Changing Thinking!

DRAFT 2

Advisory 25-3

GUIDE and Autism

PRÉCIS

The CMS-developed GUIDE model, while not specifically designed for autistic adults, offers a promising framework adaptable to their unique needs—especially those experiencing dementia. Autistic adults with dementia often present complex cognitive, behavioral, and sensory challenges that demand personalized, interdisciplinary, and autism-informed care. Many also face systemic barriers to care continuity, including reliance on a co-occurring intellectual disability diagnosis to retain Medicaid coverage. Adapting GUIDE's key components—such as tailored assessments, structured caregiver support, respite services, and coordinated care—can enhance outcomes for this population. Expanding GUIDE to explicitly include autistic adults would ensure equitable, appropriate care and better support their caregivers in navigating the dual challenges of autism and dementia.

INTRODUCTION

The GUIDE (Guiding an Improved Dementia Experience) Model, developed by the Centers for Medicare & Medicaid Services (CMS), is primarily focused on supporting individuals with dementia and their caregivers. While the GUIDE model does not specifically target adults with autism, it offers valuable insights and strategies that can be adapted to support adults with autism in need of comprehensive care coordination, caregiver support, and respite services. The GUIDE model's emphasis on interdisciplinary care, personalized care plans, and access to respite services could be beneficial for adults with autism who may also experience challenges related to dementia or other age-related health conditions.

Autistic adults with dementia often present with a complex clinical profile marked by overlapping and compounding cognitive, behavioral, and sensory features. Signal characteristics may include accelerated decline in executive functioning, increased rigidity or resistance to change, loss of previously acquired skills, and emerging confusion or disorientation that differs from lifelong neurodivergent traits. Communication changes—such as reduced verbal output, increased echolalia, or difficulty expressing needs—can signal early cognitive deterioration.

Co-occurring conditions like epilepsy or sensory processing differences may further complicate diagnosis and care. These individuals often require highly individualized, structured, and sensory-sensitive support environments, continuity in caregiving relationships, and adaptations to standard dementia assessment tools to accurately capture cognitive changes. As dementia progresses, the need for caregivers trained in both autism and dementia-informed practices becomes critical to maintain quality of life, manage distress, and ensure dignity in care.

Some autistic adults often also bear a co-diagnosis of intellectual disability. Part of this is an artifact of adolescent or autistic young adults facing heightened vulnerability during the transition to adulthood, particularly when it comes to maintaining Medicaid coverage. While Medicaid serves as a crucial safety net for many autistic people, those without a co-occurring intellectual disability tend to be at risk of losing coverage during this transition.[1] In contrast, individuals with an ID diagnosis tend to retain Medicaid benefits more consistently, as most states offer ongoing coverage to those with ID regardless of age. National Medicaid data show that approximately one in five autistic individuals between ages 8 and 25 eventually accrue an ID diagnosis, with spikes in diagnoses occurring at ages 19 and 21—critical transition points related to individual Medicaid eligibility reassessment and the loss of educational supports.[2] These patterns suggest that some ID diagnoses may not reflect newly emergent conditions, but rather strategic responses to retain Medicaid access in a system that inadequately supports autistic individuals without ID – and is carried forth to older autistic adults with dementia. Expanding GUIDE alignment and tailored services to include autistic beneficiaries (with or without intellectual disability) would ensure that autistic beneficiaries are receiving appropriate, autism-specific services as part of the GUIDE model dementia care program.

Caregivers of autistic adults with dementia face a distinct set of challenges that differentiate their experiences from those of caregivers supporting neurotypical adults with dementia. These caregivers must navigate the complexities of overlapping conditions—autism and dementia—that each effect communication, behavior, and daily functioning in unique and sometimes confounding ways. Unlike typical dementia caregiving, which often begins with a clear baseline of prior functioning, caregivers of autistic adults may struggle to distinguish between lifelong neurodivergent traits and new signs of cognitive decline. They must also account for pre-existing sensory sensitivities, atypical emotional expression, and long-standing support needs that persist and intensify with dementia progression.

