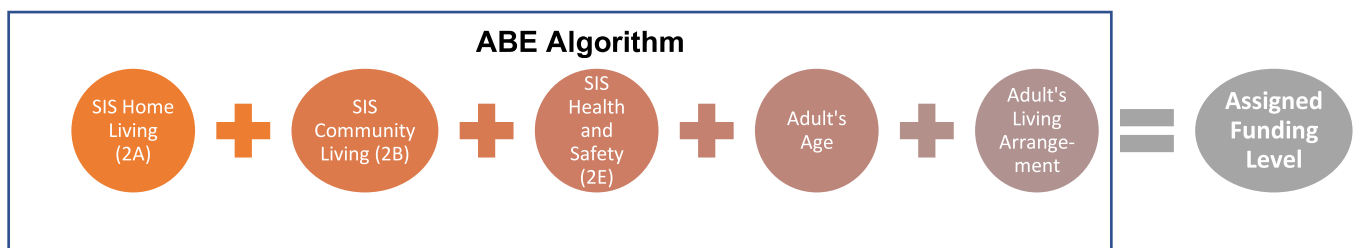


2023 Updates to the Controversial SIS-A Assessment and ABE Algorithm

Currently Virginia’s Home and Community-Based Services (HCBS) Medicaid Waiver system uses these two proprietary tools to assess support needs and set reimbursement rates for certain waiver services:

- Supports Intensity Scale - Adult (SIS-A)** was created and is owned by the American Association on Intellectual and Developmental Disabilities (AAIDD). This is an assessment tool of support used as part of the information gathering process to measure an adult’s level of need. It includes three numbered sections (1-3). Sections 1 and 2 have subsections (1A-B, 2A-F), and Supplemental Section 3 that identifies support needs for protection and advocacy. There’s a final unnumbered section of supplemental questions related to risks established in the exceptional medical and behavioral supports in section 1. Only the scores from Section 2 are standardized and scaled.
 - 1: Exceptional Medical and Behavioral Supports**
 - 1A: Exceptional Medical Support Needs
 - 1B: Exceptional Behavioral Support Needs
 - 2: Support Needs Index**
 - 2A: Home Living**
 - 2B: Community Living**
 - 2C: Lifelong Learning
 - 2D: Employment
 - 2E: Health and Safety**
 - 2F: Social Activities
 - 3: Supplemental Protection and Advocacy Scale**
 - Supplemental Questions
- ABE algorithm** was created and is owned by the independent Health Services Research Institute (HSRI). The graphic below shows how Virginia’s formula works to establish waiver funding rates: It takes scores from the bolded SIS subsections above (2A, 2B, and 2E), the person’s age, and their living arrangement into account to assign adults into one of [seven distinct waiver support needs levels](#). In other words, while a lot of information is captured through the SIS-A interview, only a small portion of that information is included in the rate setting process and not necessarily the data most relevant to autism:



Virginia adopted the ABE algorithm in the early 2000s. It is unclear whether Virginia is using the most up-to-date version of the ABE algorithm or the one from the early 2000s. DBHDS lacks transparency around the ABE algorithm. It never provided the information CRAAG requested on how levels and cutoffs for the exceptional medical, behavior data and supplemental risk questions were established. The [2020 DBHDS document](#) mentions a “mathematical formula” in # 8 without mention of ownership or details.

In a [presentation to the June 2022 AAIDD Conference](#), HSRI states that their study does not include an analysis of the exceptional medical and behavior information, although they recommend doing so. Without specification HSRI wrote that the ABE formula allows for the exceptional needs data to be captured in “alternate ways.” It is not clear what this means.

SIS Stakeholders Group: From the start, Virginia’s process for establishing support levels and rates has been criticized by autism families and other DD stakeholders. In 2019 CRAAG delved deeply into public information about the SIS-A/ABE algorithm and identified the sources of the systematic underestimation of the support needs of those with autism. [Read CRAAG’s 2019 article that described the flaws in the SIS assessment and rate calculation processes.](#)

The Virginia General Assembly mandated the establishment of a SIS Stakeholders Group to monitor the implementation of the SIS (Chapter 854, Item 307 G of the 2019 Appropriation Act). CRAAG representatives were invited to join the group after publishing an article critical of the SIS-A and ABE algorithm.

At a meeting of the SIS Stakeholders Group on January 20, 2023, DBHDS shared an initial plan for implementing the new SIS-A-2. DBHDS/DMAS did not announce whether it plans to replace the ABE algorithm or how much the agency knows about the new algorithm. DBHDS has invited SIS Stakeholders to the annual meeting on May 3, 2023, where a confirmed timeline for implementation of the SIS-A-2 and other pertinent matters will be presented.

