International Journal of Geriatric Psychiatry

WILEY

International Journal of Geriatric Psychiatry

REVIEW ARTICLE OPEN ACCESS

Autism, Diagnostics, and Dementia: A Consensus Report From the 2nd International Summit on Intellectual Disabilities and Dementia

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Received: 13 February 2025 | **Revised:** 22 May 2025 | **Accepted:** 29 May 2025

Keywords: ASD | autism | dementia | diagnostics | neuropathologies | risk factors

ABSTRACT

Objectives: The second International Summit on Intellectual Disability and Dementia, held in 2023, highlighted the unique challenges of diagnosing dementia in older autistic adults, particularly those with intellectual disabilities, due to the complex interplay of cognitive, communicative, and behavioral factors. This article addresses key diagnostic issues and post-diagnostic considerations for this population.

Method: A consensus report was developed by the Summit's Autism/Dementia Working Group through background reviews, expert discussions at the Summit, and iterative draft revisions, incorporating feedback from internal and external stakeholders. Key issues were extracted from the report and abridged for this manuscript.

Results: Diagnostic challenges stem from overlapping symptoms of co-occurring neurodevelopmental and psychiatric conditions, rendering standard dementia tools insufficient. Comprehensive evaluations tailored to autism-related traits, sensory sensitivities, and alternative communication methods are essential. Building diagnostic capacity among clinicians and fostering multidisciplinary collaboration are critical. Longitudinal assessments, initiated before dementia symptoms appear, facilitate early detection of subtle changes. Emerging biomarkers and neuroimaging techniques show promise and should be incorporated where feasible. Accommodations, such as virtual assessments in familiar settings, can enhance diagnostic accuracy by reducing anxiety. Creating transition processes from diagnostics to post-diagnostic supports will aid in mitigating challenges and enhance life quality when dementia is a factor.

Conclusions: Research and clinician education are urgently needed to improve diagnostic approaches and streamline the transition from diagnosis to tailored post-diagnostic support. An integrated framework of comprehensive efforts is vital for our better understanding of age-associated neuropathological diagnostics and enabling long-term well-being of older autistic adults with dementia.

Summary

- Assessing dementia in older autistic adults, particularly those with intellectual disability, poses significant clinical challenges due to the complex interplay of cognitive, communicative, and behavioral factors associated with these neurodevelopmental conditions.
- Longitudinal assessments and regular monitoring are essential for detecting subtle changes that may signal the onset or progression of dementia in autistic adults.
- A comprehensive approach requires a multidisciplinary framework that incorporates insights from diverse sources, including family members, caregivers, and, when possible, the individuals themselves.
- Research and education are urgently needed to improve diagnostic approaches and streamline the transition from diagnosis to tailored post-diagnostic support for older autistic adults.

1 | Introduction

The second International Summit on Intellectual Disability and Dementia, held in Toronto, Canada, on October 24–25, 2023, aimed to address several complex issues related to dementia and specific neurodevelopmental conditions. In large part, the Summit focused on examining the current understanding of autism (also referred to as "autism spectrum disorder") and associated age-related neuropathologies, including dementia. Key objectives included exploring the onset and progression of these neuropathologies and their impact on the lived experiences of older adults with autism.

The Summit conducted a thorough evidence and practice review, specifically addressing: (1) factors contributing to an elevated risk of dementia in individuals with autism and intellectual disabilities, (2) challenges associated with diagnosing dementia in older autistic adults, and (3) non-pharmacological interventions and support strategies for affected individuals. In its first publication [1], we synthesized the in-depth analysis of the literature on dementia etiology and risk, as presented in our Summit report, *Autism, Aging, and Dementia: A Consensus Report of the Autism/Dementia Work Group (A/DWG) of the second International Summit on Intellectual Disabilities and Dementia* [2]. In that publication, we noted that 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 (ID) or Down syndrome (DS).

