Barriers to and Recommendations for Addressing Dementia Assessment Challenges with Adults with Neuroatypical Conditions

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Panel: 'Barriers to Effective Cognitive Impairment Assessments for Adults with Various Neuroatypical Conditions'

What is this about?

- People with certain disabilities and conditions lack equity with respect to access for early detection of MCI and dementia…
  - *Why* are there barriers and *what* are they?
  - *What* can be done to achieve equity?

Background

- The **Affordable Care Act** (ACA) calls for conducting an early detection assessment for cognitive impairment as part of the annual wellness visit (AWV)
  - Many adults with **neuroatypical and neurodivergent conditions** are seen during the AWV, but it may be difficult for clinicians to discern newly emerging cognitive changes from pre-existing cognitive limitations
  - Current **federal guidance** for the early detection/assessment of cognitive impairment related to MCI or dementia does not include protocols or special considerations needed for the assessment of such adults
  - Inaccurate detection/assessment may lead to **mis- or under-diagnosis** and lack of treatment or interventions *or* applications of inappropriate treatments or interventions – and potentially mislead planning for post-diagnostic supports

What is required?

- The **Patient Protection and Affordable Care Act of 2010** (ACA) contains a provision for the detection of cognitive impairment that is part of a person's annual wellness visit (AWV).
- The ACA provision is intended to support the beneficiary to develop and discuss a plan of preventive care for the coming year that includes
  - receiving health advice
  - routine measurements
  - screening
  - advance care planning
  - and other tasks related to prevention
- The procedures employed require involving an adult in conversation, asking him or her to undertake certain activities to demonstrate function, and generally understand what is being asked by the clinician

What else is required?

- CMS has **detailed guidance** for cognitive assessment and care plan services
- The guidance
  - suggests that clinicians interview the adult and informants during the assessment process, use a brief cognitive test, and evaluate health disparities, chronic conditions, and other factors that may contribute to an increased risk of cognitive impairment
  - notes that if a clinician detects cognitive impairment at an AWV or other routine visit, he or she may perform a more detailed cognitive assessment and develop a care plan
  - estimates, for reimbursement purposes, that a clinician might spend 50 minutes face-to-face with a patient and independent historian to perform the follow-up elements leading to care planning*

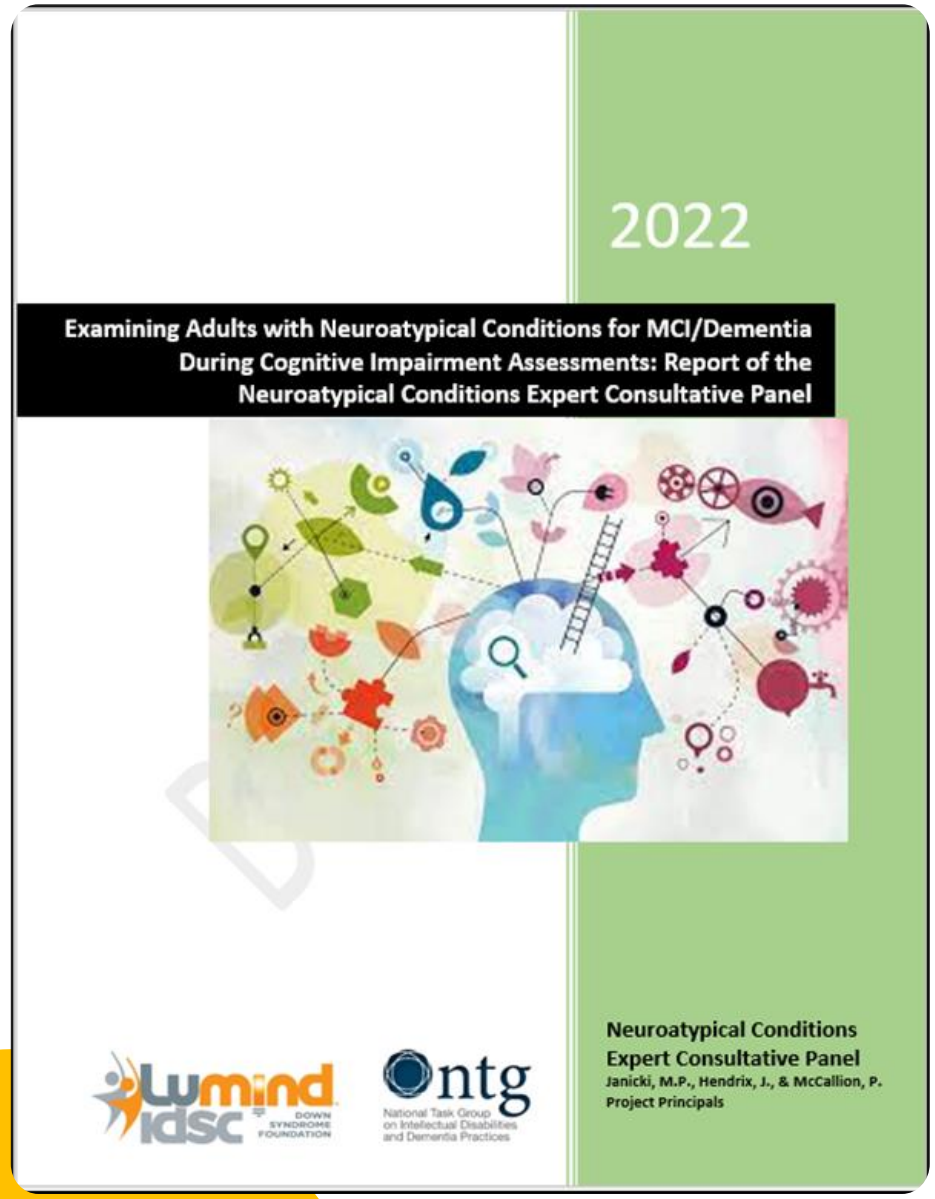
Centers for Medicare & Medicaid Services (CMS). *Cognitive Assessment & Care Plan Services*. 07/09/2021. https://www.cms.gov/cognitive

