as for how they socially interact or for expressing passion for particular interests. They reported that the impact of these adverse events can be substantial, including increasing vulnerability for poorer mental health, and contributing to development of negative self-beliefs (such as "I am different" or "I do not fit in") and shame-based difficulties. Shaw et al. (2023) found that many adults experienced self-doubt and pre-empted guilt (such as feeling that they are a nuisance) or from doctors (feeling guilty for wasting their time). These worries were reinforced by feelings of a lack of understanding about the possible implications of different symptoms. They also reported experiencing more negative relationships with their doctors, which fed into their perceptions of healthcare barriers experienced; feeling that their physicians disliked them for misinterpreting their very precise words, feeling as it their physician didn't help to relieve their anxiety because they could not convince the doctor to accept their priorities; feeling that this led to negative relationships and to their perceived questioning of their credibility as people and fostered a sense of frustration at their health concerns not being believed. One aspect is when their PCP sees their autism diagnosis, stops listening, and attributes their physical health concerns to their autism or anxiety (an example of repeated 'diagnostic overshadowing'). Some of this may be attributed to, as Weir et al. (2022) noted, many autistic adults reporting not being able to describe how their symptoms, pain, or sensory sensitivities feel in their body to healthcare professionals. Autistic adults are also often more likely than non-autistic adults to report sensory overload related to the healthcare environment, and that frequent sensory overload makes it difficult to focus on conversations with healthcare professionals.

'Helplessness and fear' was another factor. Shaw et al. (2023) found that many autistic adults reported being frustrated after reaching out for help to find none available, which compounded their experiences of doubt and left them feeling despondent. They felt that the medical system could not, or would not, be able to support their needs and that after never being diagnosed or getting any helpful treatment, they had feelings of 'it was a waste of time.' They also reported that their experiences with hospital waiting lists and tokenistic mental health services made them feel as if going to see a PCP seemed futile. Mazurek et al. (2023) also noted that autistic adults they interviewed emphasized that adverse aspects of interactions with PCPs affected their health care experiences. Featherstone et al. (2022) noted gender identification as a barrier to access and that female and nonbinary autistic adults perceived being more misinterpreted by staff and not being taken seriously compared to autistic males. This is supported by the work of Koffer Miller et al. (2022) who found that autistic adults identifying as women or 'other' gender experienced more barriers and unmet healthcare needs.

Lastly, the theme of *healthcare avoidance* was notable, where prior negative experiences dissuaded respondents from future contact with healthcare providers. Shaw et al. reported that some said that some felt so disrespected by healthcare professionals and thus would rather bear discomfort than setting themselves up for ridicule. Many just gave up with the result of a complete inability to access healthcare. The reality is that there is sizable inequality in healthcare access and provision for autistic adults. Weir et al. (2022) reported that autistic adults are more likely to have chronic health conditions alongside self-reported lower quality healthcare than others and that health inequalities between these groups are widespread and dramatic. Unfortunately, they indicated that this existed before and has persisted after the onset of the 2019 coronavirus pandemic.

Many autistic adults attempting to access healthcare may be competing for scarce resources such as appointments with non-autistic people who have an advantage. Shaw et al. (2023) posited that the nature of the doctor–patient relationship is the key in guiding the outcome of consultations. A positive relationship will lead to increased satisfaction and perceived improved outcomes. A negative doctor-patient relationship will result in feelings of not being taken seriously and experiences of diagnostic overshadowing. With recurring negative experiences, this can lead to learned helpless states, where autistic adults will develop feelings that

the healthcare system is not able to offer them health care support. Weir et al. (2022) suggested that differences in social communication may contribute to two-way communication difficulties between autistic and non-autistic individuals (such as health care workers). They noted that these challenges stem from healthcare settings, as physicians have previously noted that challenges with communication with patients as well as caregivers can serve as barriers to care. Morris et al. (2019) examined this issue from the perspective of the health care providers caring for autistic adults. Their work highlighted six themes affecting the doctor-patient relationship when treating autistic adults: (1) complexity beyond usual role, (2) limited knowledge and resources, (3) training/prior experience, (4) communication and collaboration, (5) need for information and training, and (6) need for care communication and systemic changes. Morris et al. posited that their findings support research with individuals with autism and their families identifying difficulties accessing knowledgeable providers with autism-relevant skills in effective patient-provider communication and collaboration.

Adapting office space to mitigate inequities. Another remedial factor, suggested by Doherty et al. (2023), is adapting diagnostic clinics and medical spaces for safe use by adults with autism to accommodate their sensory sensitivities. If situational variables affect the diagnostic process for determining presence of dementia they could lead to misdiagnosis. Autistic adults can be sensory avoidant, sensory seeking, or both. Hypo- or hyper-reactivity to any sensory modality is possible and a person's sensory responsiveness can vary depending on circumstances. A 'sensory diet' provides scheduled sensory input which can aid physical and emotional regulation (Dohery et al., 2023). Office and examination space can have adaptations that reduce agita (such as minimizing bright lighting, particularly fluorescent). Visual stimuli which may go unnoticed by non-autistic people, such as the flickering of fluorescent lighting or computer screens, an overhead rotary fan, or highly patterned surfaces, may all cause sensory stress in autistic adults. Many experience auditory sensitivities and auditory processing differences, which may be magnified by dementia. Zwilling and Levy (2022) reported that the use of natural lighting is recommended but avoiding direct sunlight and the use of diffuse light sources to avoid glare – which are preferable to fluorescent lighting (because of the latter's tendency to flicker and emit a low humming sound). They also recommend using simple, non-reflective, and robust materials and textures in furniture and decor. With respect to colors, they recommend using soft, natural colors, with limited color contrasts.