Autism, or autism spectrum disorder (ASD), is a lifelong neurodevelopmental condition characterized by differences in communication, social interaction, sensory processing, and behavior. It exists on a spectrum, meaning individuals may have a wide range of strengths and support needs. Globally, autism affects an estimated 1%–2% of the adult population, though prevalence varies by region and is likely underreported due to disparities in diagnostic practices and access to services Zeidan et al. [3]. Some autistic adults, especially males, may face an elevated risk of developing [4] or reported to have dementia [5] compared to the general population. As to the prevalence in older age, it has been noted that there are high rates of underdiagnosis (upwards of 90% in people over 40 years old) [6]—partially attributed to challenges in undertaking assessments [7].

Some studies also suggest potential protection against age-related cognitive decline in autistic adults, while others indicate associations between dementia and autism symptoms [1]. Primary indicators prompting suspicion of dementia in autistic adults include the decline in frontotemporal functioning, severity of behavioral and psychological symptoms, increased stereotypical behaviors, and heightened compulsivity. Generally, the understanding of this complex dynamic is hindered by overlapping symptoms, communication deficits, sometimes limited verbal expression, and atypical presentation of dementia-related symptoms.

In this paper, we synthesize the findings from the Summit report specifically regarding the diagnostic challenges of identifying dementia in older autistic adults.[1] We also discuss key factors influencing diagnostics, including co-occurring conditions, the application of assessment tools, and recommendations for clinician education and research. Although research in this area remains limited, we also acknowledged emerging studies that have underscored the importance of recognizing and diagnosing dementia within the autistic adult population (e.g., [8–10]). We note that several factors contribute to diagnostic complexity, including individual characteristics, the presence of co-occurring conditions such as Down syndrome and other intellectual disabilities, variability in clinician expertise, and regional disparities in diagnostic protocols and resource availability. Moreover, many older autistic adults have historically been undiagnosed or misdiagnosed, often receiving psychiatric diagnoses in place of autism [11, 12]. These challenges collectively impede the accurate detection and assessment of dementia in this underserved population.

2 | Methodology

This article draws on findings from the second International Summit on Intellectual Disability and Dementia, held October 24–25, 2023, in Toronto, Canada. The Summit convened an international, multidisciplinary group of approximately 30 experts to examine human rights and intellectual disability, co-occurring neurodevelopmental conditions (notably autism and fragile X syndrome), and brain health and wellness. The A/DWG was charged with examining the intersection of autism and dementia. Through structured plenary sessions, facilitated breakout groups, and iterative drafting, the A/DWG developed consensus statements informed by literature reviews and collective expertise. Drafts underwent multiple rounds of review by Summit participants and external advisors to ensure scientific rigor and consensus. A comprehensive report on autism and dementia was released by the International Summit Secretariat [2], and its key contents were then extracted by the A/DWG into three thematic articles: an overview of cross-cutting themes [1]; the present article that provides an analysis of diagnostic challenges; and an overview of dementia-related post-diagnostic support for autistic adults (under submission).

3 | Diagnostic Considerations

3.1 | Adult Assessment of Autism

A significant concern arises when autism is not diagnosed earlier in life, leaving older adults to navigate their symptoms without formal recognition. Increasingly, online quizzes and self-assessment tools provide pathways for adults to identify autistic-like traits. However, more formal diagnostic evaluations are essential for accurate identification. Commonly used tools for adult autism assessment include the Autism Diagnostic Interview-Revised (ADI-R), which examines language and communication, social interaction, and repetitive behaviors [13]; the Social Responsiveness Scale (SRS), a 65-question tool assessing social challenges; the Developmental, Dimensional, and Diagnostic Interview-Adult Version (3Di-Adult), which evaluates social communication, interactions, and obsessive behaviors [14]; and the ADOS-2 Module 4, an observational tool assessing responses to specific prompts to evaluate verbal and non-verbal behaviors [14–16].

Ideally, these assessments should be conducted prior to concerns about potential dementia. Reviewing the results of such measures later in life may aid in distinguishing lifelong autistic traits from new or aggravated symptoms that could indicate dementia onset [7]. For individuals with lifelong ID, the challenge of differentiating between autism-related and dementia-related symptoms becomes even more complex. In such cases, reviewing historical records of prior cognitive and functional assessments can provide critical context for interpreting current symptoms.

