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AUTISM P. 2



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NEW GROUP SEEKS REALISTIC SOLUTIONS FOR SEVERE AUTISM

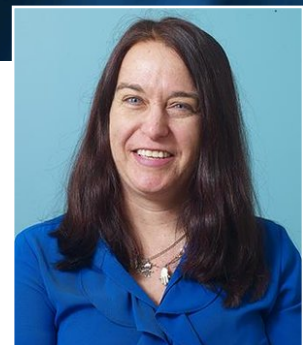


Bruce Hall

“Wishful thinking about autism won’t solve the problem”

Against a backdrop of increasing challenges for individuals with autism and their families nationwide, leading advocates have announced the formation of the **National Council on Severe Autism (NCSA)**. The new organization is created to address pragmatically the many serious challenges in services, housing, and policy facing families, caregivers and individuals affected by severe forms of autism and related disorders.

“Autism is often romanticized and sugar-coated in the media and social media,” said Jill Escher, NCSA President. “In contrast, our efforts will be



“The NCSA will be an invaluable addition for autism policy and research advocacy.”

—Lee Wachtel, MD

(Continued next page)

guided by pragmatic realities. For countless families devoted to the well being of their disabled loved ones, the daily challenges can be overwhelming, and the prospects for the future extremely bleak. We will work to increase capacity and a range of new options for this population.”

The NCSA addresses forms of autism that, **by virtue of any combination of cognitive and functional impairments, necessitate continuous or near-continuous supervision, services and supports over the lifespan. Individuals in this category are often nonverbal or have limited use of language, are intellectually disabled, and, in a subset, exhibit challenging behaviors that interfere with safety and well-being.** Data from the U.S. Centers for Disease Control, along with other population studies, suggest that nearly 1% percent of children and adolescents in the United States likely have a form of autism meeting these criteria.

“The growth of the severely disabled autistic population—nearly 1% of all children in the U.S., together with a burgeoning population of young adults—requires clear-headed, matter-of-fact policy solutions that deliver results,” said Amy Lutz, NCSA Secretary. “We look to work cooperatively with federal and state agencies to create cost-effective ways of finding quality places to live and well trained and dedicated people to help care for disabled relatives and neighbors. They deserve it, and wishful thinking about autism won't solve the problem.”

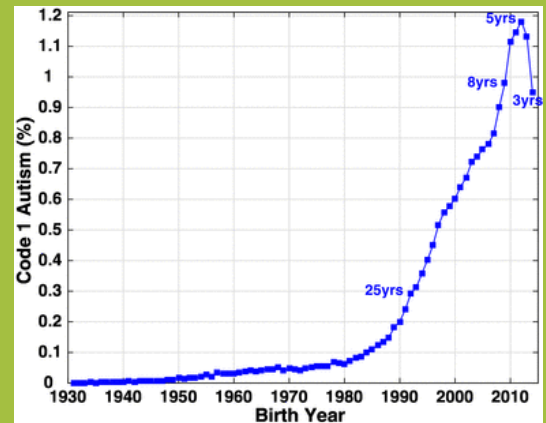
“The establishment of the NCSA will be an invaluable contribution to the autism community, both in the U.S. and beyond,” said Lee Wachtel, MD, Medical Director, Neurobehavioral Unit, of the Kennedy Krieger Institute in Baltimore, and who is not associated with the new organization. “It will provide a sensible and long-awaited voice for those living with highly challenging conditions with overwhelming impact upon individuals, carers, and the larger community.”

Prominent practitioners, professionals, and policy experts noted for successful real-world autism advocacy comprise the initial board of the NCSA. The group includes President Jill Escher, President of Autism Society San Francisco Bay Area and founder of Escher Fund for Autism (California), Vice President Feda Almaliti, who helped spearhead autism insurance reform in her state (California), Secretary Amy Lutz,

NCSA Mission

To pursue recognition, policy and solutions for the surging population of individuals, families and caregivers affected by severe forms of autism and related disorders.

A staggering increase in developmental disability-type autism cases



Autism cases by birth year, reflecting the dramatic growth in California Department of Developmental Services autism. These cases capture only the more impaired end of the spectrum. Data from 2017.

