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REVIEW ARTICLE

Examining older adults with neuroatypical conditions for MCI/dementia: Barriers and recommendations of the Neuroatypical Conditions Expert Consultative Panel

Matthew P. Janicki[1] | **James A. Hendrix**[2] | **Philip McCallion**[3] | **and the Neuroatypical Conditions Expert Consultative Panel**

[1]Department of Disability and Human Development, University of Illinois, Chicago, Illinois, USA

[2]LuMind IDSC Foundation, Burlington, Massachusetts, USA

[3]College of Public Health, Temple University, Philadelphia, Pennsylvania, USA

Correspondence
Matthew P. Janicki, Department of Disability and Human Development, University of Illinois at Chicago, 1640 W. Roosevelt Rd., 436 DHSP, Chicago, IL 60608, USA.
Email: mjanicki@uic.edu

Abstract

The Neuroatypical Conditions Expert Consultative Panel composed of numerous clinical and academic experts was convened to examine barriers to the examination of cognitive impairment in adults with a variety of neuroatypical conditions. Neuroatypical conditions affect normative intellectual development and function (such as intellectual disability and intellectual disability with conjoint psychiatric conditions), thought, moods, and cognition (such as severe mental illness), communication functions (such as the autism spectrum and hearing/vision impairments), and brain and motor function (such as cerebral palsy and acquired or traumatic brain injury). The panel concluded that current federal guidance for the assessment of cognitive impairment for mild cognitive impairment (MCI) or dementia does not sufficiently include information as to how to assess such adults. In addition, it concluded that adults with these conditions (1) challenge clinicians when attempting to discern current behavior and function from that which was pre-existing; (2) often have inherent comprehension and oral communication difficulties, motor task performance impediments, and difficulty with visuals; and (3) pose difficulties when assessed with standardized dementia measures and can benefit from the use of specialized instruments. The panel recommended that federal guidance be broadened to include adaptations of assessment practices to accommodate neuroatypical conditions; that educational packs be developed for clinicians about such conditions and on detecting and diagnosing MCI or dementia; and that research be expanded to produce more evidence-based information on both assessing adults with neuroatypical conditions for later-life adult cognitive diseases/disorders and planning post-diagnostic care.

KEYWORDS
cognitive impairment, dementia, disability, examination, neuroatypical conditions, neurodivergent conditions

1 | INTRODUCTION

Early detection of cognitive impairment associated with mild cognitive impairment (MCI) and various dementias is necessary, as it starts the process to validate the presence of brain disease or disorder, helps adults and families plan for a change in functioning, aids in working through acceptance, and assists with anticipating the need for mitigation strategies.[1,2] Detection of any cognitive impairment as part of the Affordable Care Act's annual wellness visit (AWV) in primary or health care settings is difficult in general, but can be particularly challenging when the adults seen have a pre-existing neuroatypical or neurodivergent condition. Neuroatypical or neurodivergent conditions (NACs) are defined as conditions where cognitive abilities and associated learning, mood, attention, sociability, and other mental functions do not present as typical of the larger population. When aging, adults with NACs experience additional cognitive decline stemming from numerous pre-existing cognitive, thought, and sensory impairing conditions.

There are widespread barriers to early detection, including personal preferences as "to know or not to know," resource limitations for large scale screenings, lack of trained clinicians who can discern the nuanced presentations of MCI or dementia, and lack of follow-up support services for those adults who have been determined to have dementia. Internationally it has been noted that most guidance is deficient in including information about minority or atypical populations.[3] In addition, although many organizations promote screening and early detection, the National Academies for Sciences, Engineering, and Medicine has noted that aging-associated cognitive impairment is significantly underdiagnosed.[3]

The Centers for Disease Control and Prevention (CDC) estimates that about one in four non-institutionalized adults (25.7%; 61.4 million persons) has some type of disability or impairment.[4] These adults include those having problems with cognition (10.8%), hearing (5.9%), vision (4.6%), and self-care (3.7%). It is estimated that about 1.2 million adults have an intellectual disability (ID), and some 944,000 adults have another developmental disability, including autism spectrum disorder (ASD) and cerebral palsy (CP). The National Institutes for Health (NIH) has noted that Down syndrome (DS) is a high-risk condition for Alzheimer's disease (AD)[5] and a recent analysis indicated that in the United States, adults with DS who are age 40 and older may number some 57,600.[6] In addition, the National Institute of Mental Health (NIMH)[7] has noted that there are an estimated 13.1 million (or 5.2%) adults age 18 or older with a serious mental illness (SMI). Most current guidance for assessment of cognitive impairment neglects to provide protocols to follow when assessing neuroatypical older adults with preexisting neuro-cognitive and neuro-degenerative conditions.

In 2013, the U.S. Preventive Services Task Force (USPSTF) reviewed the approaches available for assessing for MCI and dementia,[8] and identified prevalent instruments as the Mini-Mental State Examination[9] (MMSE), Clock Drawing Test[10] (CDT), Mini-Cog,[11] Memory Impairment Screen[12] (MIS), and Informant Questionnaire on Cognitive Decline in the Elderly[13] (IQCODE). Across all instruments, test performance was generally better for the detection of dementia when compared to MCI.[14] Of note, these measures typically have published normative data cutoff scores based on neurotypical individuals when assessing for age-related cognitive changes. Pre-existing cognitive deficits in adults with an NAC preclude the use of that normative data and challenges clinicians who are attempting to disentangle preexisting cognitive issues from age-related cognitive changes.