Environmental noise can cause intense distress, particularly when sudden or unexpected. Sounds unnoticed by non-autistic people, such as the humming of electrical equipment, may be perceived by autistic people without 'fade' (where inconsequential sounds are no longer noticed over time). Autistic people may not filter out environmental sounds and therefore may struggle to hear a conversation in a medical office or examination room. As autistic adults are often overly sensitive to smell and may perceive olfactory stimuli that others do not and there are many common and usually inoffensive smells that may be perceived as highly noxious, sensitivity to the presence of smells in a medical setting is important. There are many common and usually inoffensive smells that may be perceived as highly noxious. These accommodations and their rationale are explored in Zwilling and Levy (2022). These factors may be heightened in autistic adults who have early-stage cognitive impairment or have been diagnosed with dementia.

Equity policies. The WHO (2023) has proposed that people with autism require accessible health services for general health-care needs like the rest of the population, including promotive and preventive services and treatment of acute and chronic illness. It also proposes that actions be undertaken to proactively identify and redress disparities in access to services by "implementing strategies for health promotion and prevention of life-long disabilities associated with autism spectrum disorders, by developing and implementing multisectoral approaches for the promotion of health and psychosocial well-being of persons with autism spectrum disorders, the prevention of associated disabilities and co-morbidities, and reduction of stigmatization, discrimination and human rights violations, and that are responsive to specific needs across the lifespan and integrated into the national mental health and health promotion policies" (*p. 4*; WHO, 2014). Malik-Soni et al. (2020) recommended that organizations develop evidence-informed policies, programs, and technologies that

address barriers to healthcare access for autistic individuals and consider broad, equitable implementation to maximize impact. They also noted that the field needs to undertake more in-depth queries about general barriers to accessing healthcare across the lifespan of autistic individuals and examine how to ensure the best use of healthcare resources to improve social, physical, and mental health outcomes. Stakeholders must strengthen healthcare service provision by coming together to better understand healthcare needs of underserved populations and strengthen medical training on health care for autistic individuals.

Walsh et al. (2021) reported that autistic adults face significant disparities in health and physicians often report difficulties in providing care to autistic patients. To improve the quality-of-care autistic individuals receive, it is important to identify the barriers that physicians experience in providing care so that these may be addressed. They developed a preliminary version of a physician-report tool to assess barriers to providing care to autistic patients and suggest that the use of such a tool can help physicians to identify issues specific to different medical specialties and healthcare settings. It will help identify the support that physicians require to recognize and implement the required accommodations and that future research needs to be directed at identifying more clearly the tangible and professional barriers to healthcare provision for autistic patients to aid in producing systemic change in healthcare to improve care experiences and health outcomes for autistic adults. Malik-Soni et al. (2020) also suggested that there is an urgent need for more research investigating long-term access to healthcare, the impact of co-occurring conditions, medication, and cognitive decline related to autistic adults.

> ***In summary,*** the challenges autistic individuals face in accessing adequate healthcare are multifaceted and deeply impactful. Health disparities and reduced life expectancy are prevalent among this population, exacerbated by barriers to healthcare access and insufficient knowledge among healthcare professionals regarding autism; these serve as a major contributor to adverse health outcomes. The variability in autism training and knowledge among healthcare professionals further complicates matters, particularly given the heterogeneity among autistic individuals. Issues span from early developmental years to adulthood, encompassing challenges with diagnosis, historical problems associated with transitioning between pediatric and adult healthcare, and accessing appropriate care – particularly in older age and with the appearance of later-life cognitive neuropathologies. Older autistic adults face a myriad of physical and mental health conditions yet encounter significant obstacles in receiving timely and adequate healthcare. These barriers include a lack of awareness among caregivers, insufficient research into the healthcare needs of autistic adults, and a scarcity of trained healthcare professionals. Personal perceptions of barriers among autistic adults include communication mismatches, doubt, helplessness, fear, and healthcare avoidance, which further exacerbate adverse health outcomes. Addressing these challenges requires tailored approaches, such as adapting medical spaces for sensory sensitivities and developing evidence-informed policies to enhance healthcare access and outcomes for autistic individuals. Recommendations include developing evidence-informed policies and programs, strengthening enhanced medical training and interdisciplinary collaboration, and utilizing physician-report tools to identify and address barriers to care provision. The overarching goal is to improve healthcare experiences and outcomes for autistic individuals by addressing systemic barriers and enhancing support mechanisms.

7.4.1 Pain and Autism.

Chronic pain is one of the most disabling conditions particularly for older people and seems to be a risk factor for the development of dementia. Bornier et al. (2023) reported that chronic pain and dementia share common risk factors, such as advanced age, genetic impairment, depressive disorders, diabetes, obesity, social isolation, and low level of education; to which they added abnormalities of the noradrenergic system, overactivation of microglia and central neuroinflammation (the latter three factors also relate to weathering

and allostatic load). Kerckhove et al. (2023) reported that Alzheimer's disease is known to disturb pain perception and reduce the ability to report it, resulting in underestimation by practitioners and sub-optimal medical management. Analyzing data from the French national health system, they found that the prevalence of chronic pain among adults age 50+ living with dementia was greater than among age peers absent a diagnosis of dementia. They suggested that practitioners need to be alert to effective pain assessment and management in patients with dementia who may have difficulties expressing and perceiving pain.

Autistic adults are likely to experience pain in a large variety of contexts because of challenging behaviors, medical comorbidities, or life conditions (Rattaz et al., 2016). There is increasing evidence that autistic adults are at risk for or do experience pain, defined as an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage, and that personal experience and biological, psychological, and social factors shape the pain experience (Raja et al., 2020). Historically, the recognition and acknowledgement, assessment, and adequate management of pain in people with ID, including those with autism, have posed challenges (Defrin & McGuire, 2021; El-Tallowy et al., 2023). Recognition of pain can be problematic and reliance on self-reports of pain, as many autistic adults (with or absent ID) have several comorbid physical and secondary conditions which may be sources of pain. These can include musculoskeletal and gastrointestinal conditions (Bernal-Celestino et al., 2022, El-Tallowy et al., 2023, Liao et al., 2021, McGuire & Defrin, 2015). Barney et al. (2020) noted that pain is difficult to discern from other conditions or states such as distress, depression, or anxiety, even while observing a familiar person, due to overlap of manifestations and that diagnostic overshadowing can occur when signs and symptoms of pain are mistakenly attributed to an adult's behavior. Pain discernment among autistic adults with concurrent ID is also problematic. Doody and Bailey (2017) reported that while self-report is the gold standard in pain assessment, its assessment for people with ID can be challenging as some adults may be unable to self-report their pain due to difficulties in communication or level of cognitive ability. In such instances, assessment requires a combination of approaches amalgamating pain assessment, health assessment, and observation of behaviors. Zwakhalen et al. (2004) also reported the assessment difficulties when ID is severe and reading non-verbal expressions are critical to diagnosing pain.

