

Remarks of Joe Joyce
for the Interagency Autism Coordinating Committee (IACC) Panel
on the Needs of Family Caregivers

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National Institute of Mental Health (NIMH)
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Introduction

Good morning, Dr. Daniels and distinguished members of this committee. My name is Joe Joyce, and I am here today as a father of a young adult who is profoundly impacted by Autism. He is non-verbal, has an intellectual disability, and exhibits significant self-injurious behaviors. I am deeply grateful for the opportunity to share my family's experiences and highlight the urgent needs of family caregivers across our nation.

My son, David, was diagnosed with Autism at a young age. Throughout his life, he has exhibited self-injurious behaviors, which add a complex layer to his care needs. As a family, we have navigated various challenges, but the support system for families like ours remains inadequate and fragmented.

Challenges Faced by Family Caregivers

1. Emotional and Physical Toll:

- Caring for a young adult with Autism and self-injurious behaviors is emotionally and physically exhausting. The constant vigilance required to ensure David's safety is overwhelming. Many nights are spent awake, monitoring his behaviors, and trying to prevent harm. It is difficult for our family to find places to recreate and accept David's behaviors.
- We also have two other wonderful children; a daughter and a son with Down Syndrome. We all love David very much. But the emotional strain of witnessing a loved one hurt themselves is indescribable. It affects the entire family, leading to chronic stress and anxiety.

2. Financial Burden:

- The costs associated with specialized care, therapies, and interventions for individuals with Autism, like David, are substantial. Despite insurance, many

therapies that could benefit David are either not covered or only partially covered, leading to significant out-of-pocket expenses.

- Additionally, my wife had to provide full-time care, resulting in lost income and financial instability. This is extremely common for families with loved ones who are self-injurious.

3. Access to Services:

- There is a severe shortage of qualified professionals who understand the unique needs of individuals with Autism and self-injurious behaviors. Access to specialists, therapists, and appropriate programs is extremely limited, often requiring long wait times and travel over great distances.
- Many community-based services are not equipped to handle the complexities of self-injurious behaviors, leaving families without adequate support.
- We are fortunate that we have resources to pay for most of David's services and supports but many families are not able to afford care, and many are not connected to the information needed to obtain services.

4. Respite Care:

- Respite care is critical for the well-being of family caregivers, yet it is often inaccessible or insufficient. The availability of trained respite providers who can handle challenging behaviors is scarce, leading to burnout and a lack of necessary breaks for caregivers.

Recommendations

To address these challenges and better support family caregivers, I urge the IACC to recommend that Congress consider the following recommendations:

5. Increase Funding for Autism Services:

- Allocate more funding for research and development of therapies and interventions specifically designed for individuals with Autism and self-injurious behaviors. The House bill (HR 7213) to reauthorize the Autism CARES Act proposes a new Center of Excellence to focus its research in this area. It also proposes additional research to address the communication needs of those with Autism. IACC should support these efforts.
- Ensure that insurance coverage is comprehensive and includes a wide range of therapeutic options. The Affordable Care Act required rehabilitative, habilitative, and behavioral therapies as part of the required essential services to be covered by health insurance. However, in reality, most insurance plans do not cover the behavioral therapies needed by those with self-injurious behaviors. In addition, there are not enough qualified providers to provide such services.
- Fully fund and implement strategies provided by the RAISE Family Caregiver Advisory panel.

6. Support for Respite Care:

- Expand access to respite care services and ensure that providers are adequately trained to handle complex cases. The Lifespan Respite Care Act provides grants to states to start or expand respite services. However, the Act does not authorize sufficient funding so that all states can provide adequate coverage to meet the needs of families like ours. Funding must be significantly increased for caregiver support programs.

7. Workplace Flexibility and Financial Support:

- Encourage employers to offer flexible work arrangements for caregivers, including remote work options, flexible hours, and paid family and medical leave.
- Recommend to Congress to provide tax credits or financial assistance to families to offset the costs of specialized care and lost income.

8. Improved Access to Services:

- Invest in the training and education of professionals to increase the availability of qualified specialists and therapists. The LEND interdisciplinary training program and the network of developmental pediatricians should be fully funded and expanded.
- Expand community-based programs equipped to handle the needs of individuals with Autism and self-injurious behaviors. The Better Care Better Jobs Act and the HCBS Access Act are two bills pending in Congress supported by the Autism Society of America that would increase the federal Medicaid match to build the capacity of states to provide home and community-based services.
- Support legislation such as the Recognizing the Role of Direct Support Professionals that helps provide a career ladder and increase pay for professionals caring for individuals with Autism and other IDD.
- Support legislation, such as the Autism Caregivers Training Act that provides training directly to caregivers so that we can better care for our loved ones at home.

Conclusion

In closing, I want to emphasize the resilience and dedication of family caregivers. We strive to provide the best possible care for our loved ones, but we cannot do it alone. By providing recommendations to Congress that address these critical needs, the IACC can significantly improve the quality of life for individuals with Autism and their families. Individuals and families who are profoundly affected by Autism need the support and advocacy of the IAAC to shape the research, training of professionals and additional resources from Congress. Those of us in the Autism community, especially those with complex medical and behavioral support needs, deserve this from the IAAC and Congress.

Thank you for your attention and commitment to supporting family caregivers. I am happy to answer any questions you may have.