



## Autism and Policy: Seek Simplicity Then Question It

By Kevin Aldridge and Lara Palay, first posted April 5, 2012,  
[www.centerforsystemschange.org](http://www.centerforsystemschange.org)

“Disability policy is like juggling plates”, a friend once observed, “and I can’t juggle”. One of the authors learned the truth of this first-hand. “When I was hired to develop policy for the Ohio Department of Developmental Disabilities,” he said, “it seemed that all I did was run from one meeting to the next: early intervention, housing, employment, intensive behavioral supports, children and family issues. We lived off interagency agreements with other departments, and memorandums of understanding, though few of us really understood much.” Then rather suddenly there was autism; a developmental disability with ramifications for healthcare, education, mental health, employment and even the justice and corrections systems. It touched everyone’s wheelhouse, and resided in no ones.

Autism catapulted to national attention, not for the first time, in 2009 when the Center for Disease Control announced new prevalence estimates of 1 in 110 with autism, from 2007 estimates of 1 in 152. Since then, autism and autism spectrum disorders have demanded more and more attention from policy makers in every social welfare arena, as well as showing strongly and persistently on the radar of elected officials at local, state and federal levels. This effect will only intensify, as the CDC has released yet again new prevalence

estimates of 1 in 88, an astonishing 25% increase from 2009.

A CSC review of states’ responses to this policy crisis shows that the education system has responded the quickest, and that states have noted the need to ramp up teacher training as being of paramount importance. This may be due in part to the particular way this developmental disability shows itself. Some children with autism, especially those on the “high-functioning” end of the spectrum, might manage relatively well in familiar settings but have serious problems with communication and social skills, deficits that become increasingly evident in a schoolroom. Along with working on the educational system, advocates and policy makers are rallying around early diagnosis and treatment, transition-to-work (for young adults), employment, and insurance parity as key issues. All indications are that housing and emerging bio-medical approaches will join this list in the near future. Why are there so many groups involved, and why is this particular disability getting so much attention? One reason is that autism is a complex disorder, with many manifestations beyond the key features of the diagnosis. One such aspect is sensory integration issues, which can include extreme reactivity to sound, touch, or taste. A person with autism is also very likely to suffer from physical ailments such as seizure disorders, sleep issues and chronic gastro-intestinal problems. Attention-deficit disorder, obsessive-compulsive disorder and other mental health problems are frequent co-occurring conditions as well.

In all these areas, systems collaboration has risen as an essential element of a policy response, as well it should. With all its complexity, autism does not fit comfortably into any one traditional service population, so policy and program developers have to work together. Though some states have made progress in doing this, typical collaboration may not prove adequate. Agencies and disciplines need to find new ways to work together creating policy and programs if they are going to address fully

the array of issues surrounding autism.

If they can do this, innovative autism policy will benefit all people struggling with a disability, not just those dealing with autism spectrum disorders. For example, policy that targets intellectual disabilities will have limited and diminishing impact outside that particular disability category because not everyone with a disability has an intellectual deficit. Policy targeting autism, however, will cover both people with cognitive deficits and those without, because on the autism spectrum we find a wide range of IQs and ability to learn. People with other disabilities, including those with and those without cognitive limitations, will all benefit from a policy that does a good job of addressing that continuum.

Communication issues, physical and medical conditions, behavioral problems—all these elements of autism may mirror other, “simpler” disabilities. Because of the sheer magnitude of the condition, autism provides a big enough umbrella for people with other disabilities to keep out of the rain.

This notion is, admittedly, a deceptively easy guide for policy makers. Autism manifests itself in such a wide range of problems that adequate responses to the challenge must be both comprehensive and targeted at the same time. In other words, good autism policy is really well integrated autism policies. At the same time, in view of such variety, policy makers must keep cool heads rather than try to address every possible variant of the disorder with its own unique rule or initiative. To follow the dictum of British philosopher and mathematician A. N. Whitehead, disability policy makers need to seek simplicity then question it. In practical terms, this means looking for the most straightforward and simple answer that will cover the most ground, while keeping in mind that a simple answer that addresses 99% of a problem will still fail to address that remaining 1%, because nothing is entirely simple. Knowing this, policy makers will readily recognize instances when the simple answer fails and bolster it with additional remedies.

This is not a matter of treating all policy and program development as if it were to serve only people with autism. It is a confrontation of complexity. The support needs of a person with significant intellectual disabilities are not the same as the needs of someone dealing primarily with mobility issues. Applying the autism umbrella, you figure out options for people with mobility problems as an element of the larger solution, because you know that that mobility variant may occur. Again, cover everybody on the spectrum, and you cover almost everybody with any disability.

This principle also works for integrating all disabilities with broader policy agendas. Employment presents a perfect example. When it comes to improving employment for people with disabilities, if policies are not integrated into larger economic initiatives, they simply will not result in lasting change. As long as they are a special category, considered separately, people with disabilities will always run the risk of being shunted off to the sidelines, whether by being isolated in workshops or immobilized by inadequate transportation options. From a policy perspective, perceived “specialty” initiatives for people with disabilities quickly will be abandoned in times of economic hardship, as we have seen in the past four years, unless they are tied to larger issues. Employment creates tax revenue, no matter who does the work. Make more revenue with people with disabilities, and you have more revenue, period. Social welfare, for better or worse, has limited appeal, but economic development is everyone’s concern. Until we get used to thinking this way for all disabilities, autism, with its headline-grabbing statistics and wide-reaching effects, provides a unique vehicle to a permanent place in the broader policy arena.

We hope that these insights and the added pressure of increased prevalence will give policy makers pause this April, which is Autism Awareness Month. In honor of the occasion, CSC is publishing a Special Issue series on autism-related topics. We start with a policy brief on the application of the

bio-psycho-social model to autism policy. We will also examine the proposed changes to the autism diagnosis in the DSM 5, slated to come out in 2013. We will look at one state's experience in reimagining autism policy recommendations now almost a decade old. In conjunction with the Autism Center at OCALI, we will review leverage points for change in classrooms and schools for children on the spectrum.

As always, we will discuss these topics with an eye to connecting the issues with larger social policy, and doing so from a multidisciplinary perspective. Given that public reaction to the new autism prevalence rates, only hours after their release, has generated calls for a 'national strategy', it is quite clear that sound autism policy is, on closer examination, integrated autism policies.

We hope you enjoy the Special Issue and invite your comments on these and our other articles and briefs. In seeking simplicity and then questioning it, we may not become master jugglers, but we'll certainly drop fewer plates.

1. Brief: Status Report on Autism Recommendations. See Center for Systems Change:  
[http://www.centerforsystemschange.org/view.php?nav\\_id=44](http://www.centerforsystemschange.org/view.php?nav_id=44)