



NATIONAL AUTISM LAW CENTER

THE AUTISM ADVOCACY YOU DESERVE

Defending the rights of
individuals with autism
and their families

AS A NATION, WE ARE FAILING INDIVIDUALS WITH AUTISM

Housing for Adults with Autism: A Growing Crisis

By: Mandy H. Breslow, LCSW, MSEd | Indie Living, Inc.
July 1st, 2019 | adults, housing, independence, Medicaid, summer 2019 issue | 9620 | 6

Autistic defendants are being failed by the criminal justice system

The criminal justice system (CJS) is failing autistic people, argue researchers at the Autism Research Centre, University of Cambridge, after a survey of lawyers found that an overwhelming majority of their clients were not provided with adequate support or adjustments.

Autistic Individuals Have Poorer Health and Healthcare

Autism | Featured | Neuroscience | May 29, 2022

Are Autistic Students Traumatized in Schools?

By: Marcia Eckerd, PhD | Diagnostician, Therapist, Writer, and Speaker
April 1st, 2022

'So Rudderless': A Couple's Quest for Autism Treatment for Their Son Hits Repeated Obstacles

Colorado approaching a health care crisis when it comes to autism services for children

One in four autistic children wait over three years for school support, poll finds

National Autistic Society says long waits for educational help is leaving families 'on the edge of crisis'

Autism study finds high rates of unmet healthcare needs; suggests public policy solutions

Autism increases likelihood of arrest in youth

July 23, 2022 by [Jad Salem](#)

Calif. Teen with Autism Died After Being Restrained for More than an Hour, 3 School Employees Indicted

The Guiding Hands School in El Dorado Hills was shut down a week after Max Benson's death
By [Chris Harris](#) | Published on July 25, 2022 01:37PM EDT

85% of adults on the autism spectrum are unemployed – and hiring practices may be to blame

By [Paola Peralta](#) | April 21, 2023, 3:30 p.m. EDT | 6 Min Read

10-year-old with autism arrested at Florida school

By [Jacqueline Howard](#), CNN
Updated 9:17 AM EDT, Mon April 24, 2017

Parents of autistic children fight for treatment in an unforgiving market

Therapy costing up to \$40,000 a year aggravates insurance providers, whose refusal to cover it can leave parents struggling

Rockdale teachers accused of locking child with autism in bathroom, school investigates

By [Joi Dukes](#) | Published August 15, 2023 | Rockdale County | FOX Atlanta

Beyond awareness: The medical system needs to deeply reform its care of people with autism

Research | [Open Access](#) | Published: 26 May 2022
Autistic adults have poorer quality healthcare and worse health based on self-report data
[Elizabeth Weir](#), [Carrie Allison](#) & [Simon Baron-Cohen](#)

The U.S. justice system has an autism problem

The U.S. justice system is sadly outdated in its handling of autism and cognitive disabilities, in general. Without the proper training, handling people with these disabilities can be extremely taxing on the police, justice and prison systems. And the impact on some of our most vulnerable citizens is chilling.

Parents of autistic children often worry about life after high school

Dayton school employee shown on camera hitting child with autism

Autistic people at greater risk of becoming homeless – new research

Published: June 12, 2018 5:02am EDT

THE CHALLENGES ARE EXTENSIVE AND EXACERBATE EACH OTHER



HEALTHCARE

Inability of individuals and families to access effective services (e.g., Applied Behavior Analysis)

EDUCATION

Inadequate support and prejudice leading to pervasive failure to provide free and appropriate public education and post-secondary education opportunities

HOUSING

Insufficient availability of appropriate housing and recreational facilities for individuals with autism, especially those with challenging behaviors