In addition to social-communication difficulties and repetitive behaviors, autism also presents as atypical sensorimotor function and pain reactivity (Bogdanova et al., 2022). Bogdanova et al. reported that although chronic pain is a frequent comorbidity in autism, pain management is often inadequate due to difficulties in pain evaluation, resulting in worsening prognosis, and higher mortality rates. While early thinking was that the experience of pain in autism was less a factor as autistic adults were insensitive to painful stimuli, various findings in the past 15 years have challenged and complicated this belief (Hoffman et al., 2022). Both peripheral and central deviations in pain signal processing are documented in autism. Also, chronic musculoskeletal pain is an increasingly frequent feature in younger people with autistic traits. Many exhibit a range of additional physical and psychological features and fulfill criteria for fibromyalgia, which has been significantly associated with autistic traits, along with a dysfunction of the autonomic nervous system. Hypermobility, irritable bowel syndrome, and migraine are frequent comorbid conditions (Ryan et al., 2023).

Some autistic adults may display hypersensitivity to stimuli usually considered painless. These responses may be accompanied by absence of reactivity to potentially hazardous and noxious stimuli. Bogdanova et al. (2022) noted the relation between self-stimulation and self-injuring behavior (SIBs) and response to pain in some autistic adults. One study (Symons et al., 2009) examined SIBs and pain signs in non-verbal autistic individuals and found increased behavioral signs of pain in adults with chronic self-injury. The authors suggested that the SIBs might be a coping strategy to manage chronic pain.

Pain assessment and management warrants attention across the lifespan for people with autism, however, due to socio-communicative deficits, pain assessment is particularly challenging among some autistic adults (Battaglia et al., 2016). Thus, psychophysical evaluation of pain detection and discrimination may be

confounded by other factors like attentional resources, levels of anxiety or task performance capacities which may be different in autism (Bogdanova et al., 2022). However, any pain determinations in autistic adults will be successively more difficult with the progression of dementia.

> ***In summary,*** autistic adults are susceptible to experiencing pain due to numerous factors such as challenging behaviors, medical comorbidities, and life conditions. Recent studies indicate a growing recognition of pain among autistic adults, yet challenges persist in its acknowledgment, assessment, and management. Pain recognition can be complicated by reliance on self-reports, comorbid physical conditions, and overlapping manifestations with distress or anxiety. While historically thought to be insensitive to pain, recent findings suggest otherwise, with documented peripheral and central deviations in pain signal processing in autism. Chronic pain, often inadequately managed, is common in autism and associated with worsened prognosis and higher mortality rates. Autistic adults may exhibit hypersensitivity to stimuli and may use self-injurious behavior as a coping mechanism for chronic pain. Chronic pain also poses challenges for older adults, particularly those with dementia, as it may impair pain perception and expression, leading to underestimation and suboptimal management. Pain assessment and management in autistic adults require careful attention, especially given socio-communicative deficits and potential confounders in pain evaluation. However, with the progression of dementia, pain determination becomes increasingly challenging. As a result, pain assessment and management in autistic adults require careful attention, particularly as socio-communicative deficits and cognitive decline may exacerbate challenges in evaluating and treating pain effectively.

7.5 Sensory considerations

Autistic people experience hyper- or hyposensitivity to sensory stimuli (Crompton et al., 2022). Thye et al. (2018) noted that dysregulated sensory processing can be considered universal in autism and that abnormal sensory sensitivity has significant clinical and social implications. Oversensitivity to perceptual level sensory features can come at the expense of inability to filter out extraneous information and selectively attend to instruction in the therapeutic environment. Conversely, hyposensitivity to sensory stimuli in the environment can result in delayed visual and auditory processing, lack of appropriate response, and poor multisensory integration. Given the prevalence of sensory sensitivities in individuals with autism, creating a sensory-friendly environment and incorporating sensory modulation techniques can improve well-being. The development of a "sensory diet" that supports the person's specific sensory needs is based upon the person's life story and historical evidence that also incorporates normal physical changes of aging. Often an occupational therapist has the armamentarium to undertake such assessments, recommend actions to be implemented, and help a partner in developing a plan. Measures are in place that are useful in dementia care settings and can be adapted for use with residents with autism (e.g., Adolescent /Adult Sensory Profile (A/ASP; Brown et al., 2002). Ravn et al. (2018) applied an adaptation to a dementia setting and assessed its viability from the care provider's perspective.

With respect to residential environments, Crompton et al. (2022) have recommended that the care environment should be personalized and adaptable to each individual, with a particular focus on reducing strong smells from communal spaces or kitchens, bright lights or other visual stimuli, noise from other residents, staff, activities, or equipment, and furniture that exacerbates proprioceptive difficulties. In the UK, the NICE (BPS/RCP, 2012) guidelines related to sensory aspects note that in all settings, account should be taken of the physical environment in which autistic adults are assessed, supported, and cared for, including any factors that may trigger challenging behavior. It is recommended that if necessary adjustments or adaptations in the setting should be made to the (a) amount of personal space given (at least an arm's length); (b) setting using visual supports (for example, use labels with words or symbols to provide visual cues about expected behavior), (c) color of walls and furnishings (avoid patterns and use low-arousal colors such as cream), (d) lighting (reduce fluorescent lighting, use blackout curtains or advise use of dark glasses or increase natural light), (e)

noise levels (reduce external sounds or advise use of earplugs or ear defenders). Where it is not possible to adjust or adapt the environment, workers report that consideration should be given to varying the duration or nature of any assessment or intervention (including taking regular breaks) to limit the negative impact of the environment.

