

**Policy for a Singular Neurodevelopmental Disorder: A Multiple Streams
Analysis of the Combating Autism Act of 2006 Using Kingdon's Framework**

By

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A Multiple Streams Analysis of the Combating Autism Act of 2006

Abstract

Issues: The Combating Autism Act of 2006 (CAA) is a single-disorder law for the population with autism spectrum disorder (ASD), one of six neurodevelopmental disorders (NDDs). All NDDs have common origins, overlapping symptoms, and lifelong adverse individual and societal impacts. Yet, no analogous policy exists for the other NDDs. The inequity between related disorders is a curiosity, and moreover, it results in health and economic inequities with devastating consequences. This analysis examines the conditions that led to the CAA. **Analysis:** Conditions leading to the CAA were analyzed using Kingdon's Multiple Streams Framework. Problem, policy, and politics streams were studied through a literature review, conduct of key informant interviews with six experts, one autistic, in disability policy with a collective 189 years of experience, and qualitative analysis of the resulting transcripts. **Lessons:** America's political will drove the CAA most and, in turn, was influenced by powerful people, timely science, and antagonistic cultural mores. President Kennedy's 1963 "National Plan to Combat Mental Retardation" laid the foundation. Stigmatization of mental disorders and a lack of data equity have contributed to unequal attention and care for people with other NDDs. **Implications:** The social model of disability would attune the public and policymakers to the experience of people with mental disorders and reveal ways to deconstruct and destigmatize disabilities. Humane leadership rooted in the social model provides relief. It reduces fear, enabling increased empathy and the political will needed to enact equitable, empowering policy for all people, including those with NDDs. Further, awe and wonder may be leveraged to unite people and build political will.

Introduction

The tangle of US policies around mental disorders results in ineffectual care and inequities for Americans. Though policies have proliferated over the last 60 years, the US is experiencing a mental health crisis, especially for adolescents, and girls in particular.¹⁻⁴ All children experience challenges as they grow up. Still, for some, the path is extra difficult because of neurodevelopmental disorders (NDDs) that cause impairments in learning, moving, organizing, and connecting with others.⁵ NDDs include six categories: attention-deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), social communication disorders (SCDs), intellectual disability (ID), motor disorders (MDs) (e.g., Tourette's), and specific learning disorders (SLDs) (e.g., dyslexia).⁶ Unfortunately, inequitable policy protections for people with NDDs have left carers, including parents, educators, and healthcare providers, underprepared to recognize and treat some of them, such as ADHD, while focusing intently on others, such as ASD. Further, parents may not have the means to navigate, advocate for, and afford the required educational and healthcare services. Left unrecognized, the severity of impairments from NDDs can worsen and cause other problems across the socio-ecological spectrum and lifespan.⁷⁻¹⁴

Like a snowball rolling downhill, undiagnosed and undertreated NDDs tend to accumulate other mental health problems. The risk accumulates for adverse sequelae the longer children and parents with NDDs struggle without proper help. Epidemiological evidence has shown that ADHD is a predictor of anxiety, depression, isolation, and further downstream substance misuse, academic failure, incarceration, unplanned pregnancy, low socio-economic status, and suicide.^{11,14-17} Worse, diagnostic and treatment disparities exacerbate poor outcomes for females and certain races.^{18,19} In the US, ADHD affects more than three times the number of

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children with ASD^{20,21} at an estimated annual cost of more than \$156 billion.^{22–24} Nevertheless, a vast policy gap leaves these families without protections like destigmatization, adequate diagnosis, and evidence-based care. Alternately, children with ASD and their families receive substantial support under the Individuals with Disabilities Education Act (IDEA).^{25–28} Further, the 2006 Combating Autism Act (CAA)²⁹ funded research, data surveillance, an executive branch agency-level committee, and healthcare infrastructure development, all dedicated to ASD. The latter was renamed the Autism Collaboration, Accountability, Research, Education and Support, or CARES Act in 2014,³⁰ has been reauthorized thrice, and currently permits \$369.7 million for ASD-dedicated programs annually. Since 2006, both versions of this law have appropriated more than \$3.1 billion to protect children and families with autism. Children with ADHD receive far fewer protections from IDEA²⁷ if they receive them at all, and there is no analogous CARES³⁰ policy for ADHD and other NDDs.

The science of NDDs has evolved significantly in the 17 years since the CAA²⁹ was adopted, confirming their relatedness and adding Social Pragmatic Communication Disorder (SPCD) as a stand-alone NDD.⁶ Additionally, a set of common genes has been identified, variants of which link ID, ASD, and ADHD, and suggest that other disorders such as epilepsy and bipolar are also related.^{31–33} Finally, evidence^{11,12,14,34–37} has shown that unrecognized NDDs significantly adversely impact families, communities, and society. This point is especially salient for people with “invisible” or “hidden”^{38,39} NDDs, such as some forms of ASD and ADHD, SPCD, dyslexia, and others. Hidden NDDs are those with symptoms that cause impairments for the people with them but which are not apparent to others and, therefore, carry greater risk of going untreated.^{37,40–42} People with them often expend inordinate energy on managing their impairments so that they can function at school or work, leaving them with reduced capacity to

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engage socially and civically.³⁹ In turn, this can lead to their isolation and accumulation of mental health problems.³ Equipping parents and other carers with training, evidence-based interventions, and adequate cost coverage for therapies capitalizes on the opportunity to prevent emotionally and financially costly downstream crises and provide children and families with an equitable chance of reaching their potential. In this vein, all NDDs are valid and compelling policy priorities.

