



President and Co-founder of the Autistic Self-Advocacy Network (ASAN), Ari Ne'eman: Current initiatives & trends

In just ten years, [ASAN](#) has grown from a small group of volunteers to becoming the leading national advocacy organization run by and for autistic adults. ASAN is led by [President and co-founder, Ari Ne'eman](#), and is powered by a dedicated team of 10 paid staff, most working out of a Washington, DC office, with a network of volunteer grassroots chapters across the country. ASAN's mission can be nicely summarized with the phrase, "Nothing About Us, Without Us!" In recognition of Autism Awareness Month, Ari agreed to talk with the DD Council on what he believes are the most important issues impacting people with autism today.

ASAN is committed to recognizing April as [Autism Acceptance Month](#) rather than "Awareness." The philosophical difference is related to why ASAN uses [identity-first language](#) rather than person-first language to describe people with autism. ASAN views autism not as a disease to be treated or cured in the medical sense, or changed/conformed in the social sense. Rather, autism is viewed as an inseparable part of the "autistic" experience referred to as "neurodiversity." A link on ASAN's website to Autism Acceptance Month explains that neurodiversity is "...short for neurological diversity, referring to the diversity of human brains and minds - to the idea that this is a natural, valuable form of diversity. There is a great deal of variation among human brains and human minds, and this variation is called **neurodiversity**. Different people think differently – not just because of differences in culture or life experience, but because their brains are 'wired' to work differently."

When asked what Ari believes are the top initiatives or trends happening in the nation, after first recognizing the work in Maryland this year to eliminate subminimum wage, Ari launched quickly into a summary of S.1604, or the Transition to Independence Act (TIA). TAI will give states with Medicaid buy-ins (like MD) a chance to get bonuses if they meet certain standards such as elimination (or significant decrease) of subminimum wage work, more opportunity for people with disabilities to work competitively, in the community (rather than in sheltered workshops) and a shift of day services from facilities to community based settings. TAI was introduced in the U.S. Senate, and ASAN is now working with a variety of partners to introduce the bill in the House. Ari noted that any Marylanders interested in seeing the bill pass should contact their congressional delegation. Find more information about [Transition to Independence TAI/S1604 here](#) and the [status of the legislation and hearing schedules here](#).

Another significant initiative involves the rights of non-speaking students to receive the supports and technologies needed to fully participate in public education. To this end, ASAN has filed a complaint with the Department of Justice as part of a new Communication Rights Initiative. Ari elaborates, "This is one of ASAN's most exciting projects. It's a part of our larger effort to establish relevant precedence and public policy that facilitates access to augmentative and assistive technologies of a person's choosing supporting communication throughout life. Communication is at the core of so many aspects of what we could consider a good life for anyone – the right to communicate is an essential aspect of community integration. When we see public schools not supporting students' communication or policies that create barriers to access, we have a responsibility to act and to facilitate change." An example of a policy that creates barriers to communication is how extremely useful technologies, such as the iPad, are not paid for through insurance because of what is called "dual use." [Read more about ASAN's legal action on behalf of non-speaking students, and the Communication Rights Initiative, here.](#)



Maryland Developmental Disabilities Council

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Many of you know that one of Maryland's legislative triumphs in 2015 was passing legislation ensuring people with developmental disabilities will not be overlooked for an organ transplant because of disability. You may not know that [ASAN provided the toolkit to aid and support policy development and advocacy in Maryland](#). As a result, in 2015, with broad support including the DD Council, Maryland passed legislation that prohibits discrimination against a potential recipient of any anatomical gift or organ transplant solely on the basis of the person's disability, as defined in the Americans with Disabilities Act.

The DD Council recognizes the importance of organizations like ASAN that are led and staffed by people with autism or other developmental disabilities. We are pleased to support and partner with ASAN on issues and initiatives that support our mission and values. Two additional ASAN initiatives to note are this easy to read guide on supported decision making, titled [The Right to Make Choices: International Laws and Decision-Making by People with Disabilities](#) and a recent letter written to Florida's Deputy Secretary for Medicaid pointing out [clear violations in the Home and Community-Based Services Rule](#).