



Nothing about us without us!

Thank you for the opportunity to submit written comments.

The Autistic Self Advocacy Network (ASAN) continues to be deeply concerned by the allocation of autism research funding. According to the Office of Autism Research Coordination (OARC), the vast majority of NIH funding for autism research goes to investigating the biology and causation of autism, and its diagnosis and treatment in young children. In 2012, the most recent year for which data is available, only 1.82% of NIH autism research funding went to research on services, while less than one percent of this funding went to studying issues facing autistic adults. As long as research funding continues to be skewed in this way, many pressing questions with real implications for the lives of autistic people will go unanswered. There is an entire world of data which needs to be collected and analyzed before we will have a solid scientific understanding of what autistic people are experiencing throughout our lifetimes, and what will truly make a difference in our quality of life.

Lifespan and Quality of Life

Currently, there is little research on outcomes throughout the lifetime for autistic people, be it in terms of health, safety, life satisfaction, self-determination, or other measures. Yet research on quality of life and lifespan outcomes is literally life-or-death for our community. A recent study revealed that autistic people have a markedly lower life expectancy, and higher suicide rate, than the general population. Of this study, lead researcher Tatja Hirvikoski remarked, “We observed [an] increased risk of death in all categories that we could analyze — we don’t really know why.”¹ This concerning finding, and lack of related knowledge, highlights the need for further research in this area.

The study’s authors have hypothesized that a lack of disability-competent primary and preventive care could be responsible for increased mortality due to medical issues ranging from cancer to circulatory diseases. Given this, there is an urgent need for research into whether autistic people are accessing appropriate, competent health care, and receiving recommended preventive health services. Co-occurrences between autism and other conditions (such as epilepsy, depression, anxiety, disordered sleep and eating, compulsive skin-picking and hair-pulling disorders, connective tissue disorders, and others) have been entirely under-researched, particularly as applies to adults. Insight into the prevalence of these co-occurring

¹ Ann Griswold, “Large Swedish study ties autism to early death,” *Spectrum News*, December 11, 2015, <https://spectrumnews.org/news/large-swedish-study-ties-autism-to-early-death/>.

conditions, and how they can best be managed, could help to improve the health outcomes and quality of life of autistic people.

Supports and Services

Services research has long been a priority of ASAN. The 2012 OARC data demonstrates that this continues to be one of the least-funded research topics in the field of autism. However, research can and should play a crucial role in identifying effective services for those on the autism spectrum, including supports for inclusive education (from pre-kindergarten through postsecondary), transition services, employment supports, and services that allow adults to live independently in their communities. It is critical that any research agenda prioritizes the needs of autistic people who are here now; unlike research that seeks to discover the causes of autism, services research can make a crucial and positive difference in the lives of autistic people and our families.

In addition, we urge more research on assistive technology, including alternative & augmentative communication (AAC). Many autistic people rely on text-to-speech devices and other forms of AAC to communicate, but little research has been funded regarding assistive technology for communication. Many non-speaking autistic people have been denied access to promising communication methods due to the lack of research in this area. Beyond communication, many autistic people use assistive technology such as specialized timers, apps and online programs to support executive function, memory, travel and navigation, independent living, decision making, community integration, education, and employment. Research examining how autistic people are currently using assistive technology, how effective current assistive technology is, and what possible innovations might be helpful, will have real benefits for autistic people of all ages.

Diagnostic Disparities and Prevalence

While improvements in diagnosing autism have been made for some populations, considerable efforts are still needed to make diagnosis and services available to all. African-American and Hispanic autistic children continue to go under-diagnosed, as do girls on the spectrum. In addition, girls who receive an ASD diagnosis are more likely than boys to have been identified as having an additional disability, and children of color diagnosed with ASD are more likely than white children to have been identified as having an additional disability. This suggests that there are many undiagnosed autistic girls and autistic children of color who are currently either assigned a different disability level or who are being missed entirely due to not being male and white. More research is needed to determine what factors are

causing these diagnostic disparities, identify methods of combating bias, and to identify and develop diagnostic best practices which increase accuracy and ensure that all children are able to exercise their rights and access needed services.

Research is also needed to develop effective diagnostic practices and tools for autistic adolescents and adults, many of whom go undiagnosed because clinicians are not trained in identifying autism in these populations. Additionally, more data is needed on the prevalence of autism in adults. When the United Kingdom conducted an adult prevalence study, it found the same rate of autism in adults as children, helping to debunk public hysteria over a so-called “autism epidemic.” A similar study could be helpful in the US as well.

We also urge researchers to include a more accurate representation of the autistic community in their studies. Many autism studies only include white, male autistic people in the study cohort; data from such studies may or may not be applicable to the broader autistic population.

Working with the Autistic Community

ASAN is often approached by autistic people looking for information that can help them make decisions and plan for their futures, and we are often unable to provide this information because the research has not been done. The autistic community is asking for research into issues that some autistic people face, including motor planning difficulties, skill loss, struggles with nutrition, atypical response to medications, unusual pain perception, and difficulty with executive functioning. These issues are challenging to many autistic people across the lifespan, yet they are rarely studied, particularly among adolescents, adults and seniors. Additionally, the experiences of autistic people during common life events such as pregnancy, parenting, and aging have not been studied. Many autistic people have asked us for such information in order to understand what to expect as they grow older or start a family, but little to no research is available. The priorities of the autistic community - the most impacted stakeholders - are not reflected in the current research agenda.

The allocation of autism research funding has a real impact on the lives of autistic people. For that reason, ASAN believes that this funding should be allocated with the input and involvement of the autistic community. We urge the IACC to promote the involvement of autistic adults in grant review and other aspects of the research process, including through the use of Participatory Action Research models.

Again, ASAN appreciates the opportunity to provide comments on the important issue of autism research. For more information on our comments, please contact Julia Bascom, Deputy Executive Director of ASAN, at jbасcom@autisticadvocacy.org.