

Patient Portfolio: James Baek

DDA-SDS-Parent Providers

HB1053

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Name: **James Baek**, a current member of KADPA (Korean American Disabled People's Association)

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Introduction:

James Baek is non-verbal, a 23-year-old individual, diagnosed with profound intellectual disabilities. His cognitive development is equivalent to that of a one-year-old infant, requiring full-time care and supervision. James has a range of complex medical conditions, including a chromosomal abnormality, cerebral palsy, and severe cognitive delays.

Medical and Developmental Needs James' medical conditions include:

- Cryptogenic Cirrhosis of the Liver: This condition leads to portal hypertension, an enlarged spleen, and ascites, increasing his risk of infection.
- Immune Thrombocytopenic Purpura (ITP): A disorder causing excessive bruising and bleeding due to low platelet counts.
- Chronic Thrombocytopenia and Neutropenia: Weakens his immune system, making him highly vulnerable to infections.
- Scoliosis, Kyphoscoliosis, and Joint Contractures: Requires ongoing physical therapy, stretching, acupuncture, and Botox injections.
- Dysphagia and Chewing Difficulties: Due to a cleft palate and misaligned teeth, he requires continuous monitoring during meals to prevent choking.

James is entirely dependent on others for all aspects of daily living, including dressing, bathing, toileting, eating, and mobility. His daily care involves medication management, assisted feeding, physical therapy, and full assistance with wheelchair mobility.

24/7 Care Requirements and Staffing Challenges James requires round-the-clock care, including:

- Monitoring to prevent choking, pressure ulcers, and seizures.
- Overnight care for diaper changes and repositioning for comfort and safety.
- Attendance at multiple medical appointments across specialties.
- Administering over ten prescribed medications with strict schedules.

Why Self-Directed Services (SDS) Matters for James Self-Directed Services (SDS) is a lifeline for James Baek, providing flexibility to hire caregivers who understand his unique needs. Unlike traditional care service models, SDS allows James to:

- Recruit and retain skilled caregivers who are trained to handle James' medical and developmental challenges.
- Offer competitive wages to attract and maintain dedicated staff, ensuring continuity of care.
- Customize James' care schedule to accommodate his 24/7 needs, including nighttime monitoring and specialized medical supervision.
- Ensure a safe and stable environment that best meets James' complex health and behavioral requirements.

Without SDS, James would struggle to find caregivers capable of meeting James' needs. The ability to choose qualified staff ensures that James receives the quality care necessary to maintain his health, safety, and dignity.

Impact of Proposed Budget Cuts The proposed \$200 million cut to DDA and \$14.5 million cut to SDS for 2026 will severely impact James' ability to receive necessary care. These cuts threaten:

- The availability of specialized caregivers.
- The stability and quality of care James receives.
- His overall health, safety, and quality of life.

The demanding nature of James' care has resulted in high staff turnover. The inability to offer competitive wages due to the budget cut in DDA-SDS program would make it extremely difficult to attract and retain qualified caregivers. James cannot be placed in a daycare or group home due to the complexity of his needs. If he cannot hire staff, he will be left without care, putting his life at risk.

Call to Action James depends on SDS to ensure that he receives the care he needs. He urges the Maryland General Assembly to:

1. **Reject the proposed budget cuts** to DDA and SDS.
2. Advocate for fair and competitive wages for SDS caregivers.
3. Recognize the essential nature of home care for individuals with profound disabilities.

Conclusion James' care requirements necessitate a dedicated and skilled team. Maintaining DDA's SDS support is essential for his well-being. Maryland legislators should stand with families like James and protect the essential services that allow people with disabilities to live safely and with dignity.