3.2 | Aspects When Assessing Autistic Adults When ID or Another Co-Incident Condition is Present

Standard dementia assessment tools may be unsuitable for autistic adults including those with an ID due to a lack of normative data combined with sensory sensitivities and anxiety common in autism [17, 18]. Clinicians often rely on comprehensive evaluations using information from multiple sources, including family members and paid caregivers, to make a more accurate diagnosis. The A/DWG agreed that this will be particularly important when diagnosing an autistic adult. Tailored tools for this population are essential.

People with autism may have atypical cognitive profiles from an early age, and this makes it challenging to interpret current brain scans and results from cognitive tests, complicating the identification of neurodegeneration and dementia [19]. Establishing a cognitive baseline earlier in life is particularly important for autistic adults, especially those with an ID. Where formal assessments have been made of autism it is likely that assessments were also completed of cognition and function; these too should be consulted. This baseline provides a reference point for identifying deviations or declines in cognitive function over time necessary for a dementia diagnosis. Longitudinal consideration of data from early and mid-life assessments can help differentiate age-related cognitive changes, autism traits, and onset of potential dementia symptoms, enhancing diagnostic accuracy in later years.

Age-related decline trajectories in autistic adults may not be aligned with what happens in the general population. Preliminary findings in a small middle-aged autistic sample suggest a key memory brain structure, the hippocampus, may shrink faster over 2–3 years compared with adults without autism, and short-term memory may become more challenging for some [20]. Across a broad adult range, autistic adults also had reduced integrity of connections to the hippocampus and greater challenges with long-term memory [21] or accelerated visual memory decline [22].

Another complicating factor, though controversial, is the anticholinergic effect of medications commonly prescribed to autistic individuals [23]. This effect is notably amplified due to comorbidities, prolonged exposure to these drugs, and other conditions shared by adults with ID [24]. Similar findings have been reported among adults with ID alone [25, 26].

3.3 | History

History remains the foundation of any dementia diagnosis, as a key diagnostic feature is a departure from a measured baseline across domains such as function, daily skills, behavior, communication, personality, memory, and mood [27]. For older individuals, early life assessments are often unavailable or nonexistent. If autism is suspected, clinicians should investigate potential indicators such as impaired communication, social disconnection, restricted or repetitive interests and behaviors, unusual sensory responses, and extreme food selectivity, all of which may intensify with life changes [28, 29]. The lack of a prior autism diagnosis—especially in older cohorts with co-occurring ID—can complicate assessments. However, examining behaviors through the lens of autism-related traits, including social interaction patterns, communication differences, repetitive behaviors, and co-occurring conditions, allows clinicians to identify baseline characteristics [29]. These insights are critical in the diagnostic process and in shaping post-diagnostic support plans. Furthermore, preexisting autism or ID-related behaviors may mask dementia symptoms, a dynamic known as “diagnostic overshadowing” [30]. Recognizing this phenomenon can help ensure a more accurate and nuanced evaluation and provide a care plan that would include the level and degree of support which would be more appropriate.

Autistic individuals, particularly those who are minimally verbal, often face difficulties in communicating changes in their cognitive abilities, which complicates the early detection of dementia [31]. Symptoms such as agitation, withdrawal, and repetitive behaviors are sometimes misinterpreted as baseline traits rather than indicators of dementia. Overlapping executive function challenges—including difficulties with planning, flexibility, and problem-solving—are prevalent in both autism and dementia, further blurring the distinction between the two conditions [32]. Conversely, baseline traits like rigidity and preference for sameness, whether associated with autism or not, can lead to misdiagnosis. For instance, extreme agitation and

anxiety triggered by unexpected routine changes may be mistakenly attributed to emerging dementia. Accurate assessment requires an iterative clinical process that involves reflection, clarification, and careful examination of patterns and associations. Without this systematic approach, inexperienced examiners may misinterpret behavioral features, increasing the risk of misdiagnosis.

