

CROSS TALK

# Scientists, advocates hail Hillary Clinton's autism plan

BY JESSICA WRIGHT

12 JANUARY 2016

Hillary Clinton made political history last week by **proposing a plan** to ramp up autism research and services as part of her presidential bid.

Previous campaign discussions about autism have hyped fears of an autism epidemic or even resurrected the long-debunked vaccine link. By contrast, Clinton's plan emphasizes research and services that may help those in need.

Clinton's proposal backs the American Academy of Pediatrics' recommendation that young children be routinely screened for autism, rejecting the stance of the **U.S. Preventive Services Task Force**, an independent panel of medical experts, that **there is insufficient evidence** to support routine screening. If elected, she promises to launch a national outreach campaign to boost early screening rates, focusing on families that are **traditionally underserved** by healthcare.

Clinton also proposed a so-called 'Autism Works Initiative' to increase **employment and housing opportunities** for adults with autism. The initiative would help develop transition plans for teenagers with autism as they **prepare to leave the structured supports** of the school system. It would also foster public-private partnerships to establish meaningful work opportunities for adults with autism.

In addition, Clinton stated her commitment to "significantly increase" research funding for autism. The proposal specifically mentions efforts to uncover autism's complex genetic roots and calls for the first ever U.S. prevalence study of **adults with autism**.

Below, autism researchers and advocates weigh in on the details of the plan and the significance of a presidential candidate addressing the needs of people with autism.

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Deborah Fein

Professor of Psychology, University of Connecticut

*Clinton's initiative meets the pressing needs of people with autism, but needs some fleshing out.*

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## Initiative closes big gaps, leaves small holes

Clinton's autism plan seems very well thought out, informed by recent research, and specific enough to be practical and beneficial. She hits on many of the most pressing needs, including insurance coverage for evidence-based treatments and support for both families and affected individuals facing the **transition to adulthood**. She also highlights the need for serious efforts to screen for autism in children from all backgrounds in schools and preschools in order to catch children who are not screened during pediatric visits.

The Autism Works Initiative seems very important, as adults with autism are often **underemployed relative to their cognitive abilities**. Of course, it is in preliminary form and will need a good deal of fleshing out. For example, it should include an assessment of an individual's cognitive, social and behavioral functioning, as well as his or her interests. This assessment would help match people with appropriate jobs and determine the level of support they need to make the placements work.

Conducting a prevalence study for adults would also be valuable, not only to identify people in need of services, but also to shed light on the apparent increase in autism over the past few decades. An adult epidemiological study could help to reveal whether there is a true increase in rates of autism or simply a lack of diagnoses, or misdiagnosis, among adults.

## Safety concern:

Clinton's outreach plan to boost the rates of early screening for autism hits most of the major points, but raises two questions: First, who will make the diagnoses? She seems to imply that the pediatricians can make the diagnoses, but generally, pediatricians simply screen for autism and then refer children to an autism specialist for diagnosis. Sometimes, **children have to wait for months or longer** to get a competent diagnostic evaluation.

Second, she emphasizes screening at 18 and 24 months, when we would hope to pick up most cases, but does not mention the importance of a second round of screening at entry to school or a bit later to pick up milder cases that may go unnoticed before the age of 3 years. Children whose social difficulties and **restricted interests** are **not apparent until school age** may not show early autism signs such as delayed language, lack of primary attachments, lack of basic joint attention, and poor imitation or pretend play.

## Adolescent concerns:

Another concern I have is that in her proposal to keep children with autism safe, she lumps “chemical restraint,” which refers to treating an individual with a sedative, with **physically restraining** children. Certainly some people with autism are inappropriately medicated, but there are also many cases in which adolescents need medication — because, for instance, they act out in a way that is dangerous to themselves or others. Psychiatrists must have leeway to prescribe sedatives or antipsychotics without going through a bureaucracy to get permission. Clinton calls for improved safety for children with autism and supports for adults — both very important indeed — but does not specifically address adolescence. Adolescence can be a time of severe behavioral, cognitive and psychiatric deterioration. Although these changes are hopefully temporary, they can put a family in crisis. I have seen many cases in which a state denies a family temporary hospitalization or residential care because the family had not exhausted every possible home-based treatment, placing its members in emotional crisis and even physical danger. There need to be alternative services for adolescents in crisis, including dedicated autism units in psychiatric hospitals or residential schools.