Additionally, many autistic adults have limited verbal communication or rely on nontraditional means to express discomfort or confusion, making behavioral changes especially difficult to interpret. As a result, caregivers often require specialized knowledge, more intensive advocacy, and flexible, individualized care strategies that integrate both autism-informed and dementia-capable practices. With this in mind, GUIDE calls for Participant to provide caregiver support and education, with would include specialized training, connect to support groups, and autism-related resources to help them navigate caregiving responsibilities.

The GUIDE model's principles are appropriate to be applied to support adults with autism via various adaptations, including assessment and care planning, caregiver support and education, respite aid, interdisciplinary care, and care coordination.

---

[1] Carey ME, Tao S, Koffer Miller KH, Marcus SC, Mandell DS, Epstein AJ, Shea LL. Association Between Medicaid Waivers and Medicaid Disenrollment Among Autistic Adolescents During the Transition to Adulthood. JAMA Netw Open. 2023 Mar 1;6(3):e232768. doi: 10.1001/jamanetworkopen.2023.2768. Erratum in: JAMA Netw Open. 2023 May 1;6(5):e2315445. doi: 10.1001/jamanetworkopen.2023.15445.

[2] Carey, M.E., Ardeleanu, K., Marcus, S.C., Tao, S., Mandell, D., Epstein, A.J., & Shea, L.L. (2024). Short report on navigating access to care for Medicaid-enrolled autistic youth and young adults: Examining accrual of intellectual disability diagnoses in adolescence. *Autism*, 28(3), 780-785. doi: 10.1177/13623613231177559.

DEMENTIA AND AUTISM

In autistic older adults, dementia may present with a complex and sometimes atypical clinical profile due to the interplay between lifelong neurodevelopmental characteristics and acquired neurodegenerative changes. The dementia diagnosis may be at any stage—mild, moderate, or severe. GUIDE program guidelines require the determination of the presence of 'dementia', but not the clinical phenotype {but use an eligible ICD-10 dementia diagnosis code to each Dementia Care Management Payment (DCMP) monthly claim for it to be paid by CMS]. However, while most research does not show a significant risk of dementia in autistic adults, some studies do show that when it appears it is usually younger onset and associated with neurodevelopmental comorbidities.[3]

Frontotemporal dementia (FTD), often more prevalent in autistic adults, may be particularly challenging to identify in this population, as hallmark features like changes in social behavior, reduced empathy, or impulsivity may overlap with pre-existing autistic traits. However, the emergence of new behavioral disinhibition or language deterioration may signal FTD onset. In contrast, dementia stemming from Alzheimer's disease, common in the general population but more uncommon in autistic adults, typically manifests through progressive memory loss, disorientation, and functional decline; however, in autistic individuals, early signs may be harder to detect, particularly if baseline communication or social functioning has always been limited. Instead, subtle changes in routine adherence, increased confusion in familiar environments, or a decline in adaptive behavior may serve as early indicators.

Vascular dementia, not notably common in autistic adults, is often associated with stepwise cognitive declines and executive dysfunction. It may manifest as sudden difficulties in planning, navigating community settings, or self-care tasks. Lewy body dementia, also not common in autistic adults, is characterized by visual hallucinations, motor symptoms, and fluctuating cognition and may present unique risks, particularly in autistic individuals with sensory sensitivities or pre-existing motor differences. Across all types, differentiating age-related changes from dementia-related declines in autistic adults requires longitudinal knowledge of the individual's baseline abilities, structured observation, and diagnostic tools tailored for neurodiverse populations. Accurate identification depends on recognizing both shared and distinct features of dementia within the context of autism's lifelong developmental trajectory.

