



**SB 0555: Health – Dementia Services and Brain Health Program and Clinical Toolkit  
February 20, 2026  
Position: Favorable with Amendment**

The Maryland Down Syndrome Advocacy Coalition (MDAC) is a coalition of the five Down syndrome organizations in Maryland, as well as individuals with Down syndrome and their family members. We have come together to advocate for improved quality of life for all individuals with Down syndrome throughout Maryland.

MDAC strongly supports SB 0555, and appreciates the additional mention of individuals with Down syndrome in the bill language. We also request amendments to ensure that any cognitive screening, diagnostic assessment, or dementia-related evaluation required under this legislation includes tools that are validated or appropriately adapted for individuals with intellectual and developmental disabilities (I/DD), including Down syndrome.

The lifetime risk of individuals with Down syndrome developing Alzheimer’s disease is 90%.<sup>1</sup> However, traditional dementia screening tools used in the general population are not appropriate for individuals with lifelong intellectual disabilities. Without the use of validated tools for individuals with I/DD, this bill risks unintentionally reinforcing diagnostic overshadowing, where changes are attributed to disability rather than cognitive decline, and may delay appropriate intervention, planning, and support – in an already vulnerable community.

We recommend that the bill be amended to specify that screening and diagnostic processes must incorporate assessment tools validated or adapted for individuals with intellectual disabilities, including but not limited to:

- **The NTG–Early Detection Screen for Dementia (NTG-EDSD)**, developed by the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) and supported by the GLOBAL Down Syndrome Foundation. This tool is widely used by service systems and caregivers to establish baselines and detect early changes.
- **The Dementia Questionnaire for People with Learning Disabilities (DLD)**, endorsed by the National Down Syndrome Society (NDSS), which has historically been one of the most commonly used informant-based tools in Down syndrome populations.
- **The Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)**, a caregiver-completed screening tool that is well researched and effective in identifying possible dementia in adults with Down syndrome.
- **The Wolfenbütteler Dementia Test for Individuals with Intellectual Disabilities (WDTIM)**, also referred to as the **Dementia Test for Individuals with Intellectual**

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<sup>1</sup> <https://pmc.ncbi.nlm.nih.gov/articles/PMC9387748/>

**Disabilities (DTIM)**, strong when used alongside caregiver-report tools such as the DSQIID.

- **The CAMDEX-DS-II**, a structured diagnostic instrument specifically developed and validated for adults with Down syndrome.

We recognize that some of these assessment tools require purchase. However, the cost of improper assessment which can lead to delayed diagnosis, crisis placement, emergency department utilization, psychiatric misdiagnosis, and preventable institutionalization, far exceeds the cost of appropriate tools.

Amending SB 0555 with one sentence to require the use of validated, adapted assessment instruments for individuals with intellectual disabilities would:

- Improve early detection and care planning
- Reduce misdiagnosis and inappropriate psychiatric treatment
- Support families in making informed decisions
- Align Maryland with national best practices in I/DD dementia care
- Advance health equity for individuals with lifelong disabilities

MDAC's guiding principles affirm that adults with Down syndrome and other intellectual disabilities deserve access to equitable, evidence-based healthcare across the lifespan. As Maryland continues to strengthen its aging and disability systems, it is critical that dementia-related policies explicitly account for the unique clinical profile of individuals with Down syndrome and other I/DD.

By incorporating disability-specific assessment standards into SB 0555, Maryland can ensure that the bill achieves its intended impact for *all* residents, including those with lifelong intellectual and developmental disabilities. For these reasons, we urge a favorable report on SB 0555 with the recommended amendments.

Respectfully submitted,

Amanda Mummert

Executive Director, Down Syndrome Association of Maryland (DSAMd)

On behalf of the Maryland Down Syndrome Advocacy Coalition

[director@dsamd.org](mailto:director@dsamd.org) 410.321.5434