For example, for a person with minimal ID, a direct measure may be effective but is not likely to be applicable for many adults with more notable lifelong IDs. The same may apply in SMI, where psychotic or other thought disorder symptoms or lack of awareness of cognitive and function can be barriers to assessment.[15] Some additional guidance is warranted to define the tipping point of when direct interaction with the individual cannot be effectively used and sole reliance on informants is necessary, for example, with adults with ID, SMI, or other conditions who have impaired cognitive functioning. In the United States, the National Institute on Aging (NIA) and Centers for Medicare & Medicaid Services (CMS) have the primary responsibility of providing guidance for assessments of cognitive impairment. Of particular concern is the use of the NIH/NIA and the CMS' recommended functional assessments without recognition that decline or changes in function must be compared to previous limited levels and a lack of guidance or advisories for examining adults who have NACs who may be not easily assessed using otherwise recommended methods. Two barriers to dementia assessment are particularly noteworthy: communication and comorbid conditions.

Communication as a Barrier. The presence of dementia may result in difficulties in comprehension, expression, and responses to the queries or instructions of the examiner generally used with all adults. Language performance difficulties include awareness, comprehension,

RESEARCH IN CONTEXT

1. **Systematic Review**: The authors reviewed the literature using traditional (e.g., PubMed) sources and meeting abstracts and presentations. In addition, members of the Neurotypical Conditions Expert Consultative Panel were asked to consider the components of neurocognitive assessments that may pose challenges for those adults with neuroatypical conditions based on their clinical experience and/or knowledge of the literature.
2. **Interpretation**: Our findings indicate that assessment tools are lacking for adults with neuroatypical conditions, and this may lead to poor and/or delayed access to care and treatment.
3. **Future Directions**: The authors make specific recommendations for developing new assessment tools to support the assessment of adults with neuroatypical conditions of cognitive impairment.

word fluency, word production, syntax, and verbal feedback.[16] For example, adults with NACs may have diverse types of aphasia that would markedly interfere with verbal functioning. On the one hand, these difficulties may be instrumental in aiding the clinician in detecting MCI or dementia; on the other hand, their presence may be part of a pre-existing condition and therefore make a differential assessment more difficult.

The NIA's current list of assessment instruments is also largely targeted to English-language speakers and adults familiar with common American cultural references and norms. Some of these language and cultural differences pose access and other inequities in general, but undertaking screening or assessments with persons whose comprehension and communication is affected by a NAC is even more challenging.

Conditions as a Barrier. Other factors may disproportionately apply to one or more of the neuroatypical or neurodiverse groups within the American population. For example, when examining adults with ID, barriers would include the degree of ID, not knowing the immediate lived history of the individual, remote history of childhood trauma, expressed/unexpressed anxiety at the examination, and understanding of posed questions and/or pre-existing limits in expressive language skills.[17] There may also be confounding symptoms and presentations when an individual may have multiple conditions, for example, the co-occurrence of DS and ASD,[18] sensory impairments and psychiatric conditions,[19] schizophrenia and ID,[20] and CP and psychiatric disorder.[21] In addition, the presence of neuropsychiatric symptoms that can be categorized as behavioral and psychological symptoms of dementia (BPSD) and which may be already present independent of the pre-existing condition, or exacerbated by it, can be a factor in confounding assessments.[22] Those adults with acquired brain injury (ABI) may have loss of vision or visual field cuts that impact performance on visual components of any assessment. An additional challenge is the lack of familiarity of NACs by clinicians. One study noted that 85% of Medicare beneficiaries seen for cognitive impairment assessments were noted to have MCI or dementia by a "non-dementia specialist physician," with little involvement of dementia specialists following this assessment—only 22% within 1 year and 36% within 5 years—leading to the validity of many assessments being questioned. Also notable is that an "unspecified" dementia diagnosis was common when completed by non-dementia specialists (half of diagnoses were for AD).[23] Given such ambiguities in ascertainment, misdiagnoses may be more likely and prevalent when clinicians are presented with adults with NACs.

Changes in behavior such as social withdrawal, depression, oppositional behaviors, anxiety, or aggression may also be associated with the onset of dementia and should be considered in clinical exams and in interviews with informants' presentations of chronic behaviors.[24] Such notable symptoms may also reflect pseudo-dementia and thus may confound determination. Dementia symptom presentation may also be masked by a pre-existing NAC, meaning that the ability to differentiate reversible dementias from progressive, largely untreatable neurodegenerative conditions may be compromised.[25] For example, survivors of traumatic brain injury (TBI) may develop behavioral issues associated with their brain injury and differentiating this behavior from dementia with behavioral disturbance can be difficult.

