



Nothing about us without us!

U.S. House Committee on Oversight & Government Reform

November 29th, 2012

Key Issues:

- Federal autism research funding is in need of re-balancing to increase allocation of funds focused on improving the quality of service-provision and addressing the needs of Autistic adults and adolescents.
- The Autistic adult population has been largely ignored in autism policy discussions to date – future federal policy must work to try and address this issue.
- Significant racial, gender and income disparities exist in access to autism diagnosis and services.
- The Medicaid program is the primary financing mechanism for autism and disability related service-provision and support. The federal role in Medicaid remains absolutely crucial and must continue to emphasize systems change transformation towards more integrated settings for people with disabilities.

Chairman Issa, Ranking Member Cummings and esteemed members of the Committee, thank you for the invitation to speak to you today on federal policy regarding the autism spectrum. My name is Ari Ne'eman and I represent the Autistic Self Advocacy Network (ASAN), the leading national advocacy organization run by and for Autistic adults speaking for ourselves. As an Autistic person, I want to begin by thanking the committee in particular for hearing from self-advocates – that is not always a given in the autism world and I am profoundly grateful to both the majority and minority members and staff for ensuring that we are represented at this hearing about us.

Over the last decade, we have seen growing public attention towards the autism spectrum, in part driven by rising rates of diagnosis. Although additional public attention has provided an opportunity for greater visibility to the idea of autism, such visibility historically has not translated into attention or resources on the issues that matter most to Autistic people and our families.

There are a variety of reasons for this – one of the most prominent of which is the history of under-representation of adults on the autism spectrum in policy conversations about us. Additionally, one of the most important things to remember in discussing federal policy regarding autism is that the vast majority of publicly financed resources that those of us on the autism spectrum interact with carry the word disability rather than the word autism. As a result, my testimony will touch on both federal policy that is specific to autism as well as general disability policy issues, such as Medicaid, that significantly impact Autistic people and our families.

First, the majority of federal attention focused on autism in particular comes in the form of research funding. While we have been pleased to see an increase in federal autism research dollars over the course of the past decade, it is very important that we evaluate how we are spending that money. I am a big believer in the old maxim, “In God we trust, everyone else please bring data,” so let’s turn to the data and see what it shows us.

Of the approximately \$217 million dollars that the National Institutes of Health (NIH) invested in autism research in 2010 (the most recent year for which data is available), only a meager 2.45% went towards improving the quality of services and supports available to Autistic people and our families. Only 1.5% went towards research that addresses the needs of Autistic adults. When compared to research on questions of causation, etiology and biology and diagnosis, the percentage of the autism research agenda focused on the actual needs of Autistic people in order to improve their quality of life is miniscule. We are pro-research, but the research agenda must be re-balanced to incorporate both causation and quality of life.

This matters. It matters more than I can possibly articulate, but I will try to do so, nonetheless. I remember recently visiting a service provider in Manhattan earlier this year to learn more about how we can improve disability employment outcomes for people with severe disabilities. While I was there, a non-speaking Autistic man in his mid-20s came in with his father. They were

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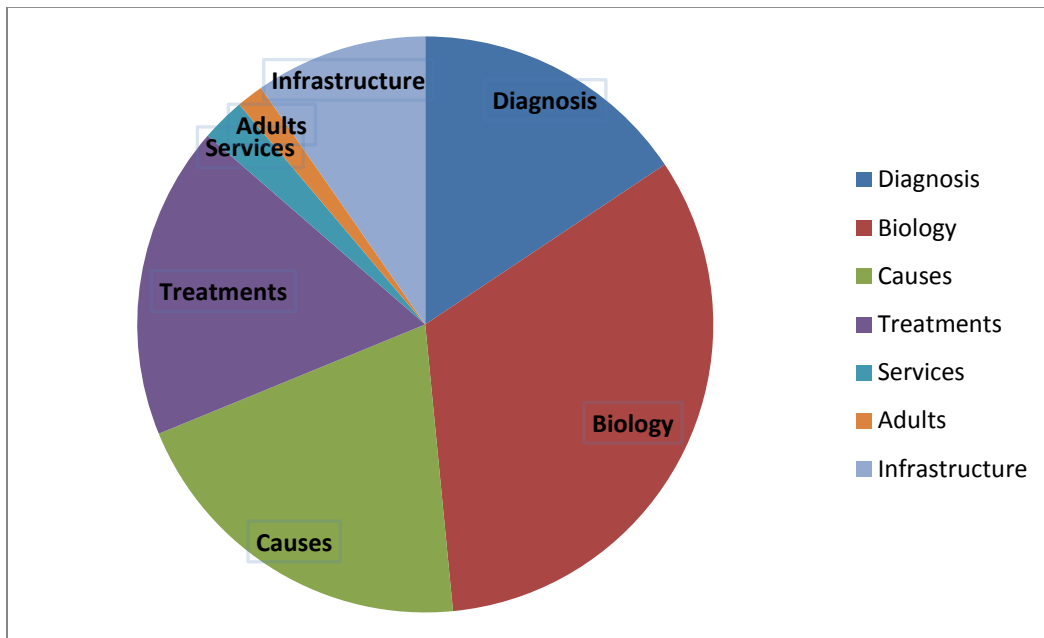
looking for some help trying to find him a job or at least something meaningful to do with his day. I asked him some questions and his father helped give responses, but it was immediately clear that his son knew exactly what I was saying, he pointed out what he was interested in, he shook his head at what he had no interest in, he raised his hands when he was excited. He had plenty to say and clearly rarely got the opportunity. I think about that young man – who probably wasn't that much older or younger than me – often, and particularly at times like this.

