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Down Syndrome/Alzheimer's Family Advocate

Public Comment
National Alzheimer's Project Act Advisory Council on Alzheimer's Research, Care and Services
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Jadene S. Ransdell, BS, Family & Disability Advocate

Thank you for the opportunity to speak with the Council today and for including people with intellectual disabilities (especially those with Down syndrome) in the National Plan. I am the mother of a 48-year-old gentleman who has multiple diagnoses including Down syndrome, Autism and Apraxia. In addition he carries an incorrect diagnosis of Alzheimer's. It is because of him that I wanted to speak to you today.

When Matt was 39 years-old, he showed signs of confusion with every-day tasks like teeth brushing and doing his laundry. When we shared our concerns with his neurologist, he immediately stated, "He's almost 40-years-old and has Down syndrome. He has Alzheimer's."

For too many years I lived with the fear and dread that I would soon lose Matt to a life-ending disease. I spent too much time believing that each birthday, each holiday might be his last. It was an awful way to live – just waiting for Matt's condition to worsen and his need for care to become much greater. No parent or sibling should have to live with such fear before it is a reality. We are fortunate because Matt has not exhibited further significant changes that would be expected if that diagnosis were correct. And thankfully, he did not have a medical condition that needed immediate attention and was left undiagnosed.

Since that diagnosis, I've met hundreds of families facing that long and painful Alzheimer's journey. Sadly, I've also met many families who have been told their young adult sons or daughters have Alzheimer's when, in fact, they have Down Syndrome Regression. I have met families who shared that their loved one had a sudden decline in skills and interests, and when seen by their doctor, was not tested for any acute infections, but was given a diagnosis of Alzheimer's.

Correctly diagnosing Alzheimer's disease in an individual with Down syndrome requires a specialized knowledge of this population, and there is a shortage of clinicians who have the requisite skills, knowledge, and experience. Therefore, I encourage you to work with Down syndrome organizations such as the National Down Syndrome Society and the National Task Group on Intellectual Disabilities and Dementia Practices to:

- **Support the creation of diagnostic tools that could provide an accurate assessment and evaluation of individuals with Down syndrome who are showing signs of cognitive decline.**

- **Provide adults with Down syndrome access to adequate clinical care** to ensure accurate diagnosis of Alzheimer's disease. A recent survey of Adult Down Syndrome Specialty Clinics indicated that they could meet the medical care needs of only five percent of adults with Down syndrome.[1]

On behalf of Matt and myself, I thank you again for the opportunity to speak with you today and share the concerns of many families in our country.

Matt Ransdell, 48-year-old gentleman from Florida.

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[1] https://pubmed.ncbi.nlm.nih.gov/33729670/
Specialty clinics for adults with Down syndrome: A clinic survey
Stephanie L Santoro, Ashlee Campbell, Archana Balasubramanian, Kelsey Haugen, Kimberly Schafer, William Mobley