It has been noted for hearing-impaired adults that hearing loss is associated with poorer cognitive scores on the MMSE and the Montreal Cognitive Assessment (MoCA), and that cognitive scoring is likely confounded by poor hearing ability.[26] Hearing impairment in adults with DS may particularly be a factor in assessment, as studies show that hearing loss rates increase with advancing age.[27] In SMI, particularly among "thought disorders," there may be confabulation of symptoms, which may make it difficult to ascertain that the behavior observed is due to cognitive neurodegeneration. Another factor is discerning the etiology of dementia. Among some NACs, the prevalent cause is AD (as in most adults with DS). However, it has been reported that dementia in schizophrenia may be a real entity with a neuropsychological signature like that of frontotemporal dementia.[28] Cognitive impairments in the range of performance that define MCI, if not AD, are commonly present at the time of the first episode of schizophrenia, even after clinical stabilization.[29]

Given all the preceding, it is disconcerting that missing from existing guidance from the NIA and CMS is a stipulation for augmenting the assessment for persons with pre-existing cognitive impairments, such as SMI, ASD, ID, or other NACs. It is also disconcerting that no guidance is provided for examination situations where there are cultural or ethnic differences or primary language barriers, particularly if the person has an NAC and is culturally or linguistic different from the examiner.

A Neuroatypical Conditions Expert Consultative Panel was convened to consider whether current CMS guidance should be augmented with alternative measures and procedures that may be applied when conducting cognitive impairment assessments in adults with a variety of NACs. This effort emanated from both discussions by the National Task Group on Intellectual Disabilities and Dementia Practices with the NIA about the lack of focused guidance for assessing neuroatypical adults, and with the Alzheimer's Association's NIH-funded "Leveraging an Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer's and Dementia "Project" (LINC-AD).[30] The effort examined current guidance and advisories provided by federal agencies, specifically the NIH/NIA and CMS regarding measures and protocols for undertaking assessments and whether the guidance and advisories considered groups of adults with neuroatypical presentations. An initial systematic scan of the guidance and advisories by the project principals indicated that they did not.

The inquiry focused on increasing the inclusion of adults with NACs in efforts to screen and assess older adults for cognitive impairment and the need to attain equity status within the production and distribution of protocols and informational materials associated with undertaking cognitive impairment assessments. The special problems experienced by adults with NACs when being examined for possible age-associated and neuropathological changes in cognitive function were also highlighted. The included conditions chosen by consensus among the principals are inherently organic derivations for brain conditions either originating at birth or during the developmental period or

emanating from disease or trauma prior to older age that has affected brain and neurological or sensory processes.

2 | THE NEUROATYPICAL CONDITIONS EXPERT CONSULTATIVE PANEL

The Neurotypical Conditions Expert Consultative Panel was composed of 20 nationally prominent clinicians and researchers familiar with each of the chosen NACs and with extensive experience working with that condition including where pre-existing cognitive limitations may (1) confound differential ascertainment of new versus longstanding cognitive impairment, and (2) create significant communication barriers (including expressing and receptive language issues) that make assessment difficult, and potentially confound presentations due to emotional or reality processing difficulties. The panel members were identified via queries posed to and recommendations received from a variety of professional and scientific organizations.

2.1 | Specific aims

2.1.1 | Aim 1: Clinical assessments

The first aim of the Expert Consultative Panel was to examine and specify what special considerations need to be given by primary care physicians and health care professionals when examining adults with select neuroatypical (e.g., ID, brain injury, severe mental illness) and neurodivergent (e.g., ASD, sensory impairments) conditions and then to provide related guidance and recommendations to CMS and NIA on adding information to previously issued statements. Discussions and reviews were targeted to what extent there are commonalities and discordances when undertaking assessment across NACs. It was agreed that the literature indicated that language use, comprehension, information processing, and performance were areas where common specialized approaches may be necessary across most conditions. It was also agreed that some conditions required idiosyncratic approaches.

2.1.2 | Aim 2: Care and support services

A second aim was to use the findings on the adaptations in the assessment process to develop recommendations for protocols for communication and other interaction methodologies when planning post-diagnostic supports and other services for individuals with NACs that will be like those for other adults diagnosed with MCI or dementia. The recommendations for specific NACs were to address what (1) is the inclusion definition for the condition—that is, at what point does the condition cross over to need special consideration; (2) is there a noted risk for dementia, if any; (3) are notable issues raised in the literature; (4) are there appropriate assessment adaptations that can facilitate and increase the accuracy of the screening process; and (5) what recommendations might facilitate a clinician's assessment of adults with the condition and improve communication and interactions outcomes for the post-diagnostic support process.

3 | METHOD

Members of the Expert Consultative Panel were asked to consider the components of an assessment that may pose challenges for those adults with NACs; comment on the issues and challenges evident in cognitive assessment and care planning; and provide recommendations for changes, adaptations, and supplements in communication, information capture, and ascertainment of functioning to improve assessment. The Expert Consultative Panel was also asked to identify:

- Critical factors in the cognitive impairment assessment interview that rely on communication and ascertainment of function from the individual as an informant and comprehension in undertaking tasks that are part of testing protocols.
- Factors that inhibit or are a barrier to the performance of requests and verbal exchanges between the examiner and the adult being examined.
- Exceptional endogenous and exogenous factors that have been identified in studies that might raise the risk for dementia in any of the NACs.
- Any compensating protocols, aids, or other adaptations that are prevalent or have been reported to help with the assessment interview.
- Screening instruments developed especially or adapted from those already in use for cognitive assessments that have been successfully applied to examining adults with any of the conditions noted in this examination.
- Post-assessment factors that would warrant adaptations to aid in more effective and functional plans of care.
- Recommendations for research that would aid in heightening knowledge about MCI and dementia in NACs.

