

We Need to Be Sure – the Approach Whose Effectiveness We Measure is Useful for the Productive Life of Each Child

The effectiveness of certain methods of support to people with autism does not go off from the world agenda, even in the current global COVID-2019 outbreak situation. On the contrary, being in conditions of distance work, education or isolation it is important to understand what approaches of support to individuals with autism are the most effective.

One of the most famous persons with autism is professor Stephen Shore. He held a [public lecture](#) "Effective approaches to education and work with children and young people with autism. International experience" at the Moscow State University of Psychology and Education with the support of the «Our Sunny World» Rehabilitation Center (May 23, 2019). Stephen is an academic professional – Doctor of Special Education (PhD), University of Boston, professor at Adelphi University, board member of the nonprofit organization "Autism Speaks", author of scientific articles and monographs on autism, including the bestselling book "[Beyond the Wall Personal Experiences with Autism and Asperger Syndrome](#)". The Psyjournals.ru presents readers the interview with Stephen SHORE that held during a visit to Moscow.

Tell few words about your latest research, please.

S.SHORE: So, my research focused on comparing approaches for supporting autistic children and the idea was rather than trying to figure out which approach is the best approach but rather I focused on how do I match recent practice to individual needs. In another words what the best method or approach for a particular child is.

What is the most important thing in the psycho-educational work with children with autism?

S.SHORE: The most important work we can do for supporting children with autism is to find the strengths and the abilities and then use those abilities to number one lead them to fulfilling and productive life and then two to help accommodate for the very real challenges they come with autism.

What are common mistakes, which are teachers and psychologists and some other professionals are doing in their work with children with autism?

S.SHORE: One of common mistakes in people who support those with autism is misattributing behavior, which, for example, can ruin teacher's day. Related to that there is a need for people to develop better understanding as to why autistic children maybe behaving the way they are.

When you were doing your research and analyzing reports, which usually called effectiveness-based interventions or evidence-based interventions, for example, made by Agency for Healthcare Research & Quality, you saw lists of effective and not effective methods. What is the best way of doing such reports?

S.SHORE: We do need to find a standardized way to access the effectiveness of different approaches. However, it is also important what we measure is ecological to the autistic child. So, what that means is making sure what we measure is useful for that child to leading to fulfilling and productive life.

Are there such effective and not effective approaches for adults?

S.SHORE: There are some specific areas where we are saying some research done on effective ways of supporting adults. Nothing is comprehensive, the thing is research is more specific. So, for example at the Adelphi University we have a program that supports autistic adults at the university. And, we've done some research on the efficacy of the approach what we are doing. We found two very interesting findings: number one – the Grade Point Average is higher for those students with autism in our program than in the general population of students. Number two what is very interesting is that the students in the program have a higher retention rate than the general student population at this university. So, what that means is with the support that they are getting they are doing better in school and they are also staying in school longer to finish their degrees. And interesting question that comes out of this is that if the population of students that are said to have difficulties or problems in higher education are not doing better than the rest of the students then other some things that we should be offering to the rest of the student population that we offering to the students on the autism spectrum.

What are the most developing fields of the research on the autism domain?

S.SHORE: In general, the most important area that we have known is supporting autistic people to transition into adulthood. First, it was how do we help autistic people transition into college for those who are going to college and then we've realized that these students need a transition out of college. So, in general it's how we can best support autistic students' successful transition into adulthood. A project that I recently worked on just ended last December focused on healthcare for autistic people. What we did is we set up a community council of mostly autistic people to help guide the research. The project team half the people are autistic, and the other half are not autistic. And we had two goals for this research, which was founded by the Patient Care Research Outcome Research Institute and we got 250,000 dollars over two years to study this. So, one area focus was what are the most challenging medical issues facing autistic people. And we decided we should ask autistic people. Not doctors, because autistic people have to live with this medical issue. And the most important issue was mental health. That is most on the minds of autistic people. We've had a couple of conferences, we asked these autistic people: "If we gave you a whole bunch of money where would you spend most of your money in supporting autistic people in terms of having a fulfilling and productive life?". What came out was social well-being. So, that was the research part. The second part of the project focused on engaging, meaningfully engaging autistic people in all aspects of research. So, what that means is going beyond including autistic people as subjects which has been done for a long time. It goes beyond occasionally asking an autistic person something about research or even having that person sit on the advisory board but rarely consulting with them. But it's really integrating autistic people in all aspects from the development of a proposal to a writing thing up to a submission, to a designing the research plan, implementing that plan, getting involved in data collection and analysis. And, finally, at the end, disseminating the research on conferences and in writings.

You are an example of that person.

S.SHORE: Well yes, I'm doing it. There are some others. We published an engagement guide to promote authentic involvement of autistic people in research. So, that was completed in December 2018. And we're finding more people, researching and involving autistic people in meaningful research. So, there is an organization called "[Autistica](#)" in United Kingdom, which also researched two medical issues similar way what we did. We didn't know they are doing research,

they didn't know we were doing research. But that I really interesting to see that results came up the same. And that was the mental health piece. There is the Participatory Autism Research Collaborative that is run by Damian Milton, an autistic person. And this collaborative is a collection of researches both autistic and others who are autistic friendly, focusing on researching issues that are important to autistic people. Getting back to the project that I worked on at the Patient Care Outcome Research Institute [Dr. Teal Benevides](#) was one of the partners who was not diagnosed on the spectrum. She is occupational therapist and it was the two of us who formed the core of developing of this research. We added a couple of other people – Alex Plank who is autistic and Patti Duncan, who is not on the autism spectrum. And again, our [team](#) was half autistic and half not autistic.

If we can summarize the general line of your research and research of “Autistica” is a research of wellbeing and the expectations of healthcare needs of children.

S.SHORE: Adults autistic people. Because we talked to autistic adults in the research so there were opinions from adults.

Interview prepared by E. Shvedovskyi

Federal Resource Center for Organization of Comprehensive Support to Children with ASD,
Moscow State University of Psychology & Education

Related links

The Participatory Autism Research Collective (Dr. Damian Milton, chair)
<https://participatoryautismresearch.wordpress.com/>

The research “Autistic Adults and other Stakeholders Engaged Together” (Dr. Teal Benevides, project lead) <http://www.autistichealth.org/>