*CPT 99483

Which groups of adults may face special challenges when being assessed?

- **Neuroatypical conditions** include:
  - Acquired and traumatic brain injury
  - Autism spectrum disorder
  - Cerebral palsy
  - Intellectual disability
    - Down syndrome
    - Intellectual disability with severe behavioral/mental health issues
  - Serious mental illness
  - Significant vision/hearing impairment

*"Each of these conditions has a range of prevalence in the adult population in the US, but in aggregate they represent a considerable number of Americans – probably between **10 and 25%** of all older adults who may initially present with MCI or dementia at their annual wellness visit or other older-age screening."*



The Neuroatypical Conditions Expert Consultative Panel

Assembled by the Lumind IDSC Foundation and the National Task Group on Intellectual Disabilities and Dementia Practices

- Composed of academic and clinical experts familiar with each of the neuroatypical conditions included

Charged with **examining** what **barriers** existed to effective screening, detection, and assessment of adults with neuroatypical conditions and with **identifying** the special **adaptations** that may be employed when examining adults with these conditions

www.the-ntg-org/screening-assessment

What are some barriers for assessing adults with neuroatypical conditions?

Assessment Barriers

- Recommended **instruments are based on normative data** appropriate for neurotypical adults but not for neuroatypical adults
- Information is lacking as to when **instruments might not apply** with adults with neuroatypical conditions
- Guidance not given on need for **baseline and sequential applications** of measures when emerging cognitive decline overlays existing cognitive impairment
- Instruments **not adapted for cultural or language factors** to make them more familiar to some adults with neuroatypical conditions
- Examinations by **clinicians unfamiliar** with neuroatypical conditions may lead to misunderstandings

Communication Barriers

- Some adults may have various types of aphasia that would interfere with **verbal functioning**
- Some adults with hearing impairments may **not hear instructions** or those with cognitive limitations may not **comprehend queries or instructions**
- Some adults may **not respond in a typical manner** or may react adversely to touch or requests for information, or lack the motor skills to complete certain performance requests
- Impediments may lead to clinician misjudging the **adult's state of mind** and/or mistake normal behaviors as symptomatic of MCI or dementia
- Clinicians not **understanding** adults with **impaired speech** (*e.g., articulation*)

Condition Barriers

- Clinicians unfamiliar with neuroatypical conditions could **misunderstand the neurological processes** in play
- Clinicians **unaware of an adult's degree of pre-existing cognitive disability** and coincident conditions, immediate lived history of the individual, remote history of trauma, expressed or unexpressed anxiety at the examination, and understanding of posed questions and/or pre-existing limits in expressive language skills can misguide assessment
- **Confounding symptoms** and presentations by adults having multiple conditions (e.g., DS and ASD; CP and psychiatric disorder) can impair assessment
- Some conditions may have **impairments that confound** the flow of the assessment process – e.g., hearing, vision, thought disorder, rigidity

Key Findings

Adults with neuroatypical conditions **face a variety of barriers to being accurately examined** and having determinations made about whether they had a new cognitive impairment.