After an initial convening of the full panel, members associated with each identified condition were asked to review the related literature and reported practice and provide a summary of the issues and related recommendations. The expert panel then met virtually to review the core concepts inherent in this report and discuss various facets raised in an initial draft of the report, which included recommendations for each chosen NAC. Subsequent discussions were held to review versions of the report and build consensus on the findings and recommendations.

Each NAC was subjected to an analytic review of definitional inclusion, risk for dementia, commonality of issues with respect to presentation for assessment or diagnosis, specialty approaches for assessment, and recommendations for practice or research. The complete analyses are found in the Panel's full report "Examining Adults with Neuroatypical Conditions for MCI/Dementia During Cognitive

Impairment Assessments: Report of the Neuroatypical Conditions Expert Consultative Panel," issued on February 3, 2022.[31]

3.1 | Included neuroatypical or neurodivergent conditions

Acquired brain injury (or ABI) involves damage, injury, and illnesses that have direct impact on central nervous system functioning, including but not limited to trauma, vascular issues (i.e., stroke and ruptured aneurysm/venous malformation), toxic exposures, hypoxia, tumors, epilepsy, autoimmune processes, and infectious processes (i.e., HIV/AIDS or coronavirus disease 2019 [COVID-19]). The diverse causes of ABI are matched by equally diverse clinical presentations of residual deficits that impact thinking and functioning that can pose challenges in screening for age-related changes associated with MCI or dementia. Survivors have been noted to be at increased risk for MCI, vascular dementia, and other neurodegenerative diseases.[32]

Traumatic brain injury (or TBI) involves disruption in brain functioning secondary to blow to the head or a penetrating injury (e.g., a gunshot wound) and is one of the leading causes of death and neurologic disability. Approximately 3.8 million TBIs occur each year in the United States, with an estimated 230,000 of those who experience a TBI seeking hospital care, and up to 90,000 survivors experiencing long-term disability.[33] The severity of the TBI is correlated with increased risk of dementia (i.e., higher risk in those adults diagnosed with a severe TBI compared to those diagnosed with moderate TBI). In addition, combat-exposed adults with TBI often show younger-onset (< age 65) dementia.[34]

Autism is included within autism spectrum disorders (ASDs) by the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) and defined as a neurodevelopmental disorder characterized by significant impairment in social communication and atypical repetitive and/or restrictive behaviors and/or interests beginning early in the development phase and causing clinically significant impairment across multiple contexts.[35] It is estimated that 2.2% (or 5.4 million) of adults aged 18 to 84 in the United States have ASD.[36] In addition, estimates are that some 10% of adults with ID[37] (and some 19% with DS[17]) have ASD. There is limited research on the specific risk for dementia among older adults with ASD, as most research surrounding ASD has been pediatric focused.[38] However, some studies of adults have pointed to an increased risk for dementia[39] and earlier onset of dementia among adults with ASD.[40] Noted also is that adults with ASD who have severe psychiatric disorders and medical conditions (such as diabetes, hypertension, and seizures) may have an increased risk of dementia.[41]

Cerebral palsy (or CP), a non-progressive motor encephalopathy, is a group of disorders that affects a person's ability to move and maintain balance and posture. People with CP have problems controlling gross and fine movement along with problems with sensation, vision, hearing, speech, cognition, communication, and behavior. Also present may be disturbances of sensation, perception, cognition, communication, and behavior, and epilepsy and secondary musculoskeletal disorders.[42] From one third to one half of persons with CP also have mild ID and about one of five have moderate to severe ID.[43] There is no definitive link between having CP and eventually developing AD and other adult cognitive diseases leading to dementia, except when there are additional health problems of coincident conditions, such as epilepsy or ID.[44] Speculated links between CP and dementia may be due to other neurologic or intellectual co-morbidities rather than as a direct effect of CP.[45]

Down syndrome or trisomy 21 is a genetic disorder caused by a partial or complete trisomy of chromosome 21 and is the most common genetic cause of ID. The phenotype of DS commonly includes ID and common behavioral characteristics. DS is marked by growth, developmental, and learning delays that vary from mild to severe, and by precocious aging.[46] With increases in the survival rates of people with DS, there are now more adults with DS in their fourth to sixth decades of life, and the number of individuals with DS older than 50 years of age is predicted to increase significantly in the coming years.[5] Adults with DS demonstrate precocious aging, often beginning in their 50s and with advancing age present with a high risk for dementia linked to AD.[47] Estimates suggest that 50% or more of people with DS will develop dementia due to AD as they age, and that by age 65 dementia will be evident in more than 80%.[48] Younger-onset dementia is a feature in people who have DS.[49]

Intellectual disability (or ID) is a condition stemming from various causes that includes the presence of deficits in intellectual and adaptive functioning, both of which have their onset from birth or during the developmental period of life and continue to older age. Estimates based on studies using adult data show prevalence among older adults range from 0.05% to 0.8% of all age adults with ID.[50] The risk for dementia for persons with ID (excluding DS) generally tends to be like that of the general population and age at onset generally approximates that of the general population when absent confounding medical/health/social factors.[46] However, risk can be higher and onset younger among some groups of adults with ID, including adults with some genetic syndromes (e.g., Down, Prader-Willi, and Williams), those with epilepsy or other neuropathological coincident conditions, and those who age prematurely.