> ***In summary,*** autistic individuals often experience heightened or diminished sensitivity to sensory stimuli, necessitating the creation of sensory-friendly environments and implementation of sensory modulation techniques for improved well-being. This involves developing a tailored "sensory diet" based on the individual's life history and incorporating aging-related changes. Occupational therapists play a crucial role in assessing sensory needs and recommending interventions. Measures like the Adolescent/Adult Sensory Profile can be adapted for dementia care settings. Residential environments should be personalized and adaptable, minimizing triggers such as strong smells, bright lights, noise, and uncomfortable furniture. Guidelines emphasize adjustments in personal space, visual supports, color schemes, lighting, and noise levels to accommodate sensory needs. When environmental adjustments are not feasible, modifying the duration or nature of assessments or interventions can mitigate negative impacts.

7.6 End-of-life care planning

The information available on end-of-life issues is the bailiwick of autism advocacy organizations (e.g., Autism and Grief Project, 2024; National Autistic Society, 2024). However, some workers have digested this issue and provided an empirical basis. Preparing for end-of-life care, including advance directives and palliative care options, is crucial to ensure the individual's comfort and dignity in the later stages of dementia (Furguson & Laurie, 2018; McCarron et al., 2018). Work exists related to addressing care and support for *advanced dementia*, when care focus is more orientated around palliative care and co-occurring end-stage disease and medical health conditions (Mitchell, 2015). Much of guidance for advanced dementia in the general population will apply to adults with neuroatypical conditions, as the primary care activities relate to aiding adults who are non-ambulatory, needing personal care, and comfort. Mitchell (2015) reported that the characteristic features of advanced dementia include profound memory deficits, minimal verbal abilities, inability to ambulate independently, inability to perform any activities of daily living, and the presence of urinary and fecal incontinence. Structurally, Vinay and Biller-Andorno (2023) examined how national dementia care guidance initiatives function and benefit advanced dementia caregiving and that most cover end-of-life care issues, re-assessing care plans, rationalizing medication, and caregiver support and well-being.

In general, Ijaopo et al. (2023) remarked that while it can be difficult to predict the timing of death, caregivers and medical personnel should be capable of recognizing the clinical signs and symptoms of imminent death in terminally-ill individuals. This capacity would enable earlier determination of care needs and better planning of care tailored to the adult's needs and aid with bereavement adjustment. Specifically with respect to autism, Ferguson and Laurie (2018) reported that support and accommodations from diagnosis through to end of life are particularly inclusive of the diversity of needs in a broad and varied spectrum of individuals. They contend that there should be an acknowledgement that peace at the end of life comes not just from medical intervention and symptom control, but from an understanding of who we are and what is important to us in life. Ferguson and Laurie offered five suggestions on providing palliative care to an autistic person: (1) ensure that the person is involved in decisions about their care; (2) provide for consistency of support and strong partnerships between health and social care teams; (3) plan and communicate to health teams what reasonable accommodations or adjustments be made to ensure best possible quality of palliative and end of life care; (4) understand the thinking style of the person being supporting to help with planning and preparing for difficult conversations, and how information is best communicated; and (5) support reflection on important events in the person's life and experiences that have given their life meaning.

In summary, end-of-life planning is crucial for ensuring comfort and dignity, particularly in the later stages of dementia. While guidance for advanced dementia exists, it applies to older adults with neuroatypical conditions like autism. Advanced dementia is characterized by significant memory deficits, minimal verbal abilities, immobility, and incontinence. For autistic individuals, comprehensive support throughout life, including end of life, should address their diverse needs. Palliative care for autistic individuals should prioritize involvement in decision-making, tailor communication methods, ensure consistent support, plan for accommodations, understand their thinking style, and encourage reflection on meaningful life experiences.

7.7 Autism and post-diagnostic supports

Globally, the WHO (2023) resolution on autism presents the support perspective. WHO's comprehensive mental health action plan 2013–2030 and World Health Assembly Resolution WHA73.10 for "global actions on epilepsy and other neurological disorders'' calls on countries to address the current significant gaps in early detection, care, treatment, and rehabilitation for mental and neurodevelopmental conditions, which include autism (WHO, 2020). It also calls for countries to address the social, economic, educational and inclusion needs of people living with mental and neurological disorders, and their families, and to improve surveillance and relevant research.

In May 2014, the Sixty-seventh World Health Assembly adopted a resolution titled '*Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders'*, which was supported by more than 60 countries. The resolution urges WHO to collaborate with Member States and partner agencies to strengthen national capacities to address autism and other developmental disabilities. WHO and its partners recognized the need to strengthen countries' abilities to promote the optimal health and well-being of all people with autism. In this regard, the WHO's efforts focus on: (a) increasing the commitment of governments to taking action to improve the quality of life of people with autism; (b) providing guidance on policies and action plans that address autism within the broader framework of health, mental and brain health and disabilities; (c) contributing to strengthening the ability of the health workforce to provide appropriate and effective care and promote optimal standards of health and well-being for people with autism; and (d) promoting inclusive and enabling environments for people with autism and other developmental disabilities and providing support to their caregivers.

The NICE guidelines (BPS/RSP, 2012) on autism provide a structural framework for providing coordination that applies equally well to older autistic adults and dementia and provide current and state-of-the-art strategies for diagnosis and treatment of ASD-related behaviors, and their level of evidence (Wilson et al., 2014). They call for a specialist autism team that would have a key role in the delivery and coordination of a broad range of supports, including (a) specialist diagnostic and assessment services, (b) specialist care and interventions, (c) advice and training to other health and social care professionals on the diagnosis, assessment, care and interventions for autistic adults (as not all may be in the care of a specialist team), (d) support in accessing, and maintaining contact with housing and public welfare services, (e) support to families, partners and carers where appropriate, (f) care and interventions for autistic adults living in specialist residential accommodation, and (g) training, support and consultation for staff who care for autistic adults in residential and community settings.