Research further indicates an increased incidence of conditions co-occurring with autism such as epilepsy, tuberous sclerosis complex, fragile-X syndrome, cerebral palsy [33], DS [34, 35], and Parkinsonism [36, 37]. As approximately 12%–40% of children and 12%–18% of adults with DS also are autistic, the coincidence of DS may contribute to a potentially higher risk of Alzheimer's disease [38–40]. The presence of a psychiatric condition may be another confounding factor, as autism frequently co-occurs with conditions like anxiety, attention deficit hyperactivity disorder (ADHD), depression, and obsessive-compulsive disorders (OCD) [41]. Overlapping cognitive and behavioral symptoms may further complicate the diagnostic process.

3.4 | Assessing Autistic Adults When ID Is Not Present

Cognitive impairment in autism encompasses a wide range of challenges, from sensory perception issues to deficits in cognitive processing, learning, and memory, with both receptive and expressive language skills influencing behavioral presentations. For autistic adults without ID, dementia assessments often necessitate adaptations to standardized tools to account for autism-specific behaviors [42]. Standardized screening methods alone are insufficient; clinicians must evaluate cognitive comorbidities in conjunction with the individual's developmental history, social functioning, and signs of cognitive decline. Effective assessment relies on building rapport, customizing evaluation methods, and ensuring predictability during testing. Utilizing familiar settings and premorbid assessments helps clinicians identify changes relative to baseline functioning. Additionally, the use of virtual assessments has gained traction, as they enable evaluations in familiar environments with personalized materials, which can enhance the accuracy of assessments across all age groups [43].

Factors such as environmental stressors, anxiety, gastrointestinal issues, sensory processing impairments and medication should be reviewed to minimize biases [33, 44]. Cognitive impairment in autism varies widely, encompassing sensory processing issues and memory deficits [45]. The absence of specific diagnostic criteria for cognitive impairment in autism, influenced by neurological, immune, and gastrointestinal factors, complicates diagnosis [46]. Comorbid psychiatric conditions like anxiety and depression can further mask dementia symptoms [17, 18, 47]. A multidisciplinary approach, incorporating feedback from family members, paid caregivers, and the individual, as well as health and mental health professionals including speech and language specialists is critical for a holistic evaluation. Longitudinal and frequent monitoring in addition to contextual comparisons can help detect early signs of dementia. Emerging tools, such as the AD8 Dementia Screener Interview [48], may provide insights into cognitive decline in adults with more neurotypical intellectual functioning. Alternative assessments like the Montreal Cognitive Assessment-NL (MoCA-NL; [49]) have shown higher sensitivity in detecting cognitive impairments in older autistic adults than traditional dementia-world tools like the Mini Mental State Examination (MMSE; [50]). However, MoCA results indicate that age significantly affects performance, with older autistic adults performing more poorly compared to neurotypical peers, highlighting the need for tailored assessment strategies and further research to improve diagnostic accuracy [7, 49]. Specialty instruments, more useful in assessing adults with ID and DS, may be more valid for autistic adults with atypical intellectual functioning and a research priority should be to test the use of such instruments [8].

3.5 | Aspects of Assessment Situations

The Neuroatypical Conditions Expert Consultative Panel [17, 18], highlighted several challenges in assessing adults with various neuroatypical conditions, including autism: (1) clinicians often struggle to differentiate current behavior and functioning from pre-existing characteristics, especially when cognitive deficits are already present; (2) common issues include problems with comprehension, communication, motor tasks, visual recognition, and comfort during testing; (3) standardized dementia assessment tools may not be appropriate for individuals with pre-existing cognitive deficits unless the tools are adapted or specifically designed for this population; and (4) for those with motor or sensory impairments, special adaptations are necessary to obtain valid results.