Adults with a combination of ID and some forms of excessive behavioral anomaly are often known by the term "*dual diagnosed*." Dual diagnosis is the co-occurrence of a major mental health disorder or SMI with a neurodevelopmental disorder such as ID. The World Health Organization (WHO) noted the distinction between *SMI-focused conditions* often attributed to biological, psychological, and social factors, and *behavioral disorders*, which are patterns of maladaptive behaviors that interfere with typical life functioning.[51] The risk for dementia may be elevated for those adults with a diagnosis of SMI-focused conditions, as studies show that risk is associated with poor mental health[52] and diagnosable severe mental illness.[53]

Serious mental illness (or SMI) is defined as a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities.[6] This includes disorders that produce psychotic symptoms, such as schizophrenia and schizoaffective disorder, and severe forms of other

disorders, such as major depression and bipolar disorder.[54] Disability is present in ≈80% of people with schizophrenia and people with bipolar illness. Older adults with schizophrenia and bipolar illness have an increased risk of receiving a diagnosis of dementia, possibly because of cognitive and functional deterioration related to the illness, comorbidities, and treatments that induce states that resemble dementia.[55] However, even with some indications of an association between "mental disorders" and dementia,[56] given the nature of the various SMI conditions, the bases for the evolution of dementias in adults with SMI have yet to be determined.

Sensory impairment can include an impairment in hearing, vision, or olfaction.[57] Estimates are that more than 90% of adults with cognitive impairment also have hearing loss and that almost a third of adults with dementia also have vision loss.[58] For the purposes of cognitive impairment testing, sensory impairment includes adults who have a self-reported hearing or visual impairment that interferes with activities of daily living. Researchers have identified some association among aging, cognitive decline, and hearing and/or vision loss,[59] and sensory impairments have been associated with a greater risk of mixed dementias among adults age 65 years and older.[59] However, these associations are not necessarily causative.

4 | FINDINGS

The panel considered two key issues; first, to what degree barriers to effective assessment of cognitive decline or impairment existed and what mitigating activities might be undertaken to increase the validity of the assessments; and second, how post-diagnostic supports and plans of care might be affected by the challenges evident in the assessments. In consideration of the first, the panel agreed that the NACs included were the most prevalent and recognized conditions with pre-existing cognitive, motor, or sensory factors, which may impede or confound the cognitive impairment assessment. Although there are other NACs posing similar barriers and these were considered by the expert panel (e.g., substance abuse, various physical or neuro/muscular degenerative disabilities) it was decided to restrict the effort to those NACs with chronic brain or sensory conditions that posed diagnostic barriers to cognitive functions.

It was also agreed that challenges for clinicians occur when trying to discern and discriminate the current presentation of behavior and function from that which is pre-existing. Most challenging was determining whether the current presentation was due to neurodegenerative decline versus atypical behavior and function due to other chronic or lifelong impairment, and discerning if compound chronic conditions had communication, motor, or sensory impairments that affected the testing situation.

Data abstractions from the deliberations highlighted that for many NACs, longitudinal follow-up is necessary, as is access to informants and the use of specialized measures either exclusively or in conjunction with general population measures. The data also highlighted common communication barriers across NACs, potentially higher risk of dementia for most, the information already available on useful adaptations, and the potential usefulness of biomarkers. The expert panel report cited earlier provides a broader discourse of these issues as well as guidance on assessing for dementia for each selected NAC. Table 1, drawn from the expert panel report, offers a synthesis of the key indicators with respect to each condition organized by the following factors: risk for dementia, dementia type, risk feature, causal feature, associative features, temporal, measures, adaptations, barriers to examination, use of informants, and biomarker utility.

The panel noted several key findings, which are summarized below in accordance with five critical factors: definitional inclusiveness, risk for dementia, instrument adaptations, practice approaches, and care planning.

4.1 | Definitional inclusiveness

Most of the NACs were able to be operationally defined and were recognized in prevalent nosological classifications and taxonomies (i.e., DSM-5 and International Classification of Diseases, Eleventh Revision [ICD-11]). Most offered diagnostic precision; for some, the inclusiveness was less precise, but was seen as having categorical cohesion by and for practitioners. A question was raised as to whether it was appropriate to use categorical diagnostic conditions over using a functional framework that encompassed common behaviors and functioning. The expert panel concluded that clinical processes are framed around diagnostic features with common neurological presentations and histories and that diagnostic specificity would be more beneficial to clinicians when researching NACs, composing notes for the medical record, and diagnosing and classifying their patients for insurance purposes and other reporting requirements.