Given the uncertainties surrounding the presence of dementia in adults with autism, differential diagnoses for type of dementia are important to dementia care planning, medical and pharmacological treatments, and judging trajectories of decline and behavioral change.[4]

RESPONDING TO CAREGIVING NEEDS OF AUTISTIC BENEFICIARIES

[3] Vivanti, G., Lee, W.L., Ventimiglia, J., Tao, S., Lyall, K., & Shea, L.L. (2025). Prevalence of dementia among US adults with autism spectrum disorder. *JAMA Netw Open,* 8(1), e2453691. doi: 10.1001/jamanetworkopen.2024.53691. Erratum in: JAMA Netw Open. 2025 Mar 3;8(3):e258224. doi: 10.1001/jamanetworkopen.2025.8224.

[4] Janicki, M.P., McCallion, P., Jokinen, N., Larsen, F.K., Mughal, D., Palanisamy, V., Santos, F., Service, K., Shih, A., Shooshtari, S., Thakur, A., Tiziano, G., & Watchman, K. (2025). Autism and dementia: A summative report from the 2nd International Summit on Intellectual Disabilities and Dementia. *Journal of Autism and Developmental Disorders,* e-published May 6. https://doi.org/10.1007/s10803-025-06843-7.

1. *Comprehensive Assessment and Care Planning:*

The GUIDE model emphasizes a comprehensive assessment by an interdisciplinary team to identify an individual's health and care needs. This approach can be adapted to assess adults with autism, focusing on their specific needs related to autism, potential co-occurring conditions (like dementia), and other support requirements. A personalized care plan should be developed, considering the individual's strengths, preferences, and needs. This plan should address both their autistic traits and any other health concerns.

2. *Caregiver Support and Education:*

The GUIDE model recognizes the importance of supporting caregivers. Adapting these principles to autism support would involve providing training and support for caregivers to understand autism, its challenges, and effective communication and behavioral strategies. Caregiver support could include access to 24/7 support lines, connections to local support groups, and resources on autism-specific topics.

3. *Respite Services*:

The GUIDE model includes respite services to provide short-term breaks for unpaid caregivers. This is crucial for adults with autism, as caregivers often need respite to maintain their own well-being and manage the demands of caring for an autistic individual. Respite services can be tailored to the individual's needs, whether it's short-term breaks for caregivers, community-based activities, or specialized autism-specific support. The GUIDE Model provides payment for GUIDE Respite Services provided in three types of settings up to an annual cap of $2,500 per beneficiary. The three types of respite covered by the GUIDE Model are respite services provided in the beneficiary's home, in an adult day center, which includes both medical and social programs, and in a facility that can provide 24-hour care. While the model provides payment to GUIDE Participants for services furnished in these various settings, GUIDE Participants will have some flexibility in the type of respite services that they make available to their beneficiaries. The GUIDE Model requires all GUIDE Participants to make available in-home respite services, either directly or by contracting with a provider of in-home respite. However, GUIDE Participants have the option and are not required to make available respite through an adult day center or a 24-hour facility.[5]

4. *Interdisciplinary Care:*

The GUIDE model's emphasis on interdisciplinary care involves bringing together professionals from various disciplines (e.g., physicians, therapists, social workers) to provide coordinated care. This approach can be applied to adults with autism, ensuring that they receive comprehensive support from a team of professionals who understand autism and its implications.

5. *Care Coordination:*

The GUIDE model focuses on care coordination to ensure that individuals with dementia receive appropriate and timely services. Adapting this to autism support would involve coordinating services

[5] CMS. (2025, Feb 27). GUIDE model frequently asked questions. https://www.cms.gov/priorities/innovation/guide/faqs#care-deliv

from different providers, ensuring smooth transitions between care settings, and preventing duplication of services.