Executive function deficits are documented in both autism and dementia [32]. The Cambridge Examination for Mental Disorders of Older People with Down Syndrome and Others with Intellectual Disabilities (CAMDEX-DS) includes both an informant interview and a direct neuropsychological assessment of the individual (CAMCOG-DS). The revised version, CAMDEX-DS-II, features an updated CAMCOG-DS -II with a strengthened focus on executive function assessment [51]. These enhancements may increase the relevance of the CAMDEX-DS-II system for autistic adults by providing a more detailed evaluation of executive function, enabling better tracking of developmental trajectories, and improving differentiation between autism-specific cognitive profiles and those related to aging or other conditions. Despite these potential benefits, the CAMDEX-DS-II has not been specifically validated for use with autistic individuals.

Assessing cognition and function in autistic adults necessitates tailored approaches to address specific challenges related to communication, anxiety, experiences of social isolation and loneliness [52] and varied cognitive profiles. Traditional assessment methods often fail to yield reliable results, particularly for individuals who struggle with verbal instructions or tasks requiring imitation. Similar challenges arise in assessments for individuals with ID such as discomfort in unfamiliar

environments and anxiety when interacting with unfamiliar evaluators, both of which can compromise test accuracy.

To improve the validity of cognitive assessments in autistic adults, the Neuroatypical Conditions Expert Consultative Panel recommended the use of several strategies [17, 18]. First, receptive and expressive language abilities should be carefully considered, with alternative communication methods employed when necessary. These methods include using non-verbal cues, visual aids, task demonstrations, and augmentative and alternative communication (AAC) systems. Second, social communication accommodations must be highly individualized to meet the unique needs of each autistic adult. Instructions should be straightforward and concrete, avoiding abstract language, while early rapport-building is essential to reduce anxiety and enhance engagement throughout the assessment process.

Physical environments play a crucial role in assessments, particularly for autistic adults, as sensory sensitivities and anxiety can further complicate the process. Bright lights, unfamiliar settings, and excessive noise may overwhelm individuals, significantly affecting their ability to engage during evaluations. This overlap between autism and dementia underscores shared challenges in sensory processing and susceptibility to sensory overload. Creating sensory-friendly environments can reduce stress and enhance the accuracy of assessments [53]. Informants, such as family members or paid caregivers, are invaluable in providing context about the individual's daily routines and behaviors in their natural living settings. Their insights can help clinicians identify cognitive decline and track changes over time, contributing to a more comprehensive understanding of the individual's condition [54].

Obtaining collateral information from family members, partners/mates, or paid caregivers (including from the adults themselves) who are familiar with the daily routines and lifestyle of autistic adults is crucial. Informants can be asked specific questions, such as: “How much of what was observed during this assessment reflects the individual's/your typical functioning?” This type of information can help contextualize cognitive performance and provide insights into any changes over time, allowing a clearer understanding of the individual's baseline abilities and potential decline.

Given the heterogeneity of autism, baseline expectations for cognitive abilities can vary widely. Some individuals with typical baseline intelligence will be able to participate in standard dementia screenings, but those with co-occurring ID or additional features may require adapted assessments and potentially multiple visits. A standardized, “one-size-fits-all” approach is not appropriate for this population; instead, an individualized assessment plan is necessary to accommodate the unique needs and communication styles of each autistic adult, ultimately ensuring a more accurate and sensitive evaluation of cognitive function and potential decline. Less discussed in studies of dementia in autistic adults is the range of cognitive profiles and the potential for differential rates of cognitive decline with age. Work with multivariate normative comparisons among autistic people (see e.g. [10]) is providing some indication of the cognitive range and encourages work on better understanding of cognitive decline as would occur in dementia.

4 | Assessment Applications

The purpose of neurocognitive assessments in autistic adults is multifaceted and must be tailored to individual needs. One primary goal is to screen for mild cognitive impairment (MCI) or dementia, enabling further diagnostic evaluations to determine the staging and nature of underlying neuropathology. These assessments are also critical for developing dementia care plans and ensuring the provision of appropriate support and services. While autistic adults with typical baseline intelligence can often undergo standard screening protocols, those with co-occurring ID, including DS, may require multiple visits and customized evaluations. Ideally, baseline information from earlier in life, such as cognitive and functional screening data commonly included in autism assessment batteries, would be available. Such data facilitate comparative evaluations to distinguish between typical cognitive aging, autism-related traits, and dementia-related decline, and they support tracking changes over time. However, in practice, many autistic adults, particularly those not previously engaged in clinical services, may lack this baseline information, complicating the assessment process.