EMPLOYMENT

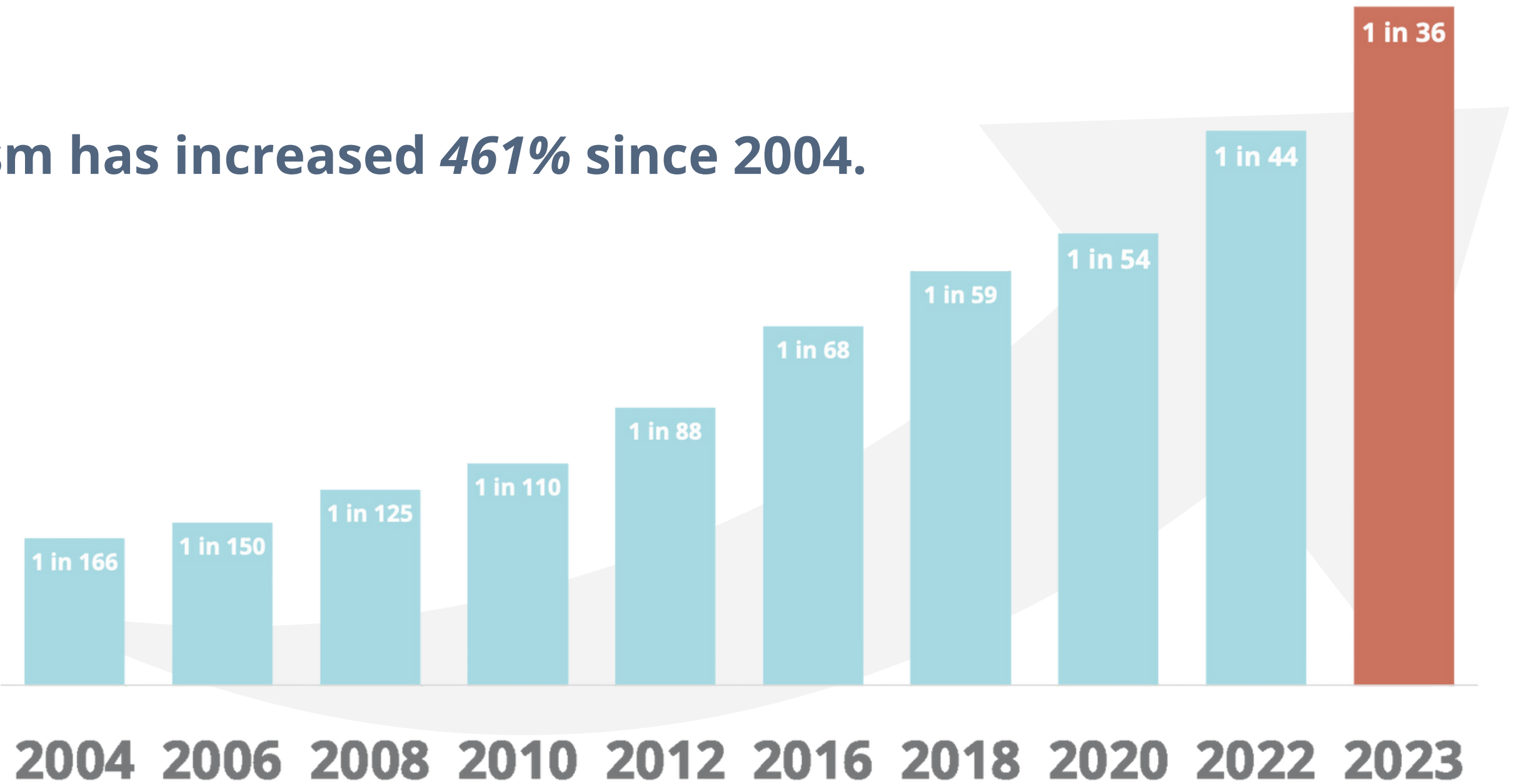
Discrimination, lack of understanding and lack of accommodations resulting in the highest rates of unemployment and underemployment of any disability

CRIMINAL JUSTICE

Lack of information and resources leading to unsafe police encounters, overcriminalization and failed justice systems for people with autism

PROBLEMS WILL ONLY CONTINUE TO GROW WITH THE INCREASING PREVALENCE OF AUTISM

Autism has increased **461%** since 2004.