Members of the Committee: Why can't we do better for him? Why can't we give him a chance to communicate more clearly, to not only sit here and testify before Congress someday but also be able to tell his supporters and friends what he wants for his life, to tell his parents that he loves them and how important they are in his life? Some people say that until we unravel the causation of autism, that is impossible. That is quite simply not the case – Augmentative and Alternative Communication technology has existed for many years now and can empower even those of us who cannot speak to make their voices heard.

If we invested a mere one-tenth of the amount of money that we currently pour into causation into empowering Autistic people to communicate, that young man and hundreds of thousands more like him would be able to communicate their needs to us today. I am not here today to speak for every Autistic person – that's impossible. What I am here for is to argue for every Autistic person to have the same opportunity to communicate that I have come to enjoy thanks to the support that I have been lucky enough to receive in my life.

Some might wonder if this gap is being filled by private sector research dollars, explaining the lack of federal investment in these areas. The data suggests otherwise – the two largest private sector autism research funders – Autism Speaks and the Simons Foundation – devote even less to these areas, with Autism Speaks investing approximately 1% of its research budget to studies on the quality of services to Autistic people (and less than one quarter of a percent to Autistic adults) and the Simons Foundation making no investments in either area. It cannot be doubted that when it comes to the needs of Autistic people today both the public and private research agendas are quite simply not responsive to the priorities of the Autistic community, itself.

2010 NIH Autism Research Funding By Category Area





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Now, this is important for multiple reasons. First, there are fundamental issues of equity when the vast majority of research dollars raised in our name is spent on things that have little to no practical impact on our quality of life. Beyond that though, we are as a country in the midst of a rather extensive conversation publicly financed programs, including Medicaid, Medicare and Social Security. These programs, most notably Medicaid, finance the great majority of services and supports that Autistic people interact with throughout our lifetime.

If we are going to have conversations on controlling costs while increasing rather than reducing the quality of service and the number of people served, it is absolutely imperative that we fund research that can support those types of outcomes. There is precedent for making progress on both quality improvement and cost savings in disability service-provision – the success of de-institutionalization and community living supports provide a perfect example of this – but research has to play an important role.

The disproportionate emphasis on questions of causation has at times been justified as a means of addressing concerns about the rising rate of autism diagnoses, with some expressing concern about an “autism epidemic”. While the possibility of increasing incidence cannot be fully discounted, a growing amount of evidence suggests that may not be the case.

If we want to put the idea of an “epidemic” to the test, one of the most compelling lines of research we could pursue is an epidemiological study of the rate of autism among the adult population. A recent study of this nature conducted by the United Kingdom’s National Health Service found a comparable rate of autism in adults as in children in England¹. Many of the Autistic adults identified by this study faced significant employment and housing related challenges. Should the CDC conduct a similar study in the United States, we would gain valuable information not only on the question of whether or not autism rates are in fact rising but also on the service and support needs of the older segment of the Autistic community.

It is important to realize that when we talk about outcomes for Autistic people, we need to discuss more than just questions of biology and even severity of impairment. Recent studies have found that racial and income disparities play a significant role in determining what happens to youth on the autism spectrum after we leave school. Studies of Medicaid-eligible children show that African-Americans are diagnosed significantly later than Caucasian children².

We also know that gender plays a big role – women and girls on the autism spectrum are largely ignored in most research and policy discussions. Many believe that the 4 to 1 ratio of boys to girls being diagnosed with autism has become something of a self-fulfilling prophecy, with girls less likely to go diagnosed because they fail to fit the stereotype of what an Autistic person looks like. Indeed, in clinic samples Autistic girls are more likely to possess accompanying intellectual disability, suggesting that girls without accompanying cognitive impairment or language delays may be going unrecognized³.