Following this logic, two compelling questions are how the US reached 2023 without equitable policy protections for the population with all NDDs, and how to develop a successful policy strategy. To begin answering them, it is first necessary to understand the historical context, salient events, and people that led to the landmark single-disorder CAA²⁹ in 2006. This analysis utilizes John Kingdon's⁴³ Multiple Streams Framework (MSF) to explore the research question, *What conditions led to policy for ASD as a singular disorder?* Understanding how ASD was defined as an issue, coupled with the CAA,²⁹ and elevated to the Congressional decision agenda, is the first step in responsibly improving health policy equity. A multiple streams analysis of the CAA²⁹ was not found in the literature search for this project. Therefore, it will add a novel perspective to the body of evidence that decision-makers may use to avoid unintended adverse consequences for the population with ASD while improving policy equity for children and families with other NDDs.

Background

Nosology: Classifying Mental Disorders, Developmental Disabilities, and Neurodevelopmental Disabilities

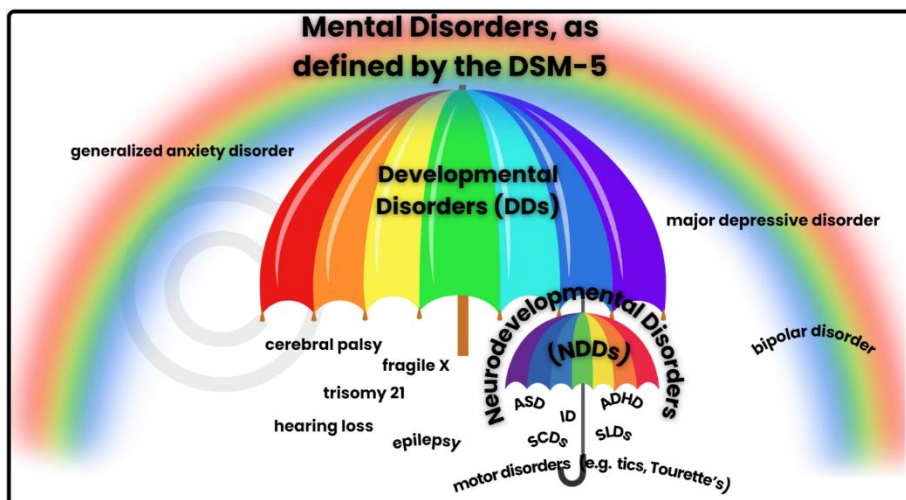
In the US, the classification, or nosology, of mental disorders by different people and jurisdictions results in confusion and the perpetuation of stigmatization of people with mental

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illnesses. Terms may be used to give preferential treatment to one condition over others or to elicit a desired reaction about a condition or people with it. For example, when IDEA²⁷ gave ASD its own learning disability category, it separated it from other mental disorders, thereby helping to destigmatize it but further marginalize other NDDs, like ADHD, in the process. Policy equity depends on the neutrality of terms and consistency with the accepted diagnostic standard.

Mental illness is the converse of mental health, and regardless of the popular and political conceptualizations and terms, the American Psychological Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders* (DSM®) is the standard of diagnosis in the US. All conditions within it fall under the classification of mental disorders. Developmental Disorders (DDs) are a group of mental disorders defined as having childhood onset and resulting from atypical psychological or physical development.⁶ NDDs are a subset of DDs that may be attributed to known genetic, environmental, or biochemical factors and for which there is a marked overlap of symptoms.^{5,31,33} Most are chronic throughout the lifespan.^{5,31,33} Figure 1 is a visual representation of the nosological groupings.

Figure 1: Nosological Groupings of Mental Disorders, Developmental Disorders, and Neurodevelopmental Disorders in the DSM®-5⁶



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Acknowledging the high degree of overlap between NDDs and their symptoms is salient to improving health equity among the population with NDDs. This overlap causes people with NDDs to experience many of the same health problems, such as gastrointestinal distress and disordered sleep, regardless of their primary diagnosis.^{5,31,33} Further, researchers⁵ have recognized that the cumulative symptom burden of co-occurring NDDs is debilitating, irrespective of whether symptoms meet the DSM®’s threshold diagnostic criteria for individual NDDs. Notably, they assert that while research definitions of NDDs should remain disorder-related, people with NDDs should be treated according to their symptom burden rather than a diagnostic label.⁵ Therefore, preferential policy for one NDD over others ignores the fact that the population with other NDDs experiences many of the same symptoms as those with ASD. Further, it is possible for a person with other NDDs to have the same or higher symptom burden as someone with ASD yet lack equivalent policy protections because their primary diagnosis is not ASD.

The US Diagnostic and Disability Disadvantage

Mental disorders and the disabilities caused by them are defined separately in most of the world, but in the US, they are conflated. In the US, the American Psychiatric Association (APA) sets out diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders⁶ (DSM®) based on a combination of symptoms and functional disability. At the same time, the World Health Organization’s International Classification of Diseases⁴⁴ (ICD) and International Classification of Functioning, Disability, and Health⁴⁵ (ICF) are used in most of the world.^{25,26,46} This creates tension between international experts endeavoring to research and develop equitable and standardized interventions for NDDs.^{25,26} The DSM® ties diagnosis, or “clinical significance,” to functional impairment and distress of an individual but leaves determining the

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diagnostic threshold open to the interpretation of the diagnostician.⁴⁶ Alternately, the ICD and ICF keep the diagnosis of mental disorders separate from the classification of disability, and the ICF does not include the term “functional impairment” as part of classifying the latter.⁴⁶ Instead, a diagnosis is rendered according to symptoms, and disability is recognized separately as impairments to 1) bodily functions, 2) limitations to daily activities, and 3) restrictions on participation in society.⁴⁶ Therefore, Americans suffer a preventive health disadvantage compared with most of the world. In the US, someone with an NDD (or other mental disorder) remains undiagnosed until their symptoms and impairments interfere with their ability to function. By the time the problem is identified, primary prevention of impairments has already been foregone. Secondary prevention to minimize the severity of impairments and further adverse outcomes is a reactive process that must counteract impairments that have already taken root and are resulting in deficits. In contrast, where the ICD and ICF are used, diagnosis and treatment of symptoms can begin before the condition leads to impairment.