LIKE OTHERS, THE AUTISM COMMUNITY NEEDS AN ORGANIZATION TO DEFEND ITS CIVIL RIGHTS AND FIGHT FOR SYSTEMIC CHANGE



“MILLIONS OF INDIVIDUALS WITH ASD ARE CURRENTLY LACKING PROPER ACCESS TO HEALTHCARE AND EDUCATION. AS WITH OTHER CIVIL RIGHTS FIGHTS, LACK OF ACCESS TO THOSE TWO FUNDAMENTAL INSTITUTIONS IS THE WORST FORM OF INJUSTICE.”

Dan Unumb, Attorney & NALC Founder

TODAY, NO NATIONAL ORGANIZATION IS FOCUSED ON THE LEGAL NEEDS OF THE AUTISM COMMUNITY

SOME ORGANIZATIONS FOCUS ON SUPPORT AND ADVOCACY FOR ASD



OTHERS PROVIDE LEGAL SUPPORT TO PEOPLE WITH BROAD DISABILITIES



WE WILL FILL THIS GAP.

THE NATIONAL AUTISM LAW CENTER WILL PROTECT AND EXPAND THE RIGHTS OF MILLIONS OF INDIVIDUALS WITH AUTISM

OUR MISSION

To enforce and expand the legal rights and protections for individuals with autism, providing support for them and their families, as well as the service providers and attorneys who assist them.

We will do this through:

- Impact litigation
- Public Policy/Advocacy
- Technical assistance and education
- And collaborating with other ASD support organizations