As Autistic children grow into Autistic adults, the research shows that racial and income disparities continue to persist. Compared to youth with other disabilities, Autistic young adults are less likely to have employment or higher education opportunities in the six years after leaving high school. At least one-third of Autistic youth have no higher education or paid employment experience after school. For African-American, Hispanic and low-income youth, the rate of unengaged youth is significantly higher. This reinforces the need for serious investment in post-secondary transition for youth with significant disabilities to try and address this gap before the upcoming generation of Autistic youth is condemned to a lifetime of social exclusion and un- and under-employment.

¹ Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., ... & Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of general psychiatry*, 68(5), 459.

² Mandell, D.S., Listerud, J., Levy, S.E., Pinto-Martin, J.A. (2009). Race Differences in the Age at Diagnosis Among Medicaid-Eligible Children With Autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, 41, 1447–1453

³ Mandy, W., Chilvers, R., Chowdhury, U., Salter, G., Seigal, A. & Skuse, D. (2012). Sex Differences in Autism Spectrum Disorder: Evidence from a Large Sample of Children and Adolescents. *Journal of Autism and Developmental Disorders*, 42, 1304-1313.

⁴ Rivet, T.T. & Matson, J.L. (2011). Review of gender differences in core symptomatology in autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5, 957–976.



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One possible solution can be found in the TEAM Acts, a collection of three bills introduced by Congressman Gregg Harper and Congresswoman Cathy McMorris-Rodgers, each of which proposes to invest in transition-focused services in our public school, voc rehab and developmental disability service-provision systems.

I was fortunate – although my family is by no means wealthy, they had the means to hire a transition support consultant when I was preparing to leave high school. Because of that, I was able to live independently, go to college and find successful employment. Not all autistic youth are getting the same opportunities. We need to invest in research and service-provision across the lifespan to fix that.

So, this leaves us with one question: what does our service-provision system need to better deliver on employment, inclusion and quality of life for Autistic people across the lifespan? First, it is important to recognize that our system depends on the Medicaid program. The vast majority of services and supports geared to Autistic people and our families are financed by Medicaid. If that program were to be block granted or subjected to ill-advised per capita spending restrictions, those services would be significantly reduced or eliminated. I cannot emphasize this enough: ending a robust federal commitment to Medicaid means ending any meaningful chance to support Autistic people, our families and all people with disabilities towards dignity and independence. We cannot allow that to happen.

Second, we need to think seriously about how we can support Autistic youth into entering the workforce. The Affordable Care Act's end to pre-existing condition discrimination and introduction of new health insurance exchanges open up significant opportunities in that direction by opening up the private health insurance market to our community. Further reforms are needed, however, most particularly to the Supplemental Security Income program which currently forces transitioning youth to choose between living without support or committing themselves to a life of poverty by swearing that they cannot work as a pre-condition for receiving services. Through the development of diversionary programs that can support youth exiting high school into the workforce without having to go on SSI in the first place, we can build more economic opportunities for the next generation of Autistic youth. These reforms would particularly impact the great number of Autistic people who are currently ineligible for Medicaid-financed supports due to not meeting level of care requirements.

Third, we need to think seriously about how we can transition away from legacy infrastructure. The Department of Justice has undertaken extraordinarily important efforts in this regard through enforcement of the Supreme Court's 1999 *Olmstead v. L.C.* decision, requiring states to offer services in the most integrated settings. To that end, additional federal investment in shifting away from institutional care and sheltered workshops would be very important and help to address cost-growth in Medicaid-financed long term services and supports while improving the quality of service-provision. Today, thirteen states have no large state-run institutions and some states have eliminated institutionalization altogether for people with intellectual and developmental disabilities. Through programs like Money Follows the Person and other Medicaid transformation initiatives, we can continue that progress. Targeted autism-focused investment in the Protection and Advocacy system, which has provided crucial rights protection and systems change advocacy, would also be exceedingly valuable.

In closing, I want to thank the Committee members for allowing my community – the Autistic community – the opportunity to have a voice in these discussions. The challenges society currently faces in integrating and supporting Autistic people and our families are not new. We have faced these challenges and made tremendous progress with other disability groups in the past. I believe that at the end the day this is a civil rights issue. I believe in the ability of the United States of America to guarantee the civil rights of all of its citizens. Autistic people want and deserve the same things that anyone else wants – inclusion in our communities, the opportunity to go to school and get a good job, the chance to make our voices heard about the things that matter to us. With your help, we can make that a reality.

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

Name:

Ari Ne'eman

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.

None.

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

Autistic Self Advocacy Network - President

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.

2011-2012: Administration for Community Living (HHS)
grant on Ethical, Legal and Social Issues in ASD Research;
\$44,935

2011-2013: Administration for Community Living (HHS) subgrant
~~for~~ for Autism NOW Resource and Information Center;
\$210,442

2011-2013: National Institute for Mental Health subgrant
on Healthcare Access for Autistic Adults
\$185,360

I certify that the above information is true and correct.

Signature:



Date:

11/28/12