4.2 | Risk for dementia

There was notable variability among NACs in the precision of defined risk for dementia in general or for specific types of dementias, and whether the risk was elevated, under par, or equivalent to that of the neurotypical population. Some NACs had noted marked elevated risk due to genetic factors or chronic brain disease and in others risk was due to brain injuries or iatrogenic factors. Risk was also notable in some genotypes or phenotypes associated with ID and some forms of serious mental illness (e.g., schizophrenia). In almost all NACs there was elevated risk due to the life stresses experienced, socioenvironmental factors, long-term medication use, and contributions of underlying physiological and neurological conditions. Risk was variable in some of the conditions included, with prevalence generally higher in focal clinic populations over that of those community populations with the same diagnoses. Risk was further seen in some conditions independent of a disease process, but associated with some impairments—for example, although adults with hearing and vision impairments showed higher rates of dementia, there was not necessarily a causal relationship. Risk was also uncertain in some NACs as empirical data were unavailable. For example, for ASD, there are equivocal findings with some

TABLE 1 Summary of factors related to dementia in select neuroatypical conditions

	Neuroatypical conditions							
Factor	ABI/TBI[a]	ASD[b]	CP[c]	DS[d]	ID[e]	ID/MH[f]	SMI[g]	Sensory[h]
Risk for dementia	Potentially higher	Potentially slightly higher	Not confirmed	Definitive and high	Potentially higher	Potentially higher	Potentially higher	Not confirmed
Dementia type	Vascular, CTE[i]	Frontotemporal in some	Unknown	Usually AD[j]	Mixed	Mixed	Frontotemporal in some, AD[j] in others	Mixed
Risk feature	CTE[i] high Stroke higher	ASD[b] & DS[d] – higher risk	Younger onset higher	Younger onset prevalent	Coincident conditions	Coincident conditions	Unknown	Unknown
Causal feature	Stroke, extensive head injury	Unknown	Coincidence with seizures and ID[f]	Genetic predisposition and coincident with seizures	Unknown	Coincidence of ID[f] and SMI[g]	Unknown	Unknown
Associative features	Behavioral functions Senses Language Loss of prior function without other explanation	Variability in communication abilities Loss of prior function without other explanation	Post-impairment syndrome Loss of prior function without other explanation	Seizures increase risk Precocious aging Loss of prior function without other explanation	Loss of prior function without other explanation	Loss of prior function without other explanation	Declines in memory and executive function Declines in memory and executive function	Reported coincidence Declines in memory and executive function
Temporal[k]	Point measures	Longitudinal measurements	Point measures	Longitudinal measurements	Longitudinal measurements	Longitudinal measurements	Longitudinal measurements	Point measures
Measures	General CIA[l] instruments	General CIA[l] instruments Specialized ID[e] instruments if appropriate	General CIA[l] instruments Specialized ID[e] instruments if appropriate	Specialized ID[e] instruments	Specialized ID[e] instruments	Specialized ID[e] instruments	General CIA[l] instruments	General CIA[l] but adapted for items affected by hearing/vision
Adaptations	Verbal measures when vision affected; Due to ABI effects use of non-normed measures	Visual testing Concrete instructions Serial assessments Individualize exam	Accessible exam room Use measures not requiring task reproduction if fine motor skill impaired	General CIA[l] instruments with mild ID[e] Special instruments with other ID[e] Serial assessments	General CIA[l] instruments with mild ID[e] Special instruments with other ID[e] Serial assessments	General CIA[l] instruments with mild ID[e] Special instruments with other ID[e] Serial assessments	Tracking short-term decline	Visuals for hearing impaired Aural for vision impaired
Barriers to examination	Variability of part of brain affected	Unfamiliar staff and clinic spaces	Speech clarity Impaired fine motor fluency	Speech clarity Comprehension Unfamiliar staff and clinic spaces	Comprehension Unfamiliar staff and clinic spaces	Unfamiliar staff and clinic spaces	Communication impairments	Lack of intact hearing or vision, or both
Use of informants	Useful	Useful	Useful	Required	Required	Required	Required	Useful
Biomarker utility	Not documented	Not documented	As with general population	Research supported	Research supported	Research supported	Not documented	As with general population

[a]ABI/TBI: Acquired/traumatic brain injury. [b]ASD: Autism spectrum disorder. [c]CP: Cerebral palsy. [d]DS: Down syndrome. [e]ID: Intellectual disability (including Down syndrome). [f]ID/MH: Intellectual disability with dual diagnosis of a mental health condition. [g]SMI: Severe mental illness. [h]Sensory: Significant vision and/or hearing impairment. [i]CTE: Chronic traumatic encephalopathy. [j]AD: Alzheimer's disease. [k]Temporal: How often to take measures (Point: generally, at exam; Longitudinal: several measures of time). [l]CIA: Cognitive impairment assessment.

speculation that the condition offered protective features against brain diseases leading to dementia and other literature showing that adults with coincident ASD and ID had a slightly higher risk.