Graph from Nevison et al 2018.

founder of the EASI Foundation (Pennsylvania), Treasurer Alison Singer, founder and Executive Director of the Autism Science Foundation (New York), and board members Frank Campagna, a television producer and popular blogger (New York), Lisa McCauley Parles, Esq., a partner in Parles Rekem, LLP a law firm representing individuals with disabilities and their families (New Jersey), Dr. Gloria Satriale, executive director of Preparing Adolescents and Adults for Life (Pennsylvania), and Dr. Matthew Siegel, Associate Professor of Psychiatry and Pediatrics of Tufts University School of Medicine, Vice President of Medical Affairs, Developmental Service, of Maine Behavioral Healthcare, and Faculty Scientist II at Maine Medical Center Research Institute (Maine).

The NCSA has published an initial set of Position Statements on important topics facing the autism community. These include: [Guardianship](#), [Vocational Options](#), [Personal Safety and Abuse Prevention](#), [Access to Appropriate Health Care and Crisis Care](#), [Medicaid HCBS Residential Policies](#), [Educational Placements](#), and [Need for Innovative Research](#).

The NCSA [homepage](#) features a sign-up block for its newsletters and updates. NCSA also hosts a popular Facebook page. The organization is planning to host a think tank on national adult autism policy as one of its initial efforts. "We have no intention to duplicate the vitally important work of other autism advocacy organizations," added Escher. "**We aim only to add a strong voice for those who cannot speak for themselves.**"

NCSA is an Internal Revenue Code 501(c)(3) nonprofit organization.

For more information:

Website: ncsautism.org

Email: info@ncsautism.org

Facebook: facebook.com/ncsautism

Twitter: [@ncsautismorg](https://twitter.com/ncsautismorg)

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NCSA Position Statements



NCSA has adopted positions on many of the pressing issues facing our community, including:

[Guardianship](#)

[Vocational Options](#)

[Personal Safety and Abuse Prevention](#)

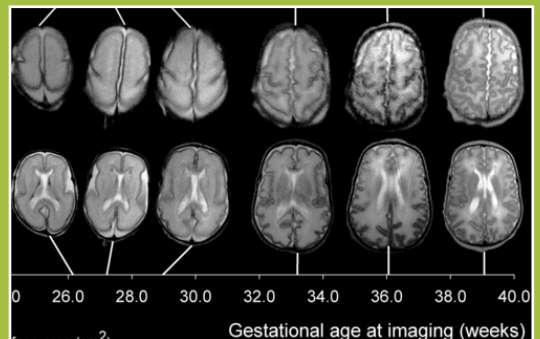
[Access to Appropriate Health Care and Crisis Care](#)

[Medicaid HCBS Residential Policies](#)

[Educational Placements](#)

[Need for Innovative Research](#)

NCSA urges intensified research to identify autism causes and treatments



See: ncsautism.org/list-of-ncsa-position-statements

No Sugar Coating

The steep increase in autism, now affecting nearly 2% of our children, represents perhaps our country's greatest public health and social services challenge.

Pragmatic, clear-headed solutions are urgently needed. Please learn more about our work at ncsautism.org.

JOIN US IN ADDRESSING THIS NATIONAL CRISIS

Help us advocate for policy reform, relevant research, and societal awareness by emailing us at info@ncsautism.org and/or donating at ncsautism.org. Or mail to:

NCSA
PO Box 26853
San Jose, CA 95159-6853

Thank you for your partnership and support!

Our blog unflinchingly addresses realities of severe autism



Suffering in Silence: The Dark Side of Autism
—VBS



I Have Yet to See Meaningful Answers that Help Our Family
—Alicia Mesa



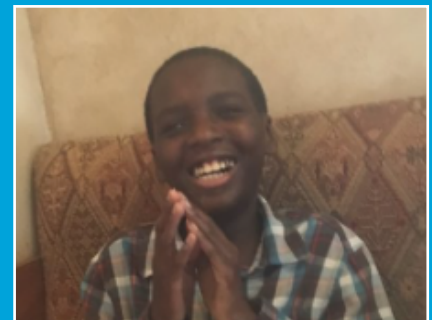
Clinical Research in Severe Autism: Working to Do Better
—Joseph Buxbaum, PhD



I'm 80 Years Old and There's No Post-Mom Transition Plan for My Severely Autistic Son
—Martha Moyer



Parent Blaming and Autism: Tragically Trending Again
—Jonathan Mitchell



Help I Need Somebody (But Since I'm the Mom the Answer Is No?)
—Beneeta Dean

This is just a sample, please see all our blogposts at ncsautism.org/blog



NATIONAL COUNCIL ON SEVERE AUTISM

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