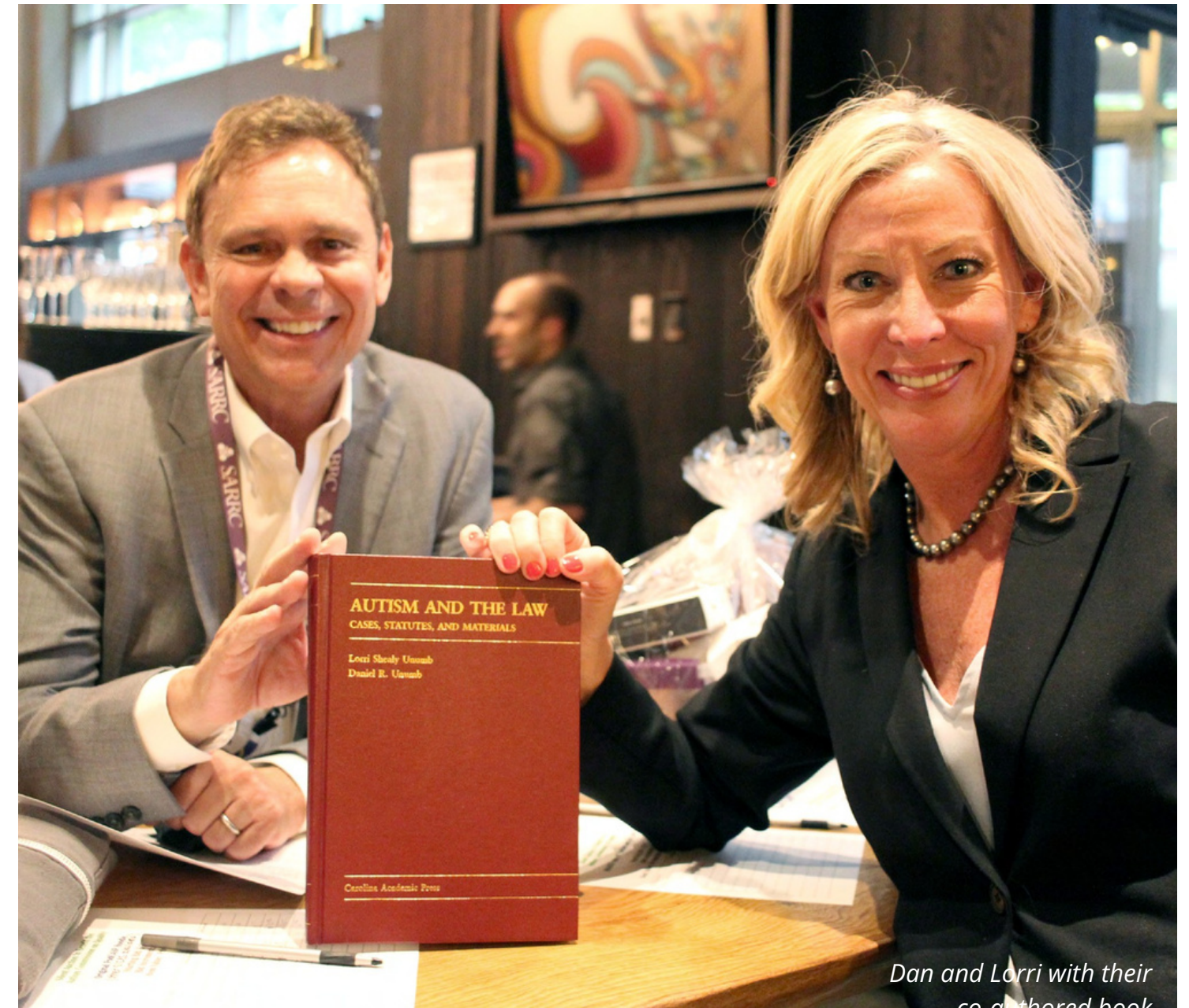
THE NALC WILL LEVERAGE THE EXPERIENCE OF LEADERS IN THE FIELD

Dan Unumb: Nationally Renowned Health Insurance Attorney, President and Founder of the NALC

Dan is one of the definitive voices advocating for autistic individuals in the U.S. In addition to his role as the litigation head of the NALC, he serves as President and Founder of the Autism Legal Resource Center, a national law firm serving autism stakeholders including autism service providers, state licensing boards and state associations as well as individuals with autism spectrum disorders and their families.

Co-authors Dan and Lorri Unumb wrote “Autism and the Law,” the only autism case textbook published in the US. Dan has also served as a subject matter expert in various publications, served on policy development panels, and provided legislative testimony and analysis.

Before beginning full-time autism advocacy, Dan was the Director of Litigation for South Carolina Legal Services, a 10-office, statewide legal aid program; counsel to a top 200 law firm; national class action counsel; and prior to that a trial attorney with the Civil Division of the U.S. Department of Justice where he practiced in federal district and appellate courts across the country.



Dan and Lorri with their co-authored book

THE NALC TEAM WILL HARNESS WIDE EXPERTISE AND COLLABORATE WITH OTHERS

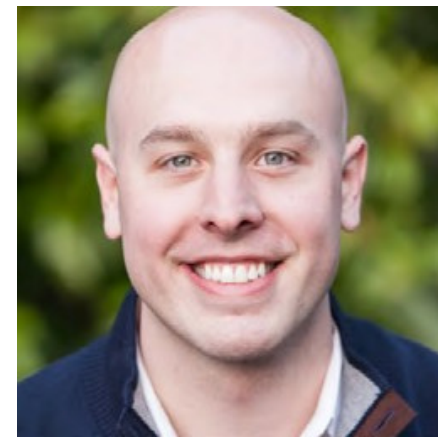
BOARD



Dan Unumb, J.D.
Founder and President of NALC



Michele Trivedi, MHA
Groundbreaking activist for healthcare coverage and the rights of autistic individuals



