

**Testimony**  
**Senate Bill No. 2305**  
**Senate Human Services Committee**  
**Senator Judy Lee, Chairman**  
January 27, 2025

Chairman Lee, and members of the Senate Human Services Committee, I am Tina Bay, Director of the Developmental Disabilities Section with the Department of Health and Human Services (Department). I appear before you to offer an update on the pilot project that was funded by SB 2276 in the 2023 legislative session. Please note that this program is not included in the Executive Budget Recommendation this is being heard in Appropriations.

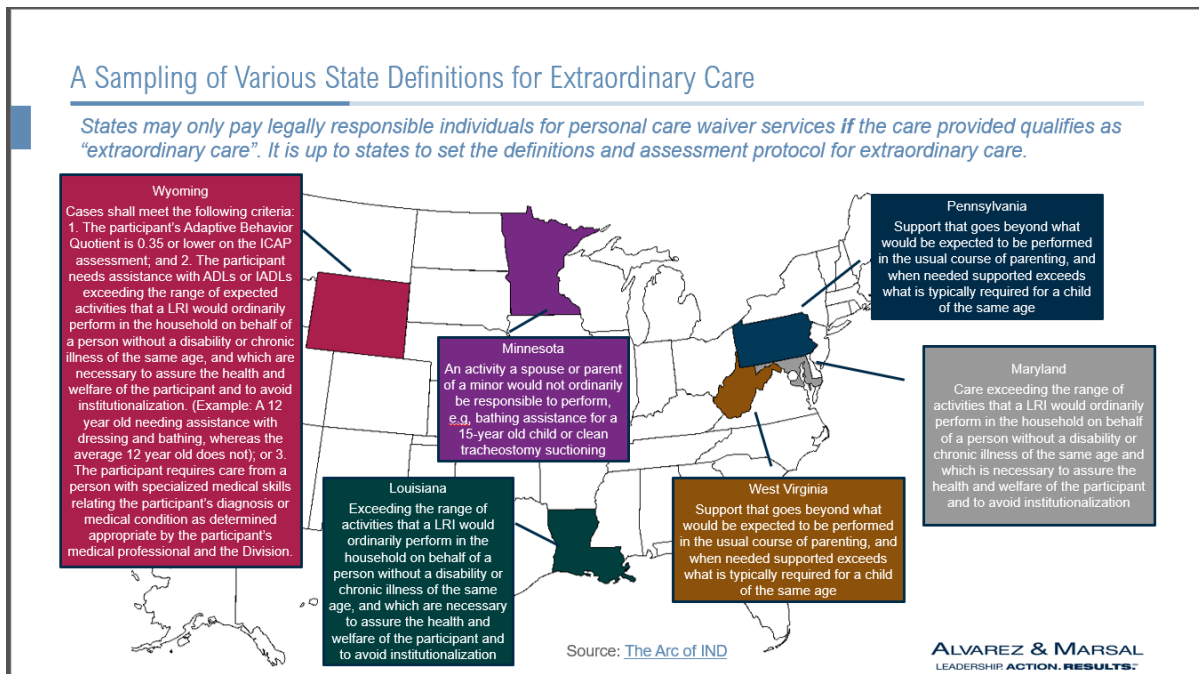
SB 2276 directed the Department to develop a family caregiver service pilot program to provide payments to legally responsible individuals offering extraordinary care to eligible individuals. This involved creating administrative rules, an assessment tool, and a payment portal, all to be implemented by April 1, 2024.

While the pilot program is funded by state general funds, our ultimate goal was to ensure the program's structure would align with Medicaid rules. If the state decided to move the family caregiver service beyond a pilot, this alignment would help pave the way for a smoother transition to Medicaid funding in the future. In accordance with the Centers for Medicare and Medicaid Services requirements, when compensating legally responsible individuals for providing care to children under 18, it is essential to demonstrate that the care provided is extraordinary, not ordinary. To meet this requirement, the Department needed to define and assess extraordinary care.

We conducted a national scan and found that no existing evidence-based assessments adequately addressed the evaluation of extraordinary care. Instead, states have developed their own assessment tools, including North Dakota, which followed a similar approach. After drafting our assessment, we worked with several families to test the tool; these families represented children, adults, and individuals with complex medical and behavioral needs. Based on their feedback, we made adjustments to the assessment, and the scoring methodology was finalized.

North Dakota’s assessment includes categories and questions that may not apply to all age groups. While every child receives points, the tool does not assign points for “ordinary” care, as determined by the age of the recipient of services.

In December, representatives from Alvarez & Marsal shared the information below with the Cross Disability Advisory Council. This provides a snapshot of how other states have defined extraordinary care.



Families expressed a strong desire to keep the process simple and avoid complicating the application procedure. In response, the Department created a process that allowed families to complete the assessment themselves, rather than requiring a third-party professional such as a physician. Families often have the most intimate understanding of an individual's needs, strengths, and challenges. However, we recognize that a self-assessment methodology creates a risk that families may unintentionally overstate or understate certain issues, which could lead to less objective evaluations.

Additionally, some families requested the inclusion of a narrative section in the assessment. While narratives can provide valuable context, not all family members are comfortable or able to convey detailed, clear, or accurate information in this format. Given the limited nature of the pilot, it was critical to ensure the assessment remained as objective as possible.

This concludes my testimony. I would be happy to try to answer any questions the committee may have. Thank you.