2023 Updates to the SIS-A: AAIDD launched the Second edition of the Supports Intensity Scale-Adult (SIS-A-2) in January 2023 and the clock started ticking on an 18-month transition period for jurisdictions to begin using it. [Watch video by the lead author of SIS-A-2](#) and [read AAIDD’s announcements about the new SIS-A-2 on its website](#)

The update was inspired in part by the need to align the tool’s representative sample with the current demographics of the population served by state DD agencies, which increasingly consists of adults with autism. The SIS-A-2 was normed, or standardized, on over 100,000 adults across the USA who are in the IDD service system. The SIS-A-2 is based on a more diverse sample in terms of age, racial and ethnic diversity, and diagnosis. A far greater proportion of people in the SIS-A-2 sample have a primary or secondary diagnosis of autism, largely because of the increased incidence rate, and because this new sample is being characterized as having autism specifically, versus a more generic “IDD” diagnosis, which is how the SIS-A-1 was developed. In other words, there were few people in the original sample who were identified as having autism, although this was not public knowledge until AAIDD’s stunningly transparent announcement about the launch of the SIS-A-2. [Read quotes from AAIDD on autism and SIS-A-2 compiled by CRAAG.](#)

AAIDD’s transparency about the reasons for adjusting the representative sample confirms CRAAG’s concern that the SIS-A first edition systematically underestimates the support needs

of adults with autism. There are three other important updates in the SIS-A-2 questions or sections of the SIS-A-2 that impact adults with autism:

- Section 3: Supplemental Protection and Advocacy Subscale is now the 7th standardized subscale and is called Advocacy Activities and is a mandatory part of the SIS-A-2 assessment.
- An open-ended communication needs question is added to the exceptional medical and behavioral needs section.
- Additional items are added to the exceptional medical and behavior needs section.

How Did Scores Change for the SIS-A and HSRI Rate Setting Formula

The SIS-A-2 came about after years of analysis, research and testing, and was publicly announced on its website in February 2020. HSRI's redesign is happening now. A Policy Associate at HSRI presented an analysis and research at the June 2020 AAIDD Conference. [See HSRI presentation](#). HSRI provided this disclaimer about the status of their work with jurisdictions as follows: "This work was done to develop a general level framework that we are working [on] with individual states to tailor to their specific population and needs. This means that anything in the PowerPoint is subject to (and likely) will change."

SIS Scores: AAIDD explained the impact of the new norms on SIS scores themselves in one of the SIS-A-2 documents on their website. "The effect of the new norms and the addition of the Advocacy Activities scale on standard scores in the second edition of the SIS-A are slight. Overall, most people (roughly 67%) will see no or almost no difference (3 or fewer points) between their overall, composite SNI score using the old and new norms. Among those with score shifts of 4 or more points, data analyses suggest that roughly 3% of people will see their overall SNI score decrease and 30% will see their overall SNI score increase. (People with higher SNI scores have more intense support needs.)" [From the SIS-A 2nd Edition Memo](#).

ABE Algorithm: HSRI uses the ABE SIS scores in their level framework. To understand the impact of the new normed ABE scores on level assignment, HSRI converted the scores from 159,107 existing SIS-As into new normed ABE scores to see which ones increased, remained the same, or decreased. The analysis did not include any exceptional medical or behavioral scores. Overall, 61% ABE scores increased even though the individual's support needs didn't change. HSRI concluded that unless the leveling "framework is adjusted, more individuals will receive a higher budget" or rates. HSRI recommends further data collection and analyses to 1) repeat the new leveling framework at the jurisdictional level; 2) validate the new leveling framework; 3) explore the financial impact of the level changes; 4) revisit rates associated with the levels; 5) plan to analyze the impact of the changes in the exceptional medical and behavioral scores.

Autism families and self-advocates are right to worry that Virginia will focus more on cost-containment than equity in establishing a rate setting formula. We must be clear that cost-containment cannot be Virginia's primary goal. Our community will only see an improvement if the Commonwealth chooses equity over cost-containment. Many have already suffered due to insufficient support for our loved ones and we want increased support based on a more accurate assessment of support needs identified in the updated SIS-A-2.