Keith Laabs, MBA
CEO at the Carolina Center for ABA and Autism Treatment



Amie Perl, MBA
Former SVP of Operations Little Leaves Behavioral Services

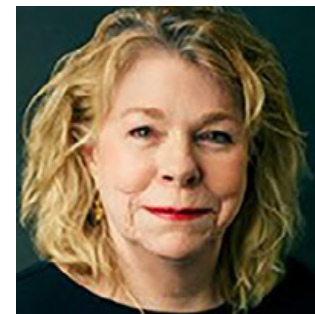


Sonja Kerr, J.D.
Renowned special education attorney

ADVISORY BOARD



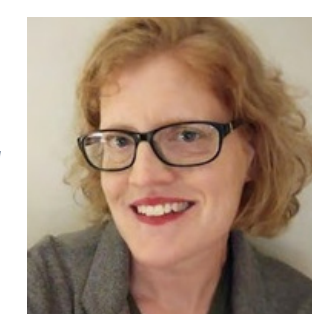
Lorri Unumb, J.D.
Internationally acclaimed advocate, former Vice President of State Government Affairs at Autism Speaks, current CEO at The Council of Autism Service Providers



Jane Howard, Ph.D.
Founder of Therapeutic Pathways and Professor Emeritus (Psychology) at California State University, author of numerous influential studies on autism treatment



Somer Bishop, Ph.D.
Associate Professor, Department of Psychiatry Director of Research, The UCSF Center for ASD & NDDs. National expert in assessment, diagnosis, and treatment of individuals with autism spectrum disorders