American psychiatric diagnosis and care are biased away from preventing disabilities and reducing their severity, especially for disorders with symptoms and impairments that are not easily seen. Moreover, while the DSM® is the medical community’s diagnostic standard, US policymakers can nevertheless specify qualification criteria for federal policy protections based on a policy’s definition of disability. Adding to the complexity, private insurance companies and Medicaid commonly add layers of administrative, diagnostic, and treatment hurdles that patients must clear before coverage is granted for a given condition, and even then, it is typically limited to evidence-based therapy deemed medically necessary. The result is a fractured US system of mental health care that creates unnecessary administrative barriers and perpetuates biases

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because it is more policy-centered than patient-centered. This is an integral part of the context within which the CAA²⁹ arose.

Prevalence and Cost

Data has not been collected systematically for ASD and other NDDs at the national level, making prevalence studies challenging. Researchers must pore over statistics from various surveys and other sources that offer data for differing age ranges and definitions of disorder status (e.g., “ever diagnosed” vs. “currently diagnosed vs. “parent indicated,” etc.). Best estimates of prevalence trends for a disorder must be viewed with discernment for the alignment of comparable data or the use of statistical methods to make it so. Early in the 20th century, ASD was thought to occur in only one out of 10,000 people, or 0.01%.^{25,47} However, with shifts in scientific understanding and diagnostic categorization and tools, the US has seen a steady rise in cases, with an increase from 0.4% of children in 1996 to 2.8% in 2020.^{21,47} Concurrently, the prevalence of ID and SLDs has plateaued as diagnoses became more sophisticated and ID was distinguished from other conditions.²⁶ When a newer diagnosis replaces an outdated one, it is called diagnostic substitution. While replacing MR with autism explains some of the increase in the prevalence of ASD, it is not believed to account for all of it.^{25,26} Likewise, the prevalence of ADHDⁱ has steadily risen, with an increase from 6.1% to 9.8% between 1997 and 2019.^{20,48}

In 2006, when the CAA²⁹ was adopted, the prevalence of autism was believed to be about 1:110 (0.67%).²¹ The total per-person lifetime cost was estimated at \$3.2 million, and the annual

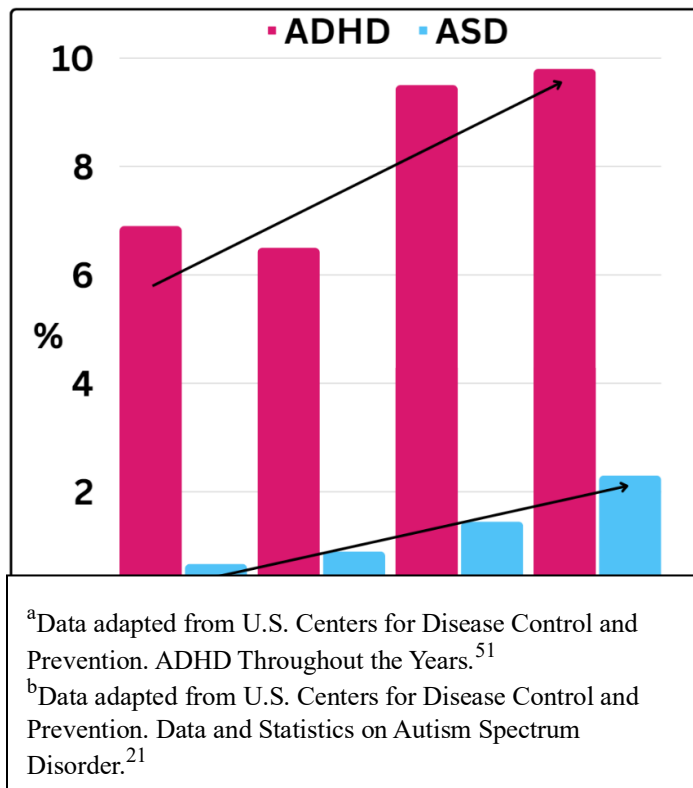
ⁱ For the purposes of the present analysis, I will rely on ADHD, another NDD with significant impacts on mental health, social connections, and work life,⁴⁸ as representative of hidden NDDs. SPCD only became a singular diagnosis in DSM®-5 (2014), so there is a lack of studies detailing its population health and economic outcomes. A discussion of outcomes for all other hidden NDDs is prohibitive given the time constraints of this project but is a suggested future research topic.

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US total direct and indirect costs of caring for individuals with autism were estimated at \$35 billion.⁴⁹ The predicted total annual cost to the US by 2025 is just over \$460 billion.⁵⁰

By comparison, ADHD had a 2005 prevalence of 4.5 to 7.6 times that of ASD, ranging from 3% to 5%.⁵¹ The annual US total of direct and indirect costs of caring for individuals with ADHD was \$31.6 billion,⁵² not far from the 2006 total for ASD. Two 2021 studies^{22,24} calculated the annual US cost of adult, adolescent, and child ADHD to be \$122.8 billion, \$13.8 billion, and \$19.4 billion, respectively. The resulting total is \$156 billion annually. While this cost is less than the cost for ASD, it is nevertheless significant enough to warrant policy attention. Approximately 3.6 times the number of families are affected by ADHD than by ASD.^{20,21} ADHD prevalence and cost estimates are likely understated, and direct comparison with ASD-related costs is impossible due to the lack of consistent data collection for ADHD.

