Scott B. Badesch

Work:

2011 to Present: President and Chief Operating Officer, Autism Society of America, Bethesda, MD

2010 to 2011 : Senior Vice President of Development and Operations, Autism Society of America, Bethesda, MD

2009 to 2010 : Chief Executive Officer, Autism Society of North Carolina, Raleigh, NC

1995 to 2009 : President and Chief Executive Officer, United Way of Palm Beach County, Boynton Beach, FL

1988 to 1995 : President and Chief Executive Officer, United Way of South Carolina, Columbia, SC

1985 to 1988 : Director of Services, United Way of Suburban Chicago, Hinsdale, IL

1982 to 1985 : Executive Director, Northwest Services Coordination, Arlington Heights, IL

1977 to 1982 : Manager of Community Planning and Grants, Suburban Cook County Area Agency on Aging, Chicago, IL

Education:

Masters of Arts Degree, School of Social Service Administration, University of Chicago, 1977

Bachelor of Arts Degree with Highest Distinction, University of Illinois, Urbana, Illinois 1975

Committee on Oversight + Government Reform

Witness Disclosure Requirement - "Truth in Testimony"
Required by House Rule XI, Clause 2(g)

Your Name: Scott B Badesch

1. Are you testifying on behalf of a Federal, State, or Local Government entity? Yes [✓ No]

2. Are you testifying on behalf of an entity other than a Government entity? [✓ Yes] No

3. Please list any federal grants or contracts (including subgrants or subcontracts) which you have received since October 1, 1999:

The Autism Society is a subgrantee of a federal grant that is provided to The Arc. We received such a subgrantee in 2010 + 2011.

4. Other than yourself, please list what entity or entities you are representing:

Autism Society of America

5. If your answer to question number 2 is yes, please list any offices or elected positions held or briefly describe your representational capacity with the entities disclosed in question number 4:

President/Chief Operating Officer of the Autism Society of America

6. If your answer to question number 2 is yes, do any of the entities disclosed in question number 4 have parent organizations, subsidiaries, or partnerships to the entities for whom you are not representing? Yes [✓ No]

7. If the answer to question number 2 is yes, please list any federal grants or contracts (including subgrants or subcontracts) which were received by the entities listed under question 4 since October 1, 1999, which exceed 10% of the entities revenue in the year received, including the source and amount of each grant or contract to be listed:

-none-

Signature:________________ **Date:** 11/21/12

Committee on Oversight and Government Reform
Witness Disclosure Requirement – "Truth in Testimony"
Required by House Rule XI, Clause 2(g)(5)

Name: SCOTT B. BADESCH

1. Please list any federal grants or contracts (including subgrants or subcontracts) you have received since October 1, 2010. Include the source and amount of each grant or contract.

The Autism Society has received a subcontract grant in 2010 & 2011 from the ARC to help them meet their obligations under an Autism Grant from HHS. 2010/ The grant total was approximately $70,000 in FY 2011 & $40,000 in FY 2011/12.

2. Please list any entity you are testifying on behalf of and briefly describe your relationship with these entities.

– none –

3. Please list any federal grants or contracts (including subgrants or subcontracts) received since October 1, 2010, by the entity(ies) you listed above. Include the source and amount of each grant or contract.

– none –

I certify that the above information is true and correct.
Signature:

Date: 11/21/12

AUTISM SOCIETY

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Chairman Issa, Ranking Member Cummings and Oversight and Government Reform Committee members...

Thank you for the opportunity to testify before the committee on the federal response to the rise in autism diagnoses and the allocations of government resources. I am the proud father of a 25 year old son with autism and serve as the President of the Autism Society of America, the nation's largest and oldest grassroots organization dedicated to the autism spectrum.

Since 1965, our organization has been a leader in assisting literally millions of people effectively impacted by autism. We are a volunteer driven organization with more than 100 local and state affiliates throughout the nation. Our priority is to help people meet their needs today while empowering them to be prepared for what may come tomorrow. We work to assure that every person with autism be provided opportunity to access the highest quality of life possible and treated with dignity and respect. We are also proud that since our founding all aspects of our organizations work is inclusive of people living with autism.

As the committee knows, the incidence of autism has shown marked increase in CDC surveillance studies-currently occurring in 1 out of 88 births. Many other children and adults may not be properly diagnosed and the numbers impacted by an autism diagnosis goes well beyond the individual. Autism is a whole body, whole life condition that affects not only the individual but also the entire family.

The significant increase in incidence represents individuals and families facing tremendous stress, it also places significant strain on an already overextended service system. Unfortunately because of this the reality for most individuals with autism is dismal. We must change the national discussion on how to address autism. The future of a child diagnosed with autism, should not depend on family resources, ethnicity, gender geographic location or the school they attend. Access to appropriate services must be provided as early as possible, when this occurs the lifetime costs can be reduced by as much as two-thirds.