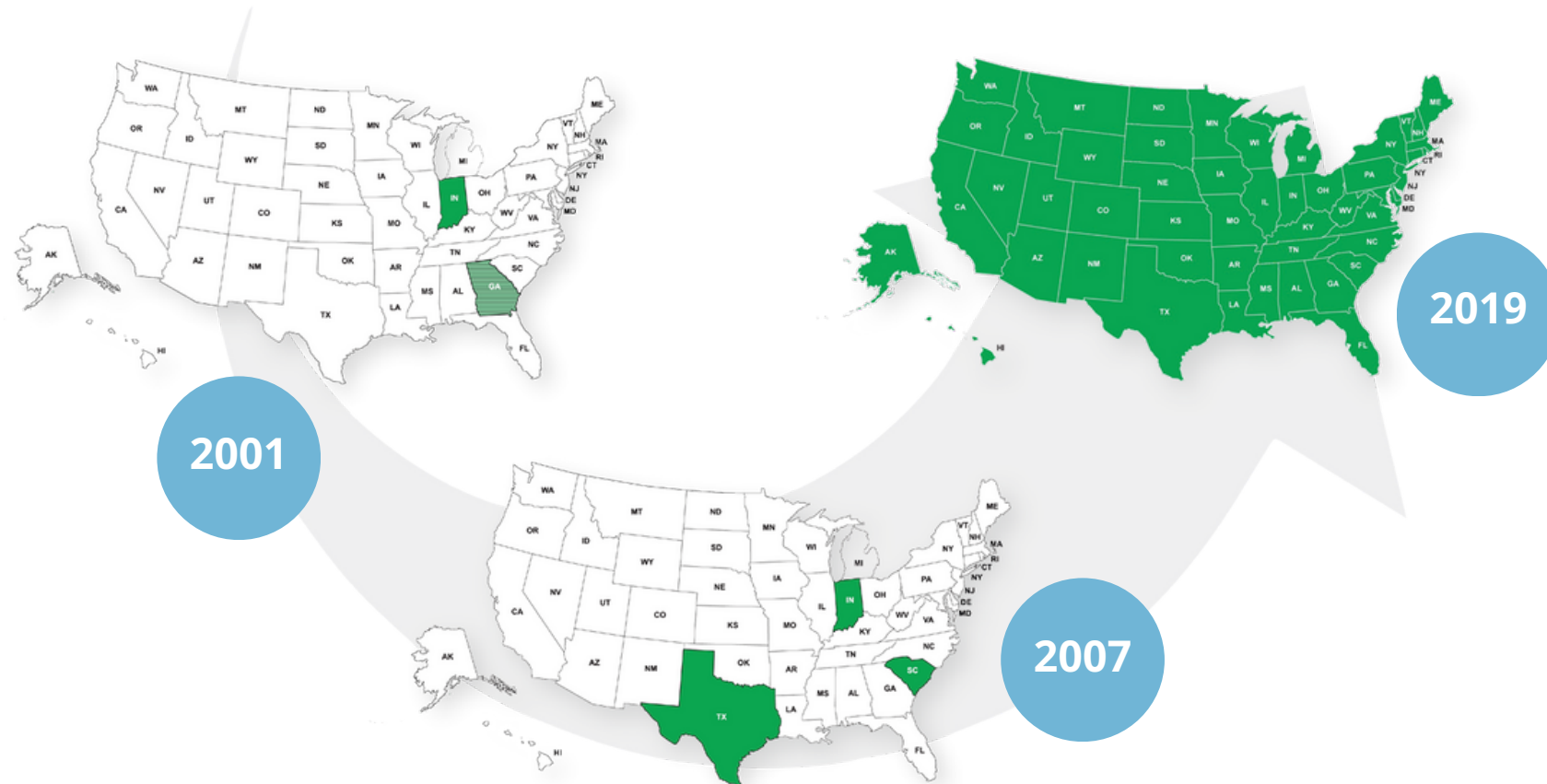


Katie Dzurec, J.D.
Former assistant counsel to the Pennsylvania DOI commissioner and former Chair, Mental Health Parity Working Group, National Association of Insurance Commissioners

AND CONTINUE THE WORK OF A TEAM THAT KNOWS HOW TO DRIVE SYSTEMIC CHANGE

✓ Autism Insurance Reform

Our progress in securing autism insurance reform in all 50 states



✓ Major Corporate Reform

We have secured elimination of financial limits, age caps and other restrictions on autism coverage in self-funded employee health plans of major companies and major hospital systems



✓ Medicaid Coverage in All 50 States

Coverage for autism services expanded to Medicaid eligible children to all 50 states, continuing work on barriers and access issues and expansion of coverage to adults

✓ The Autism Law Summit

Originated by Dan and Lorri in 2007 as an informal gathering of parents and other “doers” in the autism field, the Summit has become the annual “go to” event for autism advocacy

✓ The Autism Attorney Summit

Started by Dan in 2014, this annual meeting of attorneys brings together key attorneys, working on cutting-edge litigation to improve the lives of people with autism

THERE ARE COUNTLESS ISSUES TO ADDRESS

HEALTHCARE

Despite recent progress, there is much more to do to ensure adequate healthcare and insurance coverage

- Many families still find that there are gaps and exclusions in insurance coverage, especially self-funded and small business plans
- Adult insurance coverage is often lacking or, in many cases, completely non-existent
- Improper treatment limitations, barriers to appeals and inadequate networks still limit or delay coverage
- Low Medicaid reimbursement rates in many states make treatment inaccessible for many who rely on government funded insurance

EDUCATION

Children with autism almost universally suffer from inadequate support and discrimination in the education system

- Despite the obligation to provide a free and appropriate public education, many schools still fail to provide adequate and available supports that allow children with autism to access the school environment
- Continued silos between healthcare and education impose incalculable costs to the individual in lost functioning and huge financial and societal costs
- Teaching that truly supports autism is an emergent field that desperately needs money and resources to flourish

HOUSING

Lack of appropriate housing options is a reality for most adults who are materially affected with autism; lower income families have few suitable options

- Well-intentioned but poorly written and interpreted “settings rules” deter construction of communities designed for individuals with autism, particularly those serving individuals with Medicaid funding
- Reimbursement rates are typically woefully too low to be sustainable given the specialized training and staffing levels needed
- A relatively small number of families with financial means can access specially-designed residential settings, while the vast majority lingers on years- or decades-long waitlists for the few beds that do exist in sub-par housing options

EMPLOYMENT

Adequate accommodation of autism in the workplace is extremely lacking, with the vast majority of people with ASD being unemployed or underemployed