Routine medical and health assessments play a crucial role in identifying deviations in cognitive functioning during periodic evaluations. Cordell et al. [55] proposed a framework for integrating cognitive assessments into annual medical visits with autistic adults. This framework includes three key components: (1) *Pre-visit Screening*—the gathering background information before the appointment to identify potential concerns and establish a contextual baseline; (2) *Brief Cognitive Assessments*—utilizing validated tools that can be easily administered by non-physician clinical staff, ensuring efficiency and accessibility, and (3) *Follow-up Evaluation*—scheduling detailed follow-ups or referring adults to specialists when further cognitive assessment is necessary. These assessments can not only aid in early detection of cognitive decline but also serve to confirm a dementia diagnosis, particularly in contexts where eligibility for disease-modifying treatments is being determined.

Early diagnosis is especially critical with the advent of new disease-modifying treatments approved in various countries for treating Alzheimer's disease. These medications target amyloid-beta plaques and are most effective when administered during the early stages of Alzheimer's dementia. Accessing such treatments requires a confirmed diagnosis of Alzheimer's disease supported by biomarkers, such as amyloid positron emission tomography (PET) imaging or cerebrospinal fluid analysis. Given that some autistic adults may be diagnosed with Alzheimer's, establishing robust diagnostic protocols for use with autistic adults ensures timely intervention, maximizing the benefits of these groundbreaking therapies for eligible patients [2].

The diagnostic process for dementia in autistic adults should encompass a comprehensive evaluation, including cognitive assessments, a thorough review of body systems, sensory functions, a physical examination, and an analysis of medications, psychosocial factors, social history, and physical environment for challenges related to assessment (see [7, 17, 18]). To ensure a thorough evaluation, a differential diagnosis should be the first

step in identifying any contributing or coexisting conditions. Key considerations include sensory impairments such as vision or hearing loss, sleep disturbances like sleep apnea, hormonal imbalances such as thyroid dysfunction, nutritional deficiencies like vitamin B12 deficiency, and potential side effects from medications. Drawing upon personal and social histories is important as environmental or psychosocial changes can drive behavioral, cognitive, or mood alterations like anxiety or depression. Additional diagnostic tools, such as laboratory tests, magnetic resonance imaging (MRI) or computed tomography (CAT) scans, and sleep studies, should be employed as needed to provide a complete clinical picture [9]. This multidimensional approach aids in excluding other potentially correctable conditions, thereby facilitating a more accurate diagnosis of dementia [56]. A critical challenge in this process lies in tailoring assessment methods to accommodate the differing needs of adults functioning at population-norm intellectual levels versus those with concurrent IDs.

4.1 | Biomarkers

Diagnostic practices for Alzheimer's disease increasingly incorporate biomarkers; however, a definitive biomarker for autism and dementia has yet to be established due to the condition's heterogeneity and complex symptom interactions [57, 58]. Autism's physiological diversity poses significant challenges to identifying clinically useful biomarkers [59]. Recent studies, such as Kim et al. [60], propose that retinal photographs could serve as an objective screening tool for autism and may assist in assessing symptom severity. Despite these advancements, incorporating biomarker research into clinical practice for diagnosing dementia in autistic individuals remains difficult. Current evidence does not support the routine use of biomarkers for this purpose. Any future diagnostic biomarker must accurately reflect underlying biological processes and complement behavioral assessments and clinically relevant data for a precise diagnosis [59]. Early detection of dementia in autistic adults, irrespective of etiology, is crucial, highlighting the need for continued research into reliable biomarker-based diagnostic tools.