Figure 2: ADHD^a & ASD^b Prevalence, 2000 to 2018



History and Policy

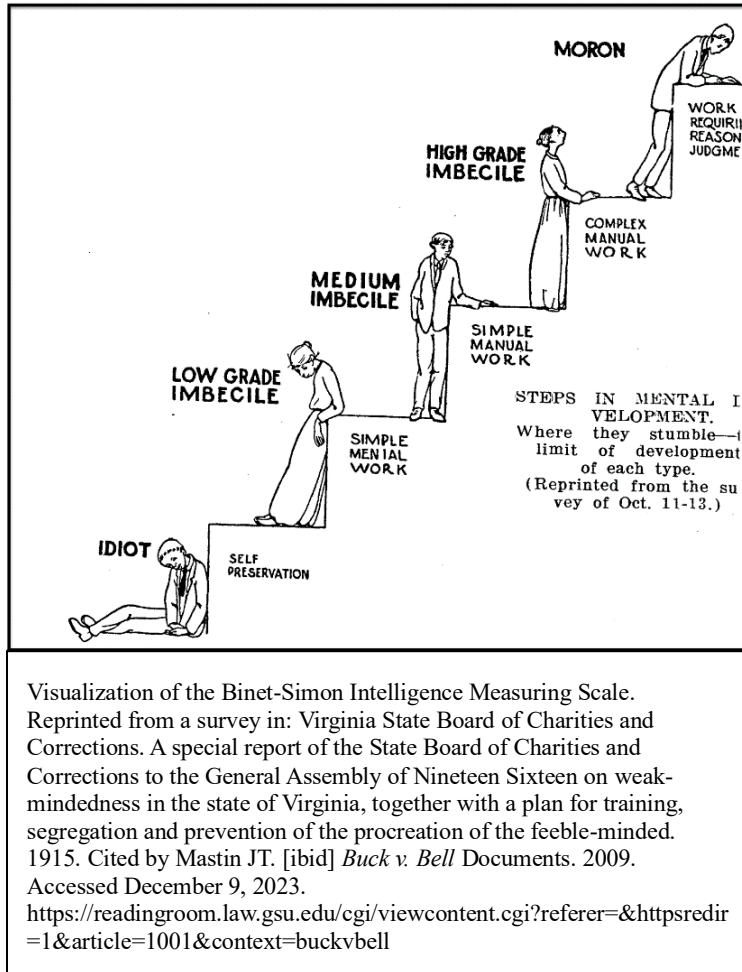
Mental Illness Stigma and Institutionalization

American societal norms oppress people with mental disorders and those that care for them. Though the DSM®-5's⁶ diagnostic criteria for NDDs appeared in 2014, the record of NDD symptoms dates back to the 1800s.^{31,53,54} The market economy, as Europeans touted it in the 17th and 18th centuries, was supposed to encourage community and enculturate empathy.⁵⁵ However, rapaciousness distorted those ideals, and science and medicine became susceptible to being used as tools for productivity.⁵⁶ Since then, lessons learned from cruel market practices, including slavery and institutionalization, have tragically instructed that governance and regulation of the market, not the market itself, define the level of empathy in a culture.^{55,56} The early 1800s separated psychiatry from physical medicine as a discipline, placing a new focus on the recognition of atypical thoughts and behaviors.⁵⁶ At that time, stigmatization of disabilities in cultures rooted in market economics became associated with a person's failure to exemplify the ideal worker.⁵⁶ Long before NDDs became a subset of DDs, people with DDs and other mental disorders were regularly isolated by doctors who advised parents to institutionalize them and by policymakers and law enforcers who saw people with mental disorders and other disabilities as defective and menacing to society.^{57,58} Parents had little choice but to comply with their doctor's advice because of social norms and because home and community-based programs for people with disabilities were rare and difficult to access.⁵⁶ Further, the stigma of having a child with disabilities likely kept parents from questioning medical providers and reaching out to one another, something still experienced today by parents of children with mental disorders. From the 1800s, people with DDs were categorized with labels including "morally feeble-minded," "idiot," "imbecile," and "moron," corresponding to a person's capacity for work.⁵⁸ America's

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deeply embedded values of capitalism and individual responsibility became entwined with mental illness stigma, devaluing the humanity of those labeled.^{56,58}

Figure 3: Binet-Simon Measuring Scale for Intelligence, Used Circa 1916



Americans with DDs and their families endured a particularly dark period of history from the 1920s through the 1950s, as they underwent forced sterilization, among other abuses and neglect by professional carers and policymakers who were supposed to center their best interests.⁵⁸

In the early to mid-1900s, the term “Mental Retardation” (MR) became a neutral substitute for other labels and was applied indiscriminately to people with a range of disabilities,

