

Support: HB847 State Coordinator for Autism Strategy and
Advisory Stakeholder Group on Autism-Related Needs

Dear Madame Chair and Members of the Health and Government Operations
Committee:

Our son Daniel is a 17-year-old young man, with Autism Spectrum Disorder (ASD), Down Syndrome (DS) and severe Celiac Disease. He is primarily nonverbal but attempts to communicate in short answers with prompts and cues, using minimal American Sign Language or intermittently using an Assistive Communication Device. He understands very well English and Spanish as his primary household language. He requires a person to dedicate, support, and provide assistance with verbal cues, prompts, visuals, for personal management skills, academics, meals, toileting, hygiene, attention and initiating of tasks, following directions and personal safety. Our goals for Daniel are for him to be as independent as possible in his personal management, self-expression and communication, engagement in the community, socialization, reading, improving handwriting, and activities of daily living (ADLs), and learn a vocation/occupation for his adult life.

We applied in 2011 for the Autism Waiver and still have been on the waiting list for the last 9 years. Daniel is in critical need of the supports that he has not been able to receive at his age of 17. He will be turning 18 years old in a few months, and has missed many educational opportunities, funds, programs, and time that would have helped improve his quality of life, especially on his social and skill sets. These are some of the challenges we have.

When Daniel comes home from school, we ask him how his day went, what did he learn, and how are his friends. Every day, he never answers. We never know what he thinks. We don't know what he's done, nor how he feels. Every conversation is like this because Daniel is non-verbal. Even though Daniel has shown frustration because of his lack in his communication skills and being understood, he still enjoys being around his family. He has a great sense of humor making the whole room laugh. He enjoys listening to music that he can dance and loves spending time outside walking.

For these reasons, I respectfully request that you support HB847, for Daniel and so many other children with their families.

Thank you all

Jose & Martha Sanchez
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