Despite evidence that autism can often be identified at or before 18 months the CDC states that the median age for an autism diagnosis is between 4.5 and 5.5 years, even when developmental concerns were recorded before age 3. The cost of autism over the lifespan is approximately 3.2 million dollars per person; 60% of those costs occur in adulthood when mandated services provided through Individuals with Disabilities Education Improvement Act have ended.

Currently, the government service system is difficult at best to navigate and too often when services *are* provided they may not be individualized or be the best approach for the needs of the individual. The Autism Society believes that government services should help focus on advancing an individual's quality of life in measurable and meaningful ways. We need to re-examine how government services can be provided, not on limited definitions of services but rather based on an individual's need.

Today there is significant disparity nationwide in the need for and the availability of publicly funded long-terms services and supports for people with disabilities. This disparity has resulted in very long waiting lists. Estimates of the number of people with developmental disabilities in the

U.S. waiting on various lists for services range from 80,000 to 200,000.

Meeting these significant needs will not only require expansion of services, we believe it requires us to think differently about the way services are delivered.

An individual determined by diagnosis to be eligible for services, when on a waiting list is being denied those critical services and has very limited options if they are unable to pay for private fee services or if they cannot access other services provided by the nonprofit or private sector community.

We recognize the realities of limited funding and encourage the committee to examine Medicaid funds spent on unnecessary administration and duplication at the expense of service provision. An example is a family that applies for services based on a diagnosis in one state needs to be reassessed for that disability if he or she moves to another state. This is an unnecessary cost to both the federal and other state governments.

We would also recommend that public schools must be prepared to provide a quality education for each child and prepare them for employment, advanced education and independent living so they are able to be successful adults. Reports from the National Center for Educational Statistics and the Department of Education show that only 43% of people with disabilities will graduate high school with a diploma. This means that 57% (likely comprised largely of students with developmental disabilities) either drop-out of school or receive a certificate of attendance that severely limits their ability to attend college or pursue competitive employment.

Related to education, Senator Harkin's Restraint and Seclusion Bill is critical for students with autism. Our society should not allow unnecessary restraint and seclusion of students with autism; they need to be present in the classroom in order to graduate with the strong educational foundation that prepared a student for the greatest degree of independence in employment and living – critical components of success in adulthood.

Quality of life for a person living with autism depends not only on the foundation that is provided in childhood but often requires ongoing supports that are specific to individual needs.

Government services must encourage work, family and savings (all common

American values) for those who access social support services. Problems such as poverty are very common for people with developmental disabilities and can result in dependence on government support as well as high rates of unemployment. Justifiably, concern rises when the national unemployment rate is above 5 or 6%. The Department of Labor reports that the unemployment rate is 78.5% for individuals with disabilities.

Government's response can be most effective when resources are available under one umbrella organization and allow more flexibility in the use of funds to help the unique needs of that individual. The committee may also examine how to more effectively coordinate the government's response through one-stop models and centralization of information.

The rules of Medicaid portability must be examined. When a person moves from one state to another, he or she loses their Medicaid Community Supportive Services and starts over again on the waiting list in their new state of residence. This has significant impact on our military families and has caused some families to maintain residence without jobs in order to maintain services.

The Combating Autism Act established the Interagency Autism Coordinating Committee which is, in concept, a great idea. But I ask you, how can true coordination occur if it is not comprised of adequate representation from both the private and not-for-profit sector? We suggest that this coordinating body must meet regularly and be made up of representatives from HHS, but also from the Departments of Labor, Justice, Housing and Defense. We also challenge the committee to examine where, in the federal government structure, IACC should be placed. When is within NIH, the coordination effort may be defined as health and research rather than focused broad-based service provision.

The Autism Society applauds the efforts of many organization and government agencies that have led the way in examining the important clinical research related to autism. Research is essential, but we believe there is an imbalance of funding directed at services or applied research. I would ask that the committee to examine the need for more service funding before any increases in research funding is provided.

Finally, I would like to encourage the committee to examine the real need for an increased federal response to the needs of adults living with autism. And each one should be given the opportunity to be a gainfully employed adult. It is not only the right thing to do, it will save tremendous resources to individuals, families and the government when those willing and able to work are provided the opportunity to earn a living wage. We must also provide a safety net for adults who still require services. I would also encourage the committee to examine the older adults with autism who are being cared for by aging parents. Again and again we hear that one of the biggest fears of parents is who will care for their child when they are no longer able.

I appreciate the interest from this committee in addressing how our nation can be more effective and responsive to people living with autism.

Thank you.