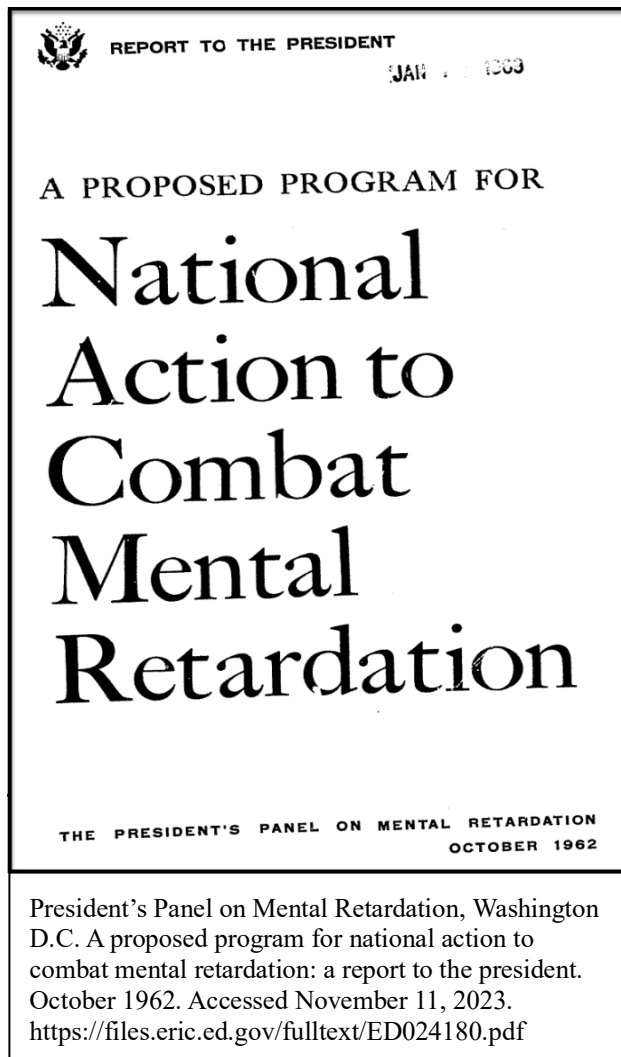
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including cerebral palsy, trisomy 21, communication problems, and more, regardless of their intelligence.^{56,58} By 1960, doctors were arguing for the lobotomization of people with MR as a cost-saving measure.⁵⁶ However, the Association of Retarded Citizens (now known as The Arc), a parent-driven advocacy organization, had formed in the 1950s and was gaining momentum.⁵⁹

Deinstitutionalization and Combating Mental Retardation

A personal connection to policy issues matters for policymakers, especially when they are in authoritative decision-making roles. Through it, they experience the issue and tend to be accepted by the public as an authority on its impacts. In 1941, Rosemary Kennedy, sister to Eunice Kennedy Shriver and John F. Kennedy, who had previously been diagnosed with mental retardation, was institutionalized after undergoing a failed lobotomy at the age of 23.⁶⁰ Eunice later assumed the leadership role at the Joseph P. Kennedy, Jr. Foundation in 1957, the goals of which aligned with those of The Arc to prevent MR by finding its causes and to improve society's treatment of people with it.^{60,61} Eunice played an instrumental role in advising her brother on the strategy for MR policy.⁶¹ Shortly after taking office, President Kennedy set up the Presidential Panel on Mental Retardation.⁶² On February 5, 1963, he presented to America his "National Plan to Combat Mental Retardation,"⁶³ in which he notably distinguished mental retardation from other mental illnesses to re-frame it and reduce its associated stigma.

Figure 4: Report to President Kennedy from the Panel on Mental Retardation, October 1962



Kennedy's plan sparked a turning point, prompting deinstitutionalization and emphasizing policy solutions for home and community-based services.⁶⁴ Further, psychiatrists and researchers worked to observe and group symptoms of mental disorders, discover etiologies, and understand impacts. This activity is reflected in successive editions of the DSM® that have increasingly differentiated the various disorders previously massed together as MR. US policymakers struggled to keep up with the swiftness of scientific revelations and their medical and social implications. Further, President Kennedy's assassination just nine months after

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initiating the national plan interrupted what should have been policymaking and public education to accompany such a seismic shift in American values and culture. Three models of disability still influenced the US policy stream: moral, medical, and social.^{56,65,66} The moral model echoes medieval times when a disability was viewed as inflicted by God due to the inadequacy of an individual.⁶⁵ It results in the stigmatization of disabled people. The medical model assumes that people with disabilities (PWDs) have limited autonomy due to their impairment. The natural consequence is their limited participation in society if they cannot be cured.⁶⁵ By its definition, it marginalizes disabled people. The social model of disability advocates for shifting social attitudes toward people with disabilities and removing social barriers to integrate as many PWDs into society as possible.⁶⁵

Kennedy had set the course to navigate away from America's moral and medical disability model mindset toward a more inclusive social one, but the post-Kennedy disability policy community floundered on this tack. The opportunity to align ideals and temper the myopic drive toward economic prosperity with the avoidance of moral injury and the sustainability of recognizing intrinsic human value was bypassed. Consequently, the current tangle of mental health terminology, provider specialties, executive branch agencies, policies, and standards is a product of differing interpretations, biases, and values. Americans, including those in the policy community, had not shed their internalized negative biases against disability, especially ones from mental illness, nor had they been given the tools to do so. For the public, especially those with mental disorders and their caregivers, the result was (and still is) confusion and administrative complexity that posed unnecessary and counterproductive barriers to diagnosis and care. Moreover, as is common in public policy, the mosaic of jurisdictions and

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roles meant to implement mental health policies created inertia and tensions when policy solutions were proposed, thereby perpetuating policy divisions and barriers to care.⁴³

ASD and ADHD Emerge

As mental retardation was parsed into discrete diagnoses, America began to understand that not all mental disorders involve ID. This created space to clarify and consider conditions such as ASD (known as autism before 2000), ADHD, and other NDDs. Autism symptoms were documented as early as 1911 but were associated with other mental disorders, including schizophrenia and MR.^{31,54} Before 1964, autism was thought to be caused by a lack of parental bonding with a child.²⁵ The term “refrigerator mother” was coined by Leo Kanner⁶⁷ and endorsed by Bruno Bettelheim,⁶⁸ the two most respected researchers at the time, to highlight a mother’s coldness to her child as a focal point of autism etiology. However, neither had empirical evidence to support the claim.²⁵ Just after JFK’s death, Bernard Rimland,⁶⁹ an influential research psychologist and father of a son with autism, re-oriented the paradigm when he described the condition as “infantile autism” and suggested a neurological etiology.