PROVIDING SUPPORTS TO AUTISTIC BENEFICIARIES OUTSIDE OF CAREGIVING SITUATIONS

Developing GUIDE model dementia care supports for autistic adults living alone, in a residential care community, or without a specific family caregiver requires careful attention to the supports most beneficial to address both neurodivergence and cognitive decline. GUIDE recognizes such 'residential care community' as a residential facility staffed to provide comprehensive care services and supports, including assistance with activities of daily living, medication management and supervision, to adults who cannot live independently but do not require intensive nursing care (such as an adult's personal home, an assisted living facility, group home, or other community setting that assures the adult's ability to live safely in the community).[6]

For individuals without consistent informal support, dementia care planning must prioritize proactive care coordination through assigned care navigators or case managers trained in autism and dementia. These professionals can ensure continuity across medical, behavioral, and community services, acting as a stable point of contact in lieu of a family caregiver.

Given the requirement of GUIDE for the assignment of a compatible designated caregiver,[7] it is important to find someone invested in the beneficiary who demonstrates an understanding of the nuances of autism and how it may interact with continuing cognitive decline associated with dementia. CMS defines this person as someone who "furnishes unpaid assistance to a person with a chronic illness or disabling condition and is in a position to assist the patient in carrying out an established treatment plan or plan of care."[8] A caregiver can be a relative, or unpaid nonrelative, who assists the beneficiary with activities of daily living and/or instrumental activities of daily living. Depending on the beneficiary's need, the assistance may be episodic, daily, or occasional.[9]

Understanding must be rooted in a dual-diagnosis framework, recognizing how lifelong autistic traits may mask or complicate dementia symptoms. Care plans should be individualized to reflect communication preferences, sensory needs, and routines that support predictability and reduce anxiety. Direction can be provided through environmental modifications, assistive technologies, and regular check-ins that support executive function and safety for those living alone. Also, periodic assessments are warranted to provide surveillance over self-direction, self-neglect, and potential self-harm related to the progression of dementia. Decisions for alternative housing options should be made so any changes in housing can be made with the least amount of disruption or impact upon the adult.

[6] CMS. (2025, April 10). Guiding an improved dementia experience (GUIDE) model amended and restated participant agreement.
[7] CMS. (2025, April 10). Guiding an improved dementia experience (GUIDE) model amended and restated participant agreement.
[8] CMS. (2025). Health-Related Social Needs FAQ. https://www.cms.gov/files/document/health-related-social-needs-faq.pdf
[9] CMS. (2025). GUIDE Model Frequently Asked Questions. [Feb 2025 update]. https://www.cms.gov/priorities/innovation/guide/faqs#ben-cgs

Engagement strategies should include structured, interest-based activities delivered in quiet, low-stimulus settings, and facilitated by trained staff attuned to both cognitive and sensory considerations. Embedding these supports within housing programs, home- and community-based services, or supported decision-making arrangements will be critical to realizing the GUIDE model's promise for this often-overlooked population.

COMMENTARY

Within GUIDE applications that lend themselves to support for autistic adult include maintaining an individualized approach. This is crucial to remember that individuals with autism have unique needs and preferences. The GUIDE model's principles should be adapted to each person's specific situation. Also, key is the application of autism-specific resources, such as access to autism-specific resources, support groups, and professionals is vital for supporting adults with autism. Important also is collaboration with the person and family, with the person with autism and their family actively involved in the development and implementation of the care plan.

In essence, the GUIDE model's principles, particularly its emphasis on comprehensive assessment, caregiver support, respite services, interdisciplinary care, and care coordination, can be valuable tools for supporting adults with autism who may require additional support for their well-being and quality of life.

-30-

Citation: National Task Group on Intellectual Disabilities and Dementia Practices. CHANGING THINKING! Advisory 25-3. GUIDE and Autism. V.May 10, 2025. https://www.the-ntg.org/ changingthinking

v. 5/10/25

This product was supported in part by the Special Olympics Systems Change for Inclusive Health Subgrant, funded by the Centers for Disease Control and Prevention. The contents of this project are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention, the US Department of Health and Human Services, or the Centers for Medicare & Medicaid Services.