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Maureen Durkin

Professor, Departments of Population Health Sciences and Pediatrics

*Clinton’s comprehensive proposal could make history, if it can be carefully carried out.*

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## Proposal could make history, if carefully carried out

I couldn’t be more enthusiastic about such a comprehensive plan to support research as well as the children, families and adults affected by autism. This may be the first time that a presidential candidate has presented such a detailed plan to advance science and services for people with developmental disabilities. I am especially enthusiastic about the focus on improving job opportunities for adults on the autism spectrum.

If Clinton is elected and able to implement this plan, it won’t be the first major presidential initiative to improve our understanding of developmental disability or the outcomes of disability for individuals and families. In 1930, Herbert Hoover’s White House Conference on Child Health and Protection made a **commitment** that children who are physically or “mentally handicapped” should be provided the care and treatment necessary to “become an asset to society.” The statement adds that this should be paid for publicly, if necessary.

In 1963, the Kennedy administration made a major commitment to research on what was then referred to as ‘mental retardation.’ And in 1990, George H.W. Bush signed into law the Americans with Disabilities Act. If implemented, the Clinton autism plan could someday be on par with these

achievements.

## Ethics issue:

Increased federal funding for autism research is very much needed, and the plan to expand autism screening and reduce disparities in access to services is impressive. However, it would be nice to see more integration between the two goals of research and screening. We need research that provides evidence for the benefits of early detection of autism and that helps establish the optimal timing and duration of treatments. We also need to look closely at the cost-effectiveness of autism treatment.

Expanding screening and early detection alone could be unethical if it is done without assurance that those who screen positive will have access to effective services and that the benefits of screening will outweigh any risks and costs. The plan to require all states to comply with Medicaid requirements to cover autism treatments could go a long way toward assuring this and reducing disparities in access to autism services.

Finally, I hope that the plan will support the development and use of free or **low-cost tools for autism screening** and diagnosis. The cost of autism diagnostic assessments in the U.S. and associated disparities in access to services is unconscionable and unsustainable. We should do more to reduce these costs to make autism diagnosis and treatment accessible to those in greatest need. It is unclear whether the plan will achieve this without greater attention to developing cost-effective tools and approaches.

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Julia Bascom

Deputy executive director, Autistic Self Advocacy Network

*Clinton's plan speaks to the concrete needs of people on the spectrum and their families.*

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## Plan speaks to needs of people on the spectrum

As an autistic self-advocate, there's a lot to like about Clinton's autism plan. The focus on substantive policy issues is great to see. You can tell the campaign did a deep dive here. The plan focuses primarily on the concrete needs of autistic people and our families, which is a refreshing change of pace from much of the national conversation about autism, which is still focused on ideas about cure and tragedy. Clinton isn't scared of autism: She recognizes autistic people and our families as constituents with very real needs and priorities, and she's got a plan to start meeting those needs.

There's an overall emphasis throughout this plan on protecting autistic people's rights — a critical

issue that is typically overlooked in discussions about autism. Clinton's commitment to protect and advance the rights of the autistic community, particularly by committing to funding an autism protection and advocacy program, is, frankly, unprecedented.

I'm excited by Clinton's many references to specific and already-existing policies. The Obama administration has led some incredibly important work to ensure that people with disabilities, including autistic people, can live in the community, attend safe and inclusive schools and exercise our civil rights. This plan references and recommits to that work; that's so encouraging to see. Another item I love about this plan is the recognition of the huge disparities across racial, ethnic, gender and socioeconomic lines in terms of who gets access to accurate diagnosis and appropriate services and supports. There's a lot to be done here. It's not acceptable for someone's quality of life and access to competent care to be dependent on accidents of birth.

## **We vote:**

The plan also calls for the first ever attempt to determine the prevalence of autism among adults in the U.S., which advocates have been urging for years. These kinds of things are the first steps toward ensuring that all autistic Americans get the support we need.

But what stands out the most to me is the extent to which this plan illustrates just how far we've come. Ten years ago, you wouldn't see a presidential candidate putting out an autism plan at all, let alone one that spoke to the needs of autistic adults — or even recognized we existed. There's no mention of 'cure' in this plan, none of the usual awful statistics we see about our 'cost to society,' no descriptions of us as natural disasters like tsunamis, devastating our families and draining everyone around us. Instead, we have a plan that talks about housing — notably, housing integrated into the community — and employment. Clinton recognizes that my community exists, and that we vote. That's huge.