Will there be a new rate setting algorithm? Will it be more autism-relevant? It will be up to

the Commonwealth of Virginia to update its rate setting algorithm to conform to the updated SIS-A-2. Updates to the SIS-A-2 prompted HSRI to analyze how the ABE algorithm needs to change to reflect the significant changes in the SIS-A-2 update. HSRI is reaching out to all the jurisdictions that use its ABE algorithm, including Virginia. It is proposing a new algorithm that uses all the scores from the seven SIS-A-2 subscales, age, and living arrangement to establish funding levels. The new algorithm would distribute into five support levels rather than the current seven and adds at least two standardized life activities subscales that are relevant to autism: Social and the new Advocacy.

AAIDD is aware that jurisdictions need to take a close look at their rate funding formulas. *“AAIDD’s focus is on the valid and reliable assessment of the individual support needs of adults with IDD using the SIS-A. Strategies to apply assessment results in individual budget allocations or to assign rate reimbursement tiers for service levels are developed independently by each jurisdiction or governing entity. Jurisdictional or governing entities are encouraged to analyze their own data to determine the extent to which changing scores (if any) might affect their approaches to allocating resources.”* [Read AAIDD Quotes of the recommendations for jurisdictions compiled by CRAAG.](#)

CRAAG is coordinating with autism advocates and organizations to spread the word on the importance of engaging with DBHDS and DMAS around an equitable new rate setting formula. We offer the following six recommendations.

CRAAG’s Recommendations

1. **Transparency**: We call on the Commonwealth of Virginia to 1) adopt a fully transparent implementation of the SIS-A-2 and a new rate setting formula based on a more accurate assessment of support needs identified in the updated SIS-A-2; 2) ensure that the formula includes all seven of the SIS standardized life activities subscales, the exceptional medical, behavioral and communication needs, and the supplemental risk questions sections; 2) ensure that the new rate setting formula and process address the needs of adults with autism, especially the unique, high support needs of adults with severe autism; 3) engage autism and DD stakeholders at every stage of this key transition period; 4) clarify its approach to adopting HSRI’s new algorithm given that it is already standardized using the SIS-A-2 and appears to be a better measure of the support needs of adults with autism and developmental disabilities; 5) identify its approach to establishing new levels and cutoffs for the exceptional medical, behavior, communication data and supplemental risk questions in the rate setting formula; and 6) clarify the process and rigor of creating a different rate setting formula if the Commonwealth does not plan to use HSRI’s new standardized algorithm.
2. **Eighteen-month Transition to Using the New SIS-A-2**: As the Commonwealth of Virginia transitions to using the new SIS-A-2, it should pause any support level reductions using the SIS-A/ABE algorithm. Adults in the DD waiver system should be held harmless during the transition period.
3. **Early Reassessment**: The Commonwealth of Virginia should commit to offering an

early SIS-A-2 reassessment to any DD waiver holder whose score is likely to change at the next reassessment.

4. **Transition Period After Redeterminations:** The Commonwealth of Virginia needs to commit to changing the current rule concerning the implementation of rate reductions. Families and providers need time to adjust when a rate changes. Guaranteeing time for the individual's care team to hold a new ISP meeting is crucial to reducing risk to the individual's health, safety, and wellbeing. In addition, the provider should be reimbursed at the old rate and continue to provide the same level of services/supports for six-months to collect data and verify that the rate reduction will not pose a risk to the individual's safety or wellbeing. The new rule should also allow providers to retroactively request reimbursement at the new rate in the case of a rate increase.
5. **Appeal Process for the DD System:** The Commonwealth of Virginia needs to establish a new rule to allow stakeholders to appeal decisions based on mathematical formulas. People with autism and those taking care of them, owing to their lived experience, have a unique understanding of their own needs or those of their loved ones. They have an essential right, based on this experience, to appeal decisions affecting the amount of support received. These decisions are very consequential for DD waiver holders and their families. The only data considered by Virginia's DD system is the SIS. The secrecy around how the support level/reimbursement is calculated is a major source of confusion to providers and individuals alike. A change in the level based on an inadvertent misunderstanding during the SIS interview could adversely affect an individual's health, safety, and wellbeing. Some individuals will lose services or be forced to make unwanted transitions. Once the final level is established, it may remain the same for up to four years. The system is not infallible. We now know that the first SIS-A did not include individuals with a diagnosis of autism without an intellectual disability. The current ABE algorithm does not include all the SIS scores that are relevant to autism. An appeal process would bolster confidence in Virginia's DD system and reassure the correctness of decisions by professionals and calculations made based on mathematical formulas. The lack of due process in the DD system is unfair and possibly illegal – it must be remedied.
6. **Community Education:** The Commonwealth of Virginia should help families by hosting regular and more frequent family education webinars to help families understand the SIS-A-2 interview process and how to effectively communicate their family member's support needs as accurately as possible during the interview.

April 10, 2023