Concurrently, during the 1960s, Ivar Lovaas,⁷⁰ a clinical psychologist, began to develop behavioral therapy to “cure” autism. Research conducted in the early 1970s⁷¹ suggested that structured teaching approaches, like those Lovaas was working on, were more beneficial for autistic children than unstructured psychotherapy, used for treating other disorders, including schizophrenia. Rimland’s⁷² 1970 dissent to Bettelheim’s⁷³ popular but fraudulent 1967 book “The Empty Fortress: Infantile Autism and the Birth of the Self” seemed to close the etiological debate and create a paradigm shift for autism and developmental disabilities overall.²⁵ DSM®-III,⁷⁴ published in 1980, was the first to recognize autism as a singular disorder, consisting of six

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symptoms manifested in young children, such as developmental regression and self-imposed isolation that could last throughout their lifespan.

Lorna Wing,⁷⁵ a pioneer pediatric developmental psychologist, brought the 1944 scientific observations of Nazi pediatrician Hans Asperger⁷⁶ back into focus in 1981⁷⁷ as a form of “high-functioning” autism (HFA), also referred to as Asperger’s Syndrome, which garnered growing attention over the next decade. In 1985, research⁷⁸ was published identifying specific brain abnormalities associated with autism, substantiating Rimland’s assertions and confirming the viability of potential cure- and prevention-related policy solutions. Lovaas then published articles about Applied Behavioral Analysis (ABA) in 1987⁷⁹ and 1993,^{80,81} claiming close to a 50% cure rate for toddlers with autism who underwent his intensive one-on-one therapy for 40+ hours per week. Serendipitously, between those two publication dates, the Autism Diagnostic Observation Schedule (ADOS)⁸² and the Autism Diagnostic Interview (ADI)⁸³ began to be utilized, hastening the frequency of autism diagnoses. Then, in 1994, autism diagnostic criteria were widened when the DSM®-IV-TR⁸⁴ included Asperger’s Syndrome in the diagnosis and defined the diagnostic threshold with a given number of symptoms from any of three domains. As autism diagnoses increased, a growing population of parents of autistic children sought a cure. The allure of ABA (i.e., up to 50% cure rate) led parents to face financial hardship or sue schools to cover its costs.^{25,26} Conversely, others without the financial means to pay for this expensive therapy had to forego treatment for their autistic children.

A 2000 revision of DSM®-IV⁸⁵ tightened diagnostic autism criteria by requiring the threshold to be met with symptoms from all domains rather than one or another. DSM®-5⁶ tightened them further by removing Asperger’s from what it named “autism spectrum disorder”

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and classifying a combination of specific symptoms as either ASD 1, 2, or 3, representing increasing severity of impairments associated with the symptoms. Finally, DSM®-5⁶ differentiated social pragmatic communication disorder (SPCD) and allowed the co-diagnosis of other NDDs, such as ADHD, with ASD. The ongoing evolution of autism science has nevertheless kept Kanner's description of its nucleus of symptoms as the accepted standard.⁸⁶

Like autism, ADHD was documented by experts historically, but because of its more subtle impairments, the symptoms, diagnosis, and treatment were controversial. Symptoms of ADHD were first published in 1775,^{31,53} and were associated with MR. In the early 1900s, the conceptualization of ADHD began to separate from MR. In 1932, Kramer and Pollnow⁵³ established symptoms for "hyperkinetic disease of infancy" that are similar to today's diagnostic criteria for ADHD. From the late 1950s to the early 1980s, ADHD was believed to stem from brain injury or asphyxia, and the group of symptoms was labeled "minimal brain damage" and then "minimal brain dysfunction."⁵³ However, critics pointed out that the symptoms were not present in some people with known brain damage and dysfunction.⁵³ The discovery of stimulants as effective medications for ADHD originated in the 1930s from unethical scientific circumstances.⁵³ This contributed to their negative public image, the portrayal of parents who considered their use as "overreacting,"⁸⁷ and drug makers as villainous predators capitalizing on schools' and parents' drive for achievement.⁸⁷⁻⁹³ ADHD has remained a contentious topic. Diagnostic criteria have been disputed, pharmaceutical companies accused of manufacturing ADHD, children with ADHD portrayed as simply disrespectful and undisciplined, and parents of children with ADHD judged for their lackadaisical boundary-setting.^{40,88,89,94-99} ADHD and SPCD were recognized as NDDs in the DSM®-5,⁶ published seven years after the CAA's²⁹ adoption.

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The Civil Rights and Disability Rights Movements

After deinstitutionalization, affirming constitutional civil liberties was the next logical step for people with disabilities. The Civil Rights Act of 1964¹⁰⁰ was an important milestone, reaffirming that 14th Amendment¹⁰¹ rights applied to all American citizens. People with disabilities mobilized.¹⁰² Two court cases^{103,104} resolved in 1972 determined that children with DDs were to be included in school. Both cases were decided using the precedent case, *Brown v. Board of Education*,¹⁰⁵ a 1954 Supreme Court case that barred racial segregation of schoolchildren.²⁵ From then on, a free and appropriate public education (FAPE) was constitutionally mandated for children with disabilities, and schools began to experience financial pressure stemming from compliance with the law.^{25,102} Further, this marked another entry of people with disabilities into society where they had been absent. Educators and parents were unprepared to adapt themselves, the classrooms, and non-disabled students' attitudes to the principles and values of inclusive education.^{25,102} Negative assumptions were made about the intellectual abilities of children with disabilities, resulting in curricula that lacked appropriate educational rigor for students capable of achievement given assistance with overcoming societally imposed barriers.¹⁰² In 1973, the Rehabilitation Act¹⁰⁶ was passed, with Section 504 partially codifying the rights of disabled persons by mandating their inclusion in the benefits and services of all federal programs. The Children's Defense Fund, a national children's advocacy organization, was also formed in 1973 to advocate for further de-institutionalization of the 760,000 children still being kept away from their homes and families.²⁵ In 1975, the Developmentally Disabled Assistance and Bill of Rights Act (DD Act)¹⁰⁷ brought landmark legislation that required states to set up protections for people with severe impairments from DDs. The Education for All Handicapped Children Act¹⁰⁸ (EAHCA, now the Individuals with