5 | Post-Diagnostic Services

Diagnostic information is critical for dementia care planning and the organization of post-diagnostic services (PDS). For aging autistic adults with dementia, managing PDS poses unique challenges due to the highly individualized nature of care needs and the evolving complexity of required supports (Janicki et al., in submission). A personalized, multidisciplinary post-diagnostic care plan is essential following a diagnosis [61]. This plan should also address physical health issues, particularly those contributing to agitation, anxiety, and behavioral changes, while ensuring that symptoms of dementia are not overshadowed by assumptions about autism or pre-existing conditions [62]. Accurate diagnostics are equally important for identifying adults who may have been misdiagnosed in long-term care settings, where they could have been subjected to inappropriate treatments [63]. However, it has been noted that many older autistic people feel that health care supports do not meet their needs, which could impede the suitability or acceptance of standardized post-diagnostic care [64].

Effective PDS can be categorized into four main areas: aging in place, environmental modifications, dementia-specific interventions and therapies, and the feasibility of implementing these measures [65]. Building on this framework, Dodd et al. [61] highlighted seven key areas for PDS which equally can apply to autistic adults: post-diagnostic counseling, psychological and medical surveillance, regular reviews and updates to care plans, early identification and management of behavioral and psychological symptoms, evaluation and adjustments for advanced dementia and end-of-life care, support for caregivers and staff, and quality-of-life assessments for all involved.

The National Institute for Health Care and Excellence [66] guidelines for autism provide a foundation that could be adapted to address the needs of older autistic adults with dementia. These guidelines include establishing a specialist autism team to coordinate services, including diagnostic support, individualized care interventions, and training for health and social care professionals. They also note that such teams are to consider housing and welfare needs, ensure dedicated care in specialized residential settings, and provide ongoing training for staff in both residential and community contexts. While this guidance can be applied to aging and dementia issues, an update of the guidelines would benefit from specific focus on aging neuropathologies.

The critical roles of paid caregivers, partners, and families must also be addressed. Jokinen et al. [67] stress the importance of formal assessments of caregiver needs, which may lead to targeted interventions such as respite care, psychoeducation, and referrals to psychological support services. Support groups for both families and autistic adults can further enhance coping mechanisms and foster a sense of community. Effective dementia care planning should also include comprehensive toolkits and tailored guidance, such as the KAER-ID Toolkit for Brain Health [68], to address the unique challenges faced by caregivers of autistic adults.

Non-clinical supports—such as advance care planning, health care proxies, and powers of attorney—play a significant role in the lives of aging autistic adults, especially those at risk for dementia. These tools not only address legal and practical needs but also uphold autonomy and person-centered values as cognitive or communicative changes emerge. Empirical evidence suggests that early planning can reduce anxiety for both autistic individuals and their carers, fostering emotional security during health or life transitions [69]. Furthermore, involving autistic adults in future-oriented decision-making has been shown to enhance trust, support self-advocacy, and promote continuity of care [70]. Included as well as is designating a trusted substitute decision-maker to aid as cognitive impairment becomes more pronounced. Integrating these supports into broader service systems, particularly for those with co-occurring ID or mental health conditions, is increasingly recognized as vital to comprehensive diagnostic review and inclusive aging strategies.

By integrating these resources into diagnostics and care plans, providers can create a more holistic and supportive approach to

managing dementia in this population. This approach ensures that both the individuals with dementia and their caregivers receive the support they need, ultimately improving the quality of life for all involved.

5.1 | Research and Diagnostics

Further research is essential to advance the assessment and diagnosis of dementia in autistic adults (e.g., [71]). An extensive research effort needs to be undertaken to bring science into the diagnostic realm and provide the framework for accurate assessments of cognitive decline and the presence of potential additional neuropathologies in older age. The A/DWG recommends that research should focus on:

- *Biomarker Research:* Investigations on biomarkers for the early detection, monitoring, and progression of dementia in autistic adults, including exploring genetic, neuroimaging, and fluid-based markers to improve diagnostic accuracy and personalized treatment approaches.
- *Cognitive Decline and Dementia Types:* Examinations of cognitive decline patterns in aging autistic adults, including the progression to dementia and the types of dementia that may be prevalent or overrepresented in this population.
- *Comparative Studies:* Research comparing autistic adults with and without co-occurring intellectual disability to identify diagnostic markers specific to these groups.
- *Exploring Autism-Dementia Associations:* Studies that investigate potential links between signs and symptoms of autism and dementia, including how these conditions interact and influence each other.
- *Identifying High-Risk Subgroups:* Research to identify subgroups of autistic individuals who are at higher risk for dementia and explore the impact of lifestyle factors, such as barriers to accessing intellectual, educational, and social opportunities.
- *Innovative Assessment Strategies:* Investigations into novel diagnostic approaches to assess neuropathology in autism, especially methods that do not rely on verbal instruction and leverage visual processing strengths, such as passive viewing tasks to assess visual memory.
- *Neurobiological Investigations:* Neurobiological research to understand the underlying causes of neuropathologies in autism and their developmental trajectories, which could clarify the relationship between autism and dementia.

Addressing these areas will help refine diagnostic criteria, improve early detection, refine prevention strategies, and guide interventions tailored to the needs of autistic adults at risk of developing dementia.

6 | Commentary

The assessment of dementia in older autistic adults, particularly those with an ID, presents distinct clinical challenges due to the intricate interplay of cognitive, communicative, and behavioral characteristics associated with these neurodevelopmental conditions. Central to this process is distinguishing new symptoms from long-standing traits, accommodating sensory sensitivities, and modifying assessment tools and environments to yield accurate and meaningful results. This effort demands clinicians skilled in recognizing autism's manifestations and discerning dementia from idiosyncratic behaviors, a nuanced task requiring expertise and adaptability.

Diagnostics are most effective when conducted within a comprehensive, multidisciplinary framework that incorporates insights from family members, paid caregivers, and, when possible, the individuals themselves. This collaborative approach ensures that the unique circumstances of each individual are considered, improving the accuracy and relevance of diagnostic outcomes. Beyond the individual, effective management must also address the needs of their support network, including caregivers, partners, and advocates, who play critical roles in care. Continued research into the clinical and social dimensions of aging in autistic adults, particularly regarding dementia, is essential for developing targeted interventions and supports that enhance quality of life and mitigate potential challenges.

It is important to acknowledge several limitations. One relates to the broader literature on autism and dementia in older age, much of which is affected by selection bias. Many autistic adults, particularly those with concomitant ID or over the age of 40 remain undiagnosed, and those identified later in life are often individuals with co-occurring conditions that increase their contact with health and social services. These comorbidities may also elevate the risk of dementia, potentially inflating prevalence estimates and limiting the generalizability of findings to the wider autistic population. A second limitation stems from the scope of work undertaken by the A/DWG, which was based on available published sources—primarily English-language literature from countries with more established diagnostic frameworks for autistic adults. Notably, although this paper does not focus on epidemiological patterns, such methodological and sampling constraints should be considered when interpreting the existing evidence base and drawing conclusions about the intersection of autism and dementia in later life. Finally, we acknowledge that the A/DWG's findings and recommendations reflect the perspectives of the expert group assembled for this task, all of whom are based in high-income countries. Broader, more inclusive efforts are needed to incorporate insights from clinical and research centers across diverse global contexts.

Acknowledgments

The Summit Secretariat acknowledges the generous underwriting and contributions of the Reena Organization, the Butz Family Fund, Azrieli Foundation, Temple University, University of Stirling, the Canadian Consortium, and the National Task Group on Intellectual Disabilities and Dementia Practices for their support of the second International Summit on Intellectual Disability and Dementia. Partial support for MPJ and KS for the development of this paper was provided by a grant from the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, the Healthy

Brain Initiative Award #1 NU58DP006782-01-00, to the University of Illinois Chicago. Contents are solely the responsibility of the authors and do not represent the official views of the CDC.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are openly available at www.the-ntg.org.

Endnotes

[1] In our work, we adopted the widely accepted framework for defining autism as outlined by key standards organizations [66, 72], while respecting diverse terminology preferences, including autism, autistic spectrum condition, autistic spectrum difference, and neurodiversity [73].

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