When older autistic adults receive a diagnosis of dementia, it necessitates a nuanced and specialized approach to intervention and support in the broadest sense. Best practices in this context encompass a range of strategies aimed at enhancing the quality of life and maintaining functional abilities:

➤ *Person-Centered Care*: Tailoring interventions to the individual's unique needs, preferences, and abilities is paramount. Focusing on their personal history, interests, and communication style (including how pain is typically expressed) helps in developing a more effective care plan. Such a perspective

stresses the importance of relational working and listening to autistic people and how this can facilitate the provision of personalized housing and care plans to enable a quality of life in tandem with dealing with the challenges of dementia (Quinn et al., 2023).

➤ *Applying a Multidisciplinary Approach*: Assembling a care group of healthcare professionals with expertise in autism (and in ID, if present) and dementia can ensure comprehensive care. This team may include a range of medical and behavioral specialists (such as physicians, psychiatrists, psychologists), as well as other allied health professions (such as speech-language therapists, occupational therapists, nutritional professionals with autism expertise and social workers), or at minimum one professional with knowledge of dementia and autism, and a collective of workers involved in support and personal care (Fulceri et al., 2023).

➤*Continuous Monitoring:* Regular assessments of cognitive and functional status are essential. These assessments should be tailored to the individual's abilities and may involve specialized tools developed for this population. On-going assessments of the person's physical health are essential and are tailored based upon known health care issues coupled with strategies colored by dementia. Anticipatory guidance can ameliorate possible urgent situations.

➤ *Legal and Financial Planning*: Assisting adults, their families, or others with legal standing in their lives, in establishing legal safeguards, such as guardianship and power of attorney, and addressing financial planning to ensure the individual's future well-being.

Broadly, Dennehy et al. (2023) reviewed salient themes in post-diagnostic supports for adults with ID affected by dementia and noted that most approaches fell into these major categories: aging in place, environmental supports, dementia-specific interventions and therapies, and the feasibility of these interventions. Dodd et al. (2018) examined more specific aspects of post-diagnostic supports as they apply to aiding adults with ID living with dementia (and their caregivers) and proposed a general model that encompassed seven focal areas: post-diagnostic counseling; psychological and medical surveillance; periodic reviews and adjustments to the dementia care plan; early identification of behavior and psychological symptoms; reviews of care practices and supports for advanced dementia and end of life; supports to caregivers/ support staff; and evaluation of quality of life. Bamford et al. (2021) identified five key themes covering post-diagnostic support in general for adults living with dementia: (1) timely identification and management of needs; (2) understanding and managing dementia; (3) emotional and psychological wellbeing; (4) practical support; and (5) integrating support. With respect to 'timely identification and management of needs,' they propose holding one or more meetings with the clinician or service diagnosing dementia, to communicate the diagnosis, discuss treatment options, and provide information and signposts.

The key to managing post-diagnostic support is proactively holding reviews involving a range of professionals at flexible intervals depending on the person's needs (Quinn et al., 2023). Also important is ensuring that physical health problems (whether multiple conditions or those related to dementia) are managed promptly and avoiding diagnostic overshadowing. As dementia progresses, it is important to the adult and his or her caregivers or family to initiate opportunities to consider the goals for the future, as well as future care preferences and emergency situations. Critical also is aid given to caregivers with accepting the implication of dementia progression and what it will bring for prolonged care (Jokinen et al., 2018). Recommendations for such dementia care also must consider the impact upon caregivers. Any helpers must consider holding formal assessments of caregiver needs which may lead to interventions such as respite, psychoeducation, or referrals to psychological or other support services.

To address *emotional and psychological wellbeing*, Bamford et al. (2021) suggested implementing interventions to enhance mood, support adjustment to dementia diagnosis, and manage anxiety; provide for opportunities to meet virtually or face-to-face with peers to share experiences, information, advice and social

activities; facilitate access to activities/groups/clubs to ensure that people with dementia have opportunities to socialize and maintain their identity through pursuing existing hobbies and interests; and recognize the impact of dementia on families and others, and provide interventions when needed.

Understanding and managing dementia can be challenging. Bamford et al. (2021) suggested employing interventions that would improve memory and thinking and which may include both pharmacological and non-pharmacological interventions. They also suggest providing tailored, accessible information about dementia to people with dementia and caregivers; implementing interventions or activities to help people with dementia and caregivers to understand and manage cognitive and functional decline in dementia; and designing interventions and activities to help understand the antecedents and impacts of non-cognitive symptoms and exploring creative management strategies. With respect to conveying information about the behavioral aspects of dementia, Burley et al. (2021) reported that some of the language used (e.g., terminology around BPSDs) need contextualization to make it more understandable and de-stigmatized. For example, they suggest a term like "agitated/hard to handle" could be contextualized to be "frustrated with cognitive decline, discriminatory behavior, and inadequate support systems." Using terms that are more readily understood by caregivers and autistic persons can help with creating a more environment.

Bagatell (2019) suggested that the *practical support* caregiving roles of autistic adults included meeting and managing daily needs, obtaining services and supports, and providing support when needed. In this context, Bamford et al. (2021) commented on the importance of supporting people with dementia to also keep their independence with an acceptable level of risk. This includes psychological aspects of feeling independent as well as functional aspects such as mobility and activities of daily living; ensuring that people with dementia are involved in decisions as much as possible and that caregivers are supported when making difficult decisions; providing opportunities for people with dementia to have a break from routine and for caregivers to have time off from caring; and ensuring undertaking research on autism and dementia. Fundamentally, it has been proposed that more must be done to ensure that families and people with autism have access to the appropriate resources and interventions to ensure their dignity and safety (Autism Speaks, 2023).