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Disabilities Education Act, or IDEA²⁷) was adopted in the same year, codifying FAPE, regardless of the severity of a student's disability. EAHCA¹⁰⁸ was judicially upheld in test cases in 1982¹⁰⁹ and 1989,¹¹⁰ and was reauthorized as IDEA¹¹¹ in 1990. Nevertheless, IDEA^{27,111} appropriations in the years since have been consistently substantially lower than the 40 percent of per-disabled-pupil costs authorized under the bill.¹¹² Mandated FAPE without the funding to support state and local schools' efforts to comply created enormous strain on educational budgets.

The 1990 revision of IDEA¹¹¹ created a new learning impairment category for autism, benefiting the autism community in three important ways. First, it distinguished autism as a developmental disability over a mental disorder, reducing the stigma associated with it.^{25,26} Second, it provided a broad array of other health assessments for children who met an educational determination of autism.^{25,26} Third, it mandated prevalence and cost reporting specifically for autism from all local school units, providing the public with ready access to these figures.^{25,26} This was another watershed moment for ASD because it enabled public access to reliable prevalence and cost data that had been unavailable before. IDEA¹¹¹ data for ADHD, on the other hand, remained aggregated with that of numerous other conditions in the Other Health Impaired (OHI) category. Using data from the Department of Education (DoE), news stories about autism became more frequent¹¹³ and began to use the term "epidemic."^{25,114}

Finally, the Americans with Disabilities Act¹¹⁵ (ADA) was passed in 1990, forbidding organizations and employers from discriminating against people with disabilities (PWD), regardless of their funding source. In addition to workplace considerations, the ADA created another boundary for schools as an added avenue to pursuing FAPE. In 2005, the US General Accounting Office (GAO) reported¹¹⁶ a 500% increase in autism over the prior decade and an

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annual per-pupil cost of \$18,000, more than three times that of students without special education services. This portended a financial disaster for American schools based on past autism trends and relative to Congress's assumed cost of two times that of educating abled students when EAHCA was passed in 1975.²⁵

Advocacy, Urgency, and Hero Parents

While protections from discrimination were considerable progress for people with DDs, families of children with ASD and their advocates pushed further toward policy focused solely on their needs. The matrix of people, expertise, wealth, and political power grew as the prevalence of autism rose through the 1990s. Moreover, the burgeoning internet served as a connector.²⁵ Parent and self-advocate networking started with a 1992 listserv created by a parent of an autistic child.²⁵ Parents of autistic children became known anachronistically as “autism parents,” though they did not themselves have autism. In 1995, Hollywood celebrities with an autistic son founded a group called Cure Autism Now (CAN) and began a campaign to raise awareness and money to fund research for an autism cure.²⁵ They enlisted the help of fellow celebrities, and even ones without autistic family members joined, testifying at Congressional hearings and making public appearances on behalf of finding a cure for autism.²⁵ Parent networks became numerous advocacy groups, including the National Alliance for Autism Research (NAAR), the Autism Society of America (ASA), and CAN.^{25,26}

The early 2000s brought substantial growth and publicity to autism advocacy. Autism Speaks, the group commonly credited with propelling autism advocacy forward with considerable funding and social capital, was founded by Bob Wright and his wife, Suzanne, who had an autistic grandson.^{25,117,118} Describing their strategy in a retrospective interview in 2012,

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Suzanne stated, “[We said]...when the AIDS epidemic started, people were afraid. We need to make this as big as that. Everyone in the world should be concerned.”¹¹⁹

Starting in 1990, educational determinations of autism began to spike after the initiation of ADOS⁸² and ADI⁸³ as diagnostic tools, while concurrently, ID determinations declined.²⁶ Meanwhile, Ivaar Lovaas’s research publications^{80,81} and the 1994 book “Let Me Hear Your Voice”¹²⁰ by Catherine Maurice, her story of “saving” her daughter from autism using Lovaas’s ABA treatments, amplified the urgency felt by parents of autistic children to obtain the costly therapy as early in their child’s life as possible.¹²¹ Insurance companies initially balked at its high cost and deemed it “not medically necessary.”¹²² However, parents prevailed in IDEA¹¹¹ due process court challenges, and its coverage became increasingly common.^{25,26,121} Then, starting in 2001, a wave of state mandates for private insurance coverage of ABA were adopted in 46 states.^{123,123} Nevertheless, mandates varied in their coverage from state to state¹²³ and families of autistic children were paying out-of-pocket fees for insurance deductibles and copays, behavioral and other services not covered, supplements, special diets, and other alternative treatments.^{25,26} Further, parents of autistic children found themselves pushing down confusion, frustration, shame, and guilt about having a child with complex needs while trying to simultaneously work, nurture families, and conduct their daily lives.²⁶ The internet allowed news and information to spread more quickly than it had been able to through other channels such as newspapers and television, and advocacy groups deftly used it to access new members and broadcast their messaging.²⁵ The overtones of media and internet autism framing were largely about the devastating consequences of autism for families and the heroic warrior parents and grandparents who cared for children with it.^{25,26,117,124–126}