Most clinicians experience difficulties in discriminating current behavior and function from that which was pre-existing in some of the conditions, particularly those that may include lifelong cognitive deficits.

Many of the **conditions included problems** with comprehension, oral communication, motor task performance impediments, recognition of assessment related visuals, and comfort in testing situations.

For conditions with pre-existing cognitive issues, **the use of standardized dementia assessment measures was not indicated** unless the measures were significantly adapted or specially designed.

For conditions **with motor or sensory impairments, special adaptations** related to compensating for the impairments were necessary to obtain valid scoring.

Some of the conditions had definable risk for MCI or dementia and were 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.

To increase the accuracy rate in the assessments, **practitioners should be aware of the nature of aging effects in these conditions**, know the expectations for cognitive decline and risk of dementia (*and what type*), and be familiar with testing adaptations that can facilitate the examination process to generate meaningful data.

Not providing **reimbursement for assessments to adults with risk for younger-onset dementia** (not yet age 65) is a **barrier** to the effective and early detection among some adults, including those with cerebral palsy, Down syndrome, some ABIs, and other neuroatypical conditions.

Recommendation #1

Broadening federal guidance to include adaptations of assessment practices to accommodate neuroatypical conditions

- Enhance existing or **developing new protocols** and **guidelines** for examining adults with primary and/or secondary or compound neuroatypical conditions
- Promote the development of **specially designed instruments** specifically for Annual Wellness Visit initial and subsequent examinations
- Adapt existing guidelines to accommodate **cultural and language diversity** – particularly targeted for neuroatypical conditions
- Create **listings and directories** of clinicians who are expert in examining adults with collective or individual neuroatypical conditions
- Expand **local diagnostic resources** and clinical services familiar with examining and treating adults with neuroatypical conditions

Recommendation #2

Enhancing education for practitioners to increase knowledge of neuroatypical conditions, how to differentially diagnose MCI or dementia, and how to develop assessment-informed plans for post-diagnostic care

- **Expand trainings** by federal agencies to reach primary and health care practitioners who are unfamiliar with many of the neuroatypical conditions
- Enlist national professional and multidisciplinary organizations and associations to **develop guidelines** for
  - examining and formally assessing dementia in adults with specific neuroatypical conditions, *and*
  - relating assessment findings to condition and dementia specific supportive resources

Recommendation #3

Expanding research to produce more evidence-based information on assessing neuroatypical conditions as part of cognitive impairment screenings

- Expand **epidemiological and demographic research** on adults to determine the prevalence, nature, and characteristics of select neuroatypical conditions in older age
- Expand **clinical proof of practice and applied research** on interventions of value following diagnosis and as part of plans of care
- Expand **research** on reliability and validity of **specialty instruments** developed or in use in cognitive impairment assessments with select neuroatypical conditions
- Obtain, when feasible, **normative data for different neuroatypical** conditions groups when using existing measures

Post-Assessment Care Planning

Glasgow Summit on Intellectual Disability and Dementia

Caregiver Staging Model

The support-staging model for caregivers assumes that if …

*care planning workers **know 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

Staging may be broken down as the:

- "**diagnostic phase"** *seeking validation as to the cause of change in function early on with an assessment for dementia as well as later with the onset of other causes that change behavior*
- "**explorative phase"** *accepting the diagnosis and exploring support options as they apply to the dementia diagnosis as well as additional conditions that arise*
- "**adaptive phase**" *managing the symptoms of dementia*
- "**closure phase"** *resolving caregiving issues and relief from responsibilities following end-of-life (where "decompression" occurs)*

Jokinen, N., Gomiero, T., Watchman, K., Janicki, M.P., Hogan, M., Larsen, F., Berankova, A., Santos, F.H., Service, K., & Crowe, J. (2018). Perspectives on family caregiving of people aging with intellectual disability affected by dementia: Commentary from the International Summit on Intellectual Disability and Dementia. Journal of Gerontological Social Work, 61(4), 411-431. DOI: 10.1080/01634372.2018.1454563

Neuroatypical Conditions Expert Consultative Panel

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