- Most workplaces still have no idea how to accommodate individuals with autism
- Discrimination and significant Americans with Disabilities Act violations in the hiring process are common
- Notwithstanding laws intended to benefit people with disabilities, vocational rehabilitation agencies and other organizations that help people with disabilities get jobs often fail to have adequate personnel and programs to deal with the specific needs and challenges of people with autism

CRIMINAL JUSTICE

The criminal justice system continues to present a considerable risk to the health, safety, and liberty of individuals with autism

- Difficulty communicating, understanding social cues, and responding to orders makes interaction with police extremely problematic and potentially lethal
- Current law is not designed for individuals with these difficulties, and is often unforgiving
- Criminal justice is inseparably linked to both healthcare and education, as individuals with autism often struggle to understand social norms and may not receive the education they need to progress in these areas

OUR INITIAL FOCUS

HEALTHCARE

- Continue to fight for coverage of evidence-based, medically necessary services
 - Remove age and spending caps
 - Remove exclusions for small group and individual plans
 - Ensure accessible alternative coverage for individuals covered via self-funded plans
- Ensure access to services is not inappropriately withheld (e.g. litigate mental health parity law violations)

EDUCATION

- Ensure that access to medically necessary services are not prohibited due to the school setting
 - Require schools to allow services (and providers) into the school setting
 - Require health insurance payors to allow school as a setting for services
- Clarify expectation of schools under IDEA and ADA standards through case law (i.e. litigate IDEA and ADA violations)

HOUSING

- Add detail and clarity into “settings rule” at federal and/or state levels to remove barrier for projects hoping to serve individuals covered by Medicaid
- Ensure reimbursement levels are sufficient to enable financially attractive projects that serve individuals across the spectrum
- Litigate when underfunding results in discrimination (e.g. excluding individuals with severe challenging behaviors)

WE NEED YOUR HELP

The expertise and leadership of pioneering figures like Dan and Lorri Unumb have already made a demonstrable difference to the lives of millions of individuals with autism. But there's still so much work to be done.

Solving issues this systemic and far-reaching takes considerable time, effort, and funding. If we're going to secure the future of autism advocacy in the U.S., we need to build a sophisticated organization designed to lead this fight.

THE NALC IS SEEKING FUNDING TO:

- **Hire attorneys and key staff** in 5 key areas (healthcare, education; housing, employment, criminal justice) to direct and manage litigation, legislation, and advocacy
- **Broaden our base of co-counsels** on the ground in each state
- Facilitate the **wide-scale training of attorneys** to develop a better understanding of how autism is impacted in each of these areas of law
- Create a **litigation fund** that will support individuals, families and attorneys willing to bring select cases
- **Author white papers and information releases** for decision makers (courts, legislators)
- Provide practical and accessible **resources for parents**




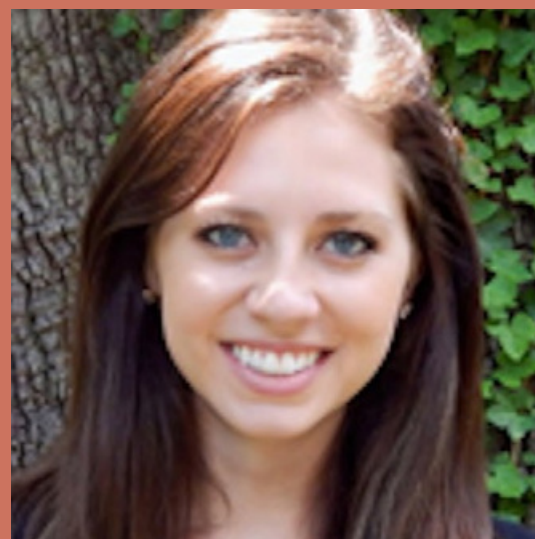
GET IN TOUCH NOW TO FIND OUT MORE ABOUT THE NALC, OR TO SCHEDULE A MEETING WITH OUR TEAM



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