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Between 1990 and 2007, the prevalence of autism increased significantly from 1:2,000 people to 1:150.⁴⁷ Referring to an autism “epidemic” became increasingly common in the news media during that time.^{25,26} In 1998, residents of Brick, New Jersey, brought their concern about a perceived unusually high prevalence of autism in their community to Representative Chris Smith (R-NJ).²⁵ The Centers for Disease Control and Prevention (CDC) investigated at Smith's request, concluding that the prevalence was within the normal range found in other studies of small communities.¹²⁷ Nevertheless, Representative Smith continued to focus on autism and sponsored Title I of the 2000 Children’s Health Act,¹²⁸ Autism Statistics, Surveillance, Research, and Epidemiology Act (ASSURE), which formed the Interagency Autism Coordinating Committee (IACC), established US regional centers of excellence in autism epidemiology, and mandated autism surveillance by the CDC. Additionally, Smith co-founded the Coalition on Autism Research and Education (CARE) in 2001, a congressional member organization solely focused on autism, otherwise known as the Autism Caucus.²⁵ IACC membership included US Department of Health and Human Services (HHS) agency heads alongside parents of autistic children and was designed to authorize funding for NIH research on US children’s health from before conception to age 21 years, with a particular focus on autism research.¹²⁸ In 2006, the IACC was reauthorized and chartered as a federal advisory committee under the CAA,²⁹ with the broad mission to coordinate all autism-related activities within HHS and monitor autism-related activities conducted within all federal departments and agencies to avoid redundancy of efforts and to report to Congress annually on autism research progress and strategy.¹²⁹ The IACC currently includes the Directors of the NIH, CDC, and other agency heads as determined by the Secretary of HHS to be appropriate, such as NIMH, the Administration for Community Living

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(ACL), and the Centers for Medicare and Medicaid Services (CMS), as well as family members of individuals with autism and autistic individuals.¹²⁹

The False Vaccine-Autism Link

In 1998, Andrew Wakefield,¹³⁰ a British researcher, published a study in *The Lancet*, a prominent medical journal, associating bowel symptoms and the onset of autism with the measles-mumps-rubella (MMR) vaccine. The article was retracted when *The Lancet* learned that Wakefield's facts and science were faulty and that his research was partly funded by a legal firm prosecuting a case against vaccine manufacturers, which Wakefield had not disclosed.^{25,26,130} Two further independent studies^{131,132} published in *The Lancet* in 1999 refuted Wakefield's assertions, concluding no connection between MMR vaccines and autism. Still, the public messaging about an autism-vaccination link was heard more loudly by the public. Dr. Bryna Siegel,²⁶ a developmental psychologist and authority on autism, forthrightly posits in her book that the energy behind the autism parents' campaign against vaccines was fueled in large part by the comparative ease of blaming vaccines rather than facing their inner guilt and stigma from having an autistic child and doing the hard work to overcome it and support them.

Despite retractions and studies showing no link between vaccines and autism, Representative Dan Burton (R-IN) remained an ardent proponent and used his three-term position as chairman of the Oversight and Government Reform Committee and one term as the head of the Human Rights and Wellness subcommittee to hold at least 20 public hearings on the topic.¹³³ Additionally, he asked the FDA to investigate vaccine safety and sponsored a bill requiring the president to call a White House Conference on Autism, which stalled.¹³³ Nevertheless, Burton provided many opportunities for autism advocacy groups to expound their

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views publicly, even when not factual. In one hearing, Andrew Wakefield was invited by Representative Burton to testify, where he again asserted there was “compelling evidence” of a link between vaccines and autism.¹³⁴ American citizens were exposed to the controversial testimony through mainstream news coverage. Additionally, anyone with a computer who searched for information about autism could not avoid seeing information about the purported autism-vaccine link.²⁵

Capital and Connections

Autism advocacy gained considerable momentum when several wealthy and well-connected New York families affiliated with the cause. In 2001, the son of a wealthy New York couple, David and Laura Slatkin, was diagnosed with autism, prompting them to partner with allies in their social network, such as Tommy Hilfiger and his wife, Dee, who had two autistic children at that time.¹¹⁸ With advice from philanthropic friends and the New York City Schools Chancellor, the Slatkins founded the New York Center for Autism (NYCA) to “...make a huge difference in the community of autism.”¹¹⁸ Promoting autism research was foremost among the directives of NYCA’s mission and key to that objective was Deeda Blair, one of the board members who was also on the board of the National Institutes of Health (NIH).¹¹⁸

Eunice Kennedy, who had heavily influenced JFK’s work on mental retardation, had been Blair’s chaperone while courting her husband in the 1950s, and her husband had served in the Kennedy administration.¹³⁵ In the early 1980s, Blair had become a protégé of Mary Lasker, a public health policy entrepreneur, and philanthropist who started the Lasker Foundation (<https://laskerfoundation.org/>) with her husband to support health through science after a bid for national insurance had failed under President Truman.^{135,136} Lasker taught Blair to appreciate

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artistic flair, fashion sense, and knowledge of the bioscience landscape, and she modeled the ability to leverage it all to gain access to political decision-makers.^{135,136} Blair quickly became a force in the federal policy community and finalized her apprenticeship with high-stakes deal-making in the 1980s biotech boom.¹³⁵ In 2004, her 41-year-old son committed suicide, resulting in her focusing her passion for science on finding and funding mental health treatments.¹³⁵