One aspect of growing older and potentially experiencing aging-related service challenges has been explored by Keller et al. (2020). They reported the reality of a sizable number of adults who go undiagnosed (they reported that in their study cohort in Italy an initial diagnosis occurred when one adult was aged 50), and that this occurs especially among women with autism. Reported also, was that as caregivers become older, there is a marked decrease in family resources, which translates into a higher level of concern for the future of autistic adults. Conceptually, they noted that high functioning autistic adults can follow a wide range of pathways during their transition to adulthood, such as attending college, entering the labor force, and achieving a degree of independent living. Less cognitively able individuals, on the other hand, may be eligible for state benefits or may access supported employment programs. They proposed that clinicians need to familiarize themselves with the unique needs of autistic adults to be able to administer specific supports and interventions to these patients to ensure their best possible social integration in the community.

Much is yet to be learned about the life trajectories and outcomes for persons with autism. Although research investment has been plentiful with respect to early childhood, school age issues, and the transitions to adulthood, little has occurred with a focus on middle age and transitions to being older (Mason et al., 2022). One study (Chamak & Bonniau, 2016) did examine the life trajectories of a French cohort of autistic adults living in some form of residential accommodation (none were living independently) and determined that those adults with severe autism had poor life outcomes, while those with moderate autism had better outcomes. The trajectories of those who were intellectual average or above were more positive, but they also remained dependent on aging parents and had few available supports. What other research exists, usually occurs with adult populations with co-occurring conditions, primarily those with ID. Numerous authors have

commented on this deficit and indicated the need to broaden the focus ranging from biological to social integration to lifetime support issues. What is known, from work with the general population, is that among older adults, a healthy lifestyle may provide a cognitive reserve to maintain cognitive abilities independently of common neuropathologies of dementia (Dhana et al., 2024). This same finding can apply to the life trajectories and outcomes among autistic adults with the implementation of effective efforts at promoting brain health and wellness.

The report of the Neuroatypical Conditions Expert Consultative Panel (Janicki et al., 2022) reported that research focusing on autism and dementia is needed which (a) examines possible associations between dementia and symptoms of autism and the interplay between the entities, and (b) compares persons with autism with and without ID to better understand potential risk and protective factors. Also, the field would benefit from studies investigating the interplay and possible associations between dementia and symptoms of autism, including neurobiological research as to the etiologies of neuropathologies and their trajectories; studies examining the nature and degree of cognitive decline among aging autistic adults and degree of transition to dementia, studies examining the nature or types of dementias that may be present, or perhaps over-represented, in older autistic adults and their etiologies. Further, needed are studies identifying subgroups of individuals on the autism spectrum who might be at higher risk for dementia, as well as lifestyle factors related to reduced access to appropriate services in autism (e.g., barriers to accessing intellectual, educational, and social opportunities) and studies examining potential testing strategies to assess neuropathology in autism that do not require verbal instruction and capitalize on visual strengths (e.g., passive viewing tasks to examine visual memory).

In summary, we recognize the extant global initiatives and frameworks, such as the WHO resolutions and NICE guidelines, aimed at improving support for individuals with autism. There is a need for coordinated efforts to address gaps in early detection, care, treatment, and rehabilitation for mental and neurodevelopmental conditions, including autism. The WHO's focus includes increasing government commitment, providing guidance on policies, strengthening the health workforce, and promoting inclusive environments. The NICE guidelines offer a comprehensive structural framework for coordinating support for older autistic adults and dementia. Others have presented sets of key themes on post-diagnostic support for adults with dementia and call for timely identification, emotional wellbeing, understanding and managing dementia, practical support, and integrating support. What is evident is the gaps in research on the life trajectories and outcomes for individuals with autism, especially in middle age and aging. These emphasize the need for broader research and highlighting the importance of investigating associations between autism and dementia, neurobiological research, and potential testing strategies tailored to the unique characteristics of individuals with autism.

8.0 Commentary

The interplay between ID, autism, and dementia is a complex web of genetic, neurobiological, and environmental factors. Addressing these multifaceted challenges requires an integrated approach that encompasses assessment, intervention, and support, all tailored to the individual's unique needs and circumstances. In addressing the intersection of autism, intellectual disability, and dementia requires a holistic and person-centered approach. Recognizing the unique needs and challenges of these individuals is essential for providing them with the best possible care and support as they navigate the complexities of aging with neurodevelop-

mental disorders. Continued research and collaboration among healthcare professionals, researchers, and advocacy groups are crucial for advancing our understanding and improving the quality of life for this vulnerable population.

Addressing gaps for better understanding the latter part of the lifespan for autistic adults calls for prospective, longitudinal studies employing both cross-sectional and longitudinal methods to unravel the nuances of typical and atypical aging in autism. Studies are needed to assess healthcare providers knowledge about autism in general and further how they would manage assessing for later age cognitive and functional decline. There is also a pressing need to evaluate the effectiveness of interventions for diverse sub-groups of older autistic adults. The insufficiency of data on the medical history, development, therapies, and educational backgrounds of autistic adults poses limitations on establishing reliable clinical and neurobiological correlations. The imperative for longitudinal studies on autism and aging, encompassing the collection of biological samples and brain tissue, is underscored to enhance understanding of the disorder's progression over the life course and improve correlations between clinical phenotypes and neurobiological mechanisms. The current challenges in research involving brain tissue stem from the heterogeneity among autism spectrum disorders, differing clinical presentations, and diverse developmental trajectories, adding layers of complexity to the pursuit of comprehensive insights.

Given the dearth of extended focus on the aging trajectories and outcomes for autistic adults, there are areas of research that warrant further inquiry, among them are the following:

1. Investigate social isolation and living arrangements for older autistic individuals, particularly those with intellectual disability, and explore the need for tailored housing options.
2. Enhance understanding of the epidemiology, symptoms, assessment approaches, and disease trajectory of dementia and age-associated conditions in autistic individuals, accounting for variations in intellectual functioning and comparing with the general population and age peers with other developmental disabilities.
3. Explore best practices for educating autistic individuals and their families about dementia, available supports, caregiver assistance, and post-diagnostic support.
4. Examine the cognitive aging trajectory in autistic adults, considering factors such as intellectual functioning level and coincident conditions.
5. Undertake studies to determine the most prevalent types of dementia among autistic individuals and investigate underlying neuropathology contributing to autistic behaviors and dementia risk.
6. Assess the knowledge base of healthcare providers regarding cognitive and functional decline in autistic adults, emphasizing the need for education and training.
7. Research efficacy of various health and wellness programs tailored for autistic individuals.
8. Diversify research methodologies, outcome measures, and sample sizes to ensure representation of older autistic adults in research.
9. Investigate the relationship between autism and dementia, focusing on mechanisms underlying this connection.
10. Explore the potential of pre- and probiotics in mitigating dementia risk among autistic individuals, considering the variability of bacterial strains.
11. Examine holistic approaches to diagnosis and treatment, considering the unique needs of autistic individuals.
12. Develop tailored assessment methods for dementia diagnosis in autistic adults.
13. Explore classic risk factors for late-onset Alzheimer's disease within the autism population.
14. Investigate mortality factors within the autism population to better understand health outcomes.
15. Evaluate the applicability of novel medications for Alzheimer's disease in autistic individuals.

By addressing these research recommendations, we envision an advance in our collective understanding of aging, autism, and dementia and improve outcomes for autistic individuals as they age.

9.0 Conclusions and statement

This report systematically addressed key inquiries to advance our understanding of the complex relationship between autism, ID, and dementia. The specific questions explored were: *(a)* key findings from previous efforts; *(b)* the connections between autism, ID, and dementia; *(c)* factors contributing to the increased risk of dementia in individuals with autism and ID; *(d)* challenges in diagnosing dementia in older autistic adults; *(e)* recommended non-pharmacological interventions and supports for diagnosed individuals; and *(f)* a research agenda derived from this report.

Regarding *(a)*, the analysis found that previous attempts to define the intersection of dementia and autism lacked conclusive determinations. Concerning *(b)*, the report highlighted links between certain life factors, bio-neurological processes, and dementia risk in autistic adults, but noted the absence of a definitive relationship between the genesis of a brain disease or neurodegenerative disorder and behavioral expressions of dementia. Exploring *(c)*, the literature supported associations between adverse social determinants of health and clinical expressions of dementia but did not establish a definitive trajectory in autism overall. Recognizing the need for adaptations in diagnostic processes *(d)* acknowledged the impact of cognitive variations in autistic adults, particularly considering co-occurring ID and psychiatric conditions. For *(e)*, the report emphasized that customary practices for neurotypical adults with dementia could be applied to autistic adults, with special considerations for sensory sensitivities, environmental factors, and socialization aspects. For *(f)*, the proposed research agenda underscores the nascent stage of aging studies in autism and calls for increased investment, especially in diagnostics and biomarkers related to dementia and neurological processes, and contributory factors and the broader impact of neurocognitive decline in autism.

In addressing the ongoing challenge of understanding the precise mechanisms underlying these associations, future research endeavors may uncover intricate relationships between genetic, neurobiological, and environmental factors contributing to the heightened risk of a neurodegenerative disorder or dementia in individuals with ID and autism, particularly as their mean survival age increases. Insights derived from such investigations will be crucial for developing targeted prevention and intervention strategies. Consequently, we recommend increased international commitment from universities, research institutes, civil society organizations, and ministries and governmental agencies to allocate additional resources for research on aging, older age, and autism, and possible neuropathologies, and more importantly continue to convene study groups to explore and digest new findings.

Thus, the Summit Autism/Dementia Work Group offers the following:

1 Our understanding of the risk factors for dementia among autistic adults is still evolving, it is evident that a complex interplay of genetic, neurobiological, and environmental factors contributes to this vulnerability and that better understanding the precise mechanisms underlying these associations remains an ongoing challenge.

2 There is some evidence of variable influences on the evolution of dementia among some autistic adults but not significantly above the norm for the general population, and absent is any evidence for the contention that Alzheimer's disease may be a significant outcome or that autism is a risk factor for Alzheimer's disease.

3 Among individuals with autism, there is some evidence that secondary neurological conditions such as intellectual disability, Down syndrome, and seizure disorder, as well as secondary health conditions, such as cardiovascular disease, may be associated with heightened risk for dementia compared with individuals with autism without these secondary conditions.

4 An understanding of the intersection between autism and dementia will be aided by a more evolved understanding of the aging trajectory of individuals with autism.

5 A dearth of older-age focused research on autism has hampered a better understanding of life conditions, age band transitions, adaptations, health, aging effects, and aging-related neuropathologies.

6 A lack of clear practice guidelines for assessment and diagnosis of dementia or other later-age neuropathologies is impairing early detection and screening for cognitive changes among aging autistic adults.

7 National and international initiatives are required to prepare social welfare and health services for an aging population of autistic adults.

9.1 Statement

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 particular 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 and 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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Table: Reports and Key Findings of Previous Efforts

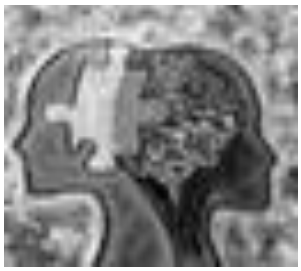
Title of report/article	*Year*	*Type*	*Key Finding(s)*	*Reference*
Neurodevelopmental Conditions and Aging: Report on the Atlanta Study Group Charrette on Neurodevelopmental Conditions and Aging	2008	Meeting report/journal Scientific meeting held in 2007 at CDC in Atlanta, Georgia (U.S.)	1. The difficulty with ascertaining aging-related issues among older-age adults with autism is sparse case identification, low numbers of older adults among established study participants, and negligible focus on aging among autism researchers. 2. Little is known about the adverse health status of older persons with autism or if there are any predictable trajectories common to people affected by autism.	Janicki, M.P., Henderson, C.M., Rubin, I.L. & Neurodevelopmental Conditions Study Group. (2008). Neurodevelopmental conditions and aging: Report on the Atlanta Study Group Charrette on Neurodevelopmental Conditions and Aging. *Disability and Health Journal,* 1(2), 116-124. doi: 10.1016/j.dhjo.2008.02.004.
Autism Spectrum Disorders in Older Adults: Toward Defining a Research Agenda	2011	Meeting report/journal Multidisciplinary expert group convened March 2010 (U.S.)	1. Little is known about the phenomenology and associated features of autism as individuals age, about underlying long range neuro-biological changes, and about specific medical, psychiatric, and social aspects. 2. Studies on autism and aging are practically nonexistent.	Piven, J., Rabins, P. & Autism-in-Older Adults Working Group. (2011). Autism spectrum disorders in older adults: toward defining a research agenda. *Journal of the American Geriatric Society*, 59(11), 2151-2155. doi: 10.1111/j.1532-5415.2011.03632.x. Epub 2011 Nov 8.

Ageing in People with Autistic Spectrum Disorder	2012	Journal article/review	1. Although there is a growing body of evidence on pathological, imaging, neuropharmacological and other key brain abnormalities in autism, these are, to date, confined to children and young (only rarely to middle aged) adults. 2. Lacking any published evidence, there is a clear need to design cognitive and behavioral assessment tools appropriate to aging in adults with autism, as was done with dementia in general.	Mukaetova-Ladinska, E.B., Perry, E., Baron, M., Povey, C. on behalf of the Autism Ageing Writing Group. (2012). Ageing in people with autistic spectrum disorder. *International Journal of Geriatric Psychiatry,* 27(2), 109-118. First published: 27 April 2011 https://doi.org/10.1002/gps.2711
Into The Unknown: Aging With Autism Spectrum Disorders	2012	Journal article/review Academic work by authors	1. The impact of aging processes and aging-related outcomes for individuals with autism remains relatively unknown. 2. The emerging literature indicates that autism's behavioral characteristics appear changeable across the lifespan, and comorbidities, including epilepsy and ID, and mental health issues, including anxiety and depression, can reduce quality of life.	Perkins, E.A., & Berkman, K.A. (2012). Into the unknown: Aging with autism spectrum disorders. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 478-496. DOI: 10.1352/1944-7558-117.6.478
Aging in Autism Spectrum Disorders: A Mini-Review	2012	Journal article/review	1. The trajectories of change in cognitive and social functioning in autism in old age remain unknown. 2. Studies using prospective, longitudinal methods are needed to identify the nature of age-related changes in behavior, cognition, and neurobiology.	Happé, F. & Charlton, R.A. (2012). Aging in autism spectrum disorders: a mini-review. *Gerontology,* 58(1), 70-8. doi: 10.1159/000329720. Epub 2011 Aug 24.

Aging and Autism: A Think Tank Round Table - Autism in Later Life: A Think Tank on the Effects of Aging on the Autism Spectrum	2018	Meeting report Multidisciplinary expert group convened October 2017 (Canada)	1. 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. 2. Needed are specialized training programs for staff in residential care facilities and the development of alternatives to facility-based care. 3. Some evidence exists 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. 4. Needed is more information 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.	Autism Canada, Autism Research Institute, and Pacific Autism Family Network. (2018). Autism in later life: A think tank on the effects of aging on the autism spectrum. Bothwell, Ontario, Canada. https://autismcanada.org/wp-content/uploads/2018/04/AC_2017-ThinkTank_Final.pdf

Older Adults with ASD: The Consequences of Aging Insights from a series of special interest group meetings held at the International Society for Research	2019	Meeting report/journal Scientific panel meetings held in London UK, and other cities in 2016-17	1. Consensus was not reached regarding effective diagnostic approaches to later life assessments, earlier referral for diagnosis, and establishing post-diagnostic support pathways for autistic adults across the adult life course. 2. Cross-sectional and longitudinal methods need to be employed to enhance research knowledge in: (a) understanding of typical and atypical aging in autism; and (b) the relative effectiveness of intervention approaches for different sub-groups of older adults with autism.	Roestorf, A., Bowler, D.M., Dassing, M.K., Howlin, P., Klinger, L., McConachie, H., Parr, J.R., Powell, P., Van Heijst, B.F.C., Geurts, H.M. Older Adults with ASD: The Consequences of aging insights from a series of special interest group meetings held at the International Society for Autism Research 2016-2017. *Research in Autism Spectrum Disorders*. 2019 Jul; 63:3-12. doi: 10.1016/j.rasd.2018.08.007.
Strategies for Research, Practice, and Policy for Autism in Later Life: A Report from a Think Tank on Aging and Autism	2021	Meeting report/journal 'Think Tank' meeting held October 2017 (Canada)	1. Data are lacking with respect to details regarding medical history, development, therapies, and educational backgrounds, or adults with autism, thus limiting opportunities for reliable clinical and neurobiological correlations. 2. Needed are longitudinal studies on autism and aging to obtain biological samples and eventually brain tissue. 3. Needed are studies to provide detailed insight into how autism progresses over the life course and improve correlations between clinical phenotypes and neurobiological mechanisms. 4. Current research involving brain tissue is impeded by the heterogeneity among the spectrum's disorders as well as differing clinical or functional presentations and developmental trajectories.	Edelson, S.M., Nicholas, D.B., Stoddart, K.P., Bauman, M.B., Mowlam, L., Lawson, W.B., Jose, C., Morris, R., Wright, S.D. Strategies for Research, Practice, and Policy for Autism in Later Life: A Report from a Think Tank on Aging and Autism. *Journal of Autism and Developmental Disorders*. 2021 Jan;51(1):382-390. doi: 10.1007/s10803-020-04514-3. *See also:* Autism Canada, Autism Research Institute, and Pacific Autism Family Network. (2017, October). Aging and autism: A think tank round table. Bothwell, Ontario, Canada. https://autismcanada.org/wpcontent/uploads/2018/04/AC_2017-ThinkTank_Final.pdf

CDC = Centers for Disease Control and Prevention



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