4.3 | Instrument adaptations

Data abstracted from the panel deliberations highlighted that for many NACs, the recommended instruments with utility with the neurotypical population were applied with difficulty or were inappropriate to use with adults with certain NACs. These problems were attributed to a lack of clinician experience with assessing adults with certain NACs; lack of awareness of how different instruments were not measuring decline but reflecting typical level of functioning; comprehension factors or innate inabilities among those assessed to perform required tasks; missing sensitive or masked decline due to the presentation of the NAC; and unavailable guidance for adapting instruments to special assessment situations. The panel also noted that in many cases "one-off" assessments could not capture decline and that longitudinal follow-up was necessary, as was access to informants, and use of specialized measures either exclusively or in conjunction with general population measures. They also highlighted communication barriers across NACs, potentially higher risk of dementia for most, availability of information on useful adaptations, and the potential usefulness of biomarkers.

4.4 | Assessment applications

The position of the expert panel was that there are deficiencies in the manner and processes of assessment of adults with certain neuroatypical and neurodivergent conditions both in the AWV detection of cognitive impairment and most follow-up visits—except perhaps when an adult is seen in a specialty service.

There is a lack of guidance about conducting cognitive impairment evaluations of adults with NACs, who may present symptoms differently and/or have difficulties in assessment situations leading to problematic assessment outcomes, where cognitive impairment may be un- or underdiagnosed or misdiagnosed and/or other factors underlying behavior and function are missed. 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.

4.5 | Practice approaches

The expert panel noted that research supported that some of the conditions reviewed had definable risk for MCI or dementia backed by a significant field of study; others were still beginning to be studied and presented with varied expectations for risk of dementia and inherent factors affecting cognitive decline. There are commonalities among adults with NACs including communications issues (both in receptive and expressive language), comprehension challenges posed by examination queries, anxiety in the testing situation, and for some, difficulties in fine and gross motor functions, and/or hearing and/or vision impediments. For some of the NACs, confounding presentations of pre-existing behavior and function may impede assessments of current changes and decline. Post-assessment or post-diagnostic care planning would be helped if more accurate assessments of cognitive impairment were conducted. As a remedy, the panel noted a need for materials and education that would aid examiners when conducting assessments of adults with NACs. To address inequities, materials available or developed also need to respond to diverse populations, including adults unfamiliar with American cultural norms, non–English-language speakers, and/or sub-populations with various backgrounds.

4.6 | Care planning

In accordance with the second request (noted above), panel deliberations and recommendations recognized that care plans need to be developed with a categorical NAC in mind (e.g., when considering medications, planning environmental modifications in housing or program spaces, treating dual NACs, and addressing program eligibility considerations). If cognitive impairment is detected, a detailed care plan of initial supports and services should result. Most processes for care planning used with the general population also apply to adults with an NAC. However, such strategies may often need to be modified to accommodate the situation that the NAC presents. Specialized care planning will better meet the needs of the adult with dementia as well as his or her immediate caregivers by addressing information and knowledge needs, and providing support in managing care recipients' activities of daily living (ADLs), instrumental ADLs, and BPSDs.

A "right size" planning model should consider, besides generally acknowledged interventions applicable to most adults with dementia, how caregivers perceive and act with respect to knowing that their family member may have an emerging neurodegenerative condition in addition to a pre-existing emotional, cognitive, or sensory condition. One such model involving consideration of family caregivers, emanated from the Glasgow Summit on Intellectual Disability and Dementia for work in ID care planning,[60] has application for other NACs. The panel noted that this support-staging model for caregivers assumes

that if care planning workers know generally the "mind set" of new or long-term caregivers, related to new information on a relative being diagnosed with dementia, or wrestling with new ascribed or assumed caregiving responsibilities, then aid and advice can be tailored more effectively—a "right sized" approach.

5 | COMMENTARY

The position of the expert panel was that there are deficiencies in the manner and processes undertaken to assess dementia in adults with certain neuroatypical and neurodivergent conditions. Absence of guidance may lead to problematic assessment outcomes, where cognitive impairment may be un-, under-, or misdiagnosed and/or other factors underlying noted behaviors and function are missed. With additional attention to the divergencies that do appear, and through their validation using normative data for NACs rather than reliance on standard population-based normative data, the panel noted that it should be possible to develop guidance that will be functional and fit within the parameters noted by Cordell et al., which suggests (1) completing a previsit 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.[61]

In addition, to support the achievement of this outcome, practitioners as well as researchers must participate in the gathering and sharing of information on specialized instruments and processes outside of the norm and applicable to individuals with NACs, and there must be new efforts to consider applications of biomarker measurement to reduce reliance on difficult to administer and interpret instruments. More specifically, there should be support for a more systematic approach to assessment in these populations.

6 | RECOMMENDATIONS

With respect to public policy or federal or state agency practices, the Expert Panel proposed:

- That the Department of Health and Human Services organize and convene a consultative group for the purpose of examining barriers to diagnostic services and post-diagnostic support planning resident in legislation and federal agency policies and procedures for adults with NACs and their caregivers.
- That the National Plan to Address Alzheimer's Disease, developed by the Federal Council on Alzheimer's Research, Care, and Services, include recommendations for actions at the federal and state level to further the effective inclusion of adults with NACs in diagnostic, support, and caregiver assistance services, as well as affirming accessibility and accommodation compliance by clinicians in accordance with the Americans with Disabilities Act (ADA).
- The CMS and the NIA expand their guidance and protocol documents to include specific information on populations with NACs regarding cognitive impairment evaluations during the AWV and any subsequent follow-up assessments, both for diagnostic evaluations and for dementia care planning.
- That federal and state regulatory authorities be encouraged to adapt their reimbursement rates for diagnostic services to accommodate the time and specialty clinical services needed to examine adults with NACs and that states consider building into waiver applications a tailored expansion of Medicaid targeting better detection, diagnosis, and Home and Community Based Services supports for people with NACs who have younger-onset cognitive decline; and that public policy or legislative relief provide for the reimbursement of costs associated with assessing adults with younger-onset dementia.
- That the NIA convene an expert panel to: develop consensus guidelines for assessments in the population with NACs with the currently available screening tools for MCI and dementia; expand its guidance and protocol documents to include specific information on populations with NACs regarding cognitive impairment assessments during the AWV; and add specialized information related to MCI and dementia for several diverse NACs.
- That discipline-specific professional organizations be encouraged to produce and disseminate guidance and protocols that consider the specific dementia assessment adaptation needs of persons with NACs.

With respect to research that should be undertaken to broaden the state of knowledge about MCI and dementia and adults with NACs, the Expert Panel proposed:

Research on instruments and processes that would: examine how to best use dementia screening tools matched to specific conditions; support the development of new scales to help identify MCI and dementia in adults with various NACs; examine effectiveness of a short, adapted functioning/ADL tool that may be repeated across visits and that may highlight concerns for more in-depth follow-up; support digital adapted versions of common cognitive impairment assessment instruments that minimize bias and increase accuracy when examining adults with NACs; review the reliability of informant-based medical history information as an aid to determining the presence of MCI or dementia; examine adaptations of existing instruments to evaluate their capacity to pick up on MCI or dementia during the assessment of persons with sensory impairments; and review whether the settings in which screening instruments are administered influence assessment outcomes.

Research focusing on specific NACs that would examine: possible associations between dementia and symptoms of ASD; compare persons with ASD with and without ID to better understand potential risk and protective factors; the extent of dementia in adults with ID (excluding DS) and other conditions deemed to be a developmental disability; differences in behavioral profiles among adults with psychopathology in comparison to adults in various stages of cognitive decline; rates of adults with ID who have coincident neuropsychiatric conditions; rates of pseudodementia and bipolar dementia in adults with NAC;

examine the conversion rates of MCI to dementia among adults with NAC; the trajectories of serious mental illness for individuals with ID (with and without DS); and the prevalence of AD and other adult cognitive diseases in individuals with dual diagnoses and NACs.

Research focusing on peri- and post-assessment that would examine: the sequelae from assessment to provision of post-diagnostic supports for adults with NACs (with an emphasis on compensatory approaches to support independence, safety, quality of life, social networks, and purposeful meaningful activity); and proof of concept of caregiver staging and assistance models with families of adults with an NAC and dementia.

Research with a bio-medical focus that would examine: the applicability of biomarkers in defining the presence of adult cognitive disease in various NACs; and the evolution of neurodegenerative brain conditions across NACs to aid in the development and application of pharmaceuticals.

7 | FINAL THOUGHTS

The work of the expert panel has highlighted concerns prevalent within the disability community, provided much information to digest, and proffered recommendations for actions to undertake. Furthermore, the panel emphasized the need for working to secure equity for persons with NACs during screenings and assessments for cognitive impairments.

Where might these findings lead us? We now know that much of existing guidance and protocols issued or recommended by federal agencies do not consider the needs of adults who fall outside the typical presentations at clinicians' offices and that amendments or adaptations for guidance issued by the NIA and CMS are needed to also include advice and requirements useful for assessing adults with NACs. In addition, there is a need for the development of guides or toolkits of instructional materials covering examination practices when assessing adults with an NAC. These guides or toolkits can be produced, disseminated, and sustained by inter-organization efforts and collaborations that focus on those adults in older age who have NACs. Furthermore, beneficial would be toolkits on condition-specific needed services for both persons with dementia and their caregivers, with identified funding sources and easily accessed through condition specific providers, organizations, and local governmental agencies. Finally, to enable equity, needed also are listings or directories of clinics and clinicians who are expert in select NACs that can help with in-depth assessments for MCI and dementia, as well as an expansion of clinical resources adept at such assessment.

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CONFLICT OF INTERESTS

Each of the authors participated in developing, writing, editing, and authorizing for submission of the manuscript. The three authors were the principals organizing the review and meetings of the Expert Panel, and except for connections with the National Task Group (where M.P.J. is the Board President and P.M. is on the Board of Directors) and the LuMind IDSC Foundation (where J.H. is the Scientific Director), they have no other conflicts or interests.

ORCID

Matthew P. Janicki https://orcid.org/0000-0003-1053-1748
Philip McCallion https://orcid.org/0000-0001-5129-6399

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