As a person with multiple disabilities, I'm hopeful that Clinton will soon release a broader disability plan as well. Very few of the autistic community's concerns are unique to us. Issues such as housing, employment, mental health parity and rights protection are high priorities for the broader disability community as well. The disability community is a vast and untapped constituency — it's in the best interest of any and all campaigns to pay attention to us. Here's hoping this autism plan is just the start.

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Joseph Piven

Professor, UNC School of Medicine

*Clinton's broad initiative includes resources for all aspects of autism, from jobs to genetics, and a lifespan approach to understanding the condition.*

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## Broad initiative includes lifespan approach

I am impressed that Clinton and her colleagues have tackled this topic in such a serious way. I think it is all on target, which speaks to how thoroughly they must have looked into this with stakeholders, scientists and others.

They are proposing that more resources go toward all aspects of autism — from genes to jobs. That broad view is unique: Most autism researchers and stakeholders focus narrowly on their own piece of the pie.

I was impressed with suggestions to fund scientific efforts, specifically genetics and the adult prevalence study. But I would be more in favor of simply proposing increased funding in major areas of research — such as genetics or clinical brain-behavior — and leave it up to the research community and stakeholders to set specific research priorities.

Adult prevalence, in particular, is important to figure out, for sure. Autism is generally a lifelong condition, and so I believe we need to move toward a lifespan approach to understanding autism. Finding out how many adults are out there and determining what they look like, their quality of life and the services they use, would go a long way toward improving things for people with autism.

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David Mandell

Associate Professor, Perelman School of Medicine at University of Pennsylvania

*Clinton's proposal protects important rights, but its research scope is narrow.*

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## Proposal protects rights, but research scope is narrow

This plan hits a lot of great points. I am particularly delighted by the frequent mention of families that lack resources, and the need to improve services in low-income and rural areas. I'm also delighted that Clinton has embraced the American Academy of Pediatrics recommendations regarding screening.

Protecting the physical safety and civil rights of children with autism in schools and elsewhere is, of course, important. I also appreciate that her plan specifically advocates for the right of children with autism to be **educated with their neurotypical peers**.

Her comments about adults are spot on — especially the focus on their rights to independent living and protection against discrimination under the Americans with Disabilities Act and the need for more employment and housing support.

However, I would like to see more from two aspects of Clinton's plan: The push to cover autism

interventions through health insurance, and her research focus — in particular, the call for a study of autism prevalence in adults.

For one, a lot of money is already spent on autism treatment — not enough, but a lot. So we should be doing more to prepare, train and support our educators and clinicians so that they can deliver what research tells us is the best care. The data to date suggest that evidence-based interventions **are not delivered in the community** the way they were intended and outcomes in the community are worse than reported in university-based intervention studies. We need to close this research-to-practice gap.

I would have also liked to see her research agenda encompass more than genetics. For example, to develop better services and supports for individuals with autism across the lifespan will take rigorous research.

I also don't think that an adult prevalence study is the way to go. The children who were in the first Centers for Disease Control and Prevention-funded prevalence studies are now adults. We know how many adults with autism there are. We would have to conduct a prevalence study among 10,000 people to find 100 adults with autism. If we really want to learn about the service and support needs of adults with autism, let's survey 10,000 adults with autism. We'll get richer, better data that will have much more practical implications for what we do next.

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Connie Kasari

Professor of Psychological Studies in Education and  
Psychiatry, The University of California, Los Angeles

*Clinton spotlights disparities, safety and bullying.*

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## Clinton spotlights schools, bullying

Overall, I think the proposal is a positive sign that Clinton plans to shine a spotlight on some real disparities in healthcare and education for people with autism. It's great that she will authorize a prevalence study of adults and encourage screening at the other end of the age range, in infants. Her comments about safety and interventions in schools were interesting. Schools need more funding and support for autism interventions, as they tend to be underfunded for special-needs children in general. It's also clear that teachers — particularly general education teachers — have limited training in this area. With adequate training and funding, schools are the best places to address disparities because nearly all children attend them.

We really have limited research on bullying in autism, so I was surprised that Clinton highlighted bullying in particular. I think this could be an important area for future research, along with effective interventions for providing access to communication for all, such as tablets with **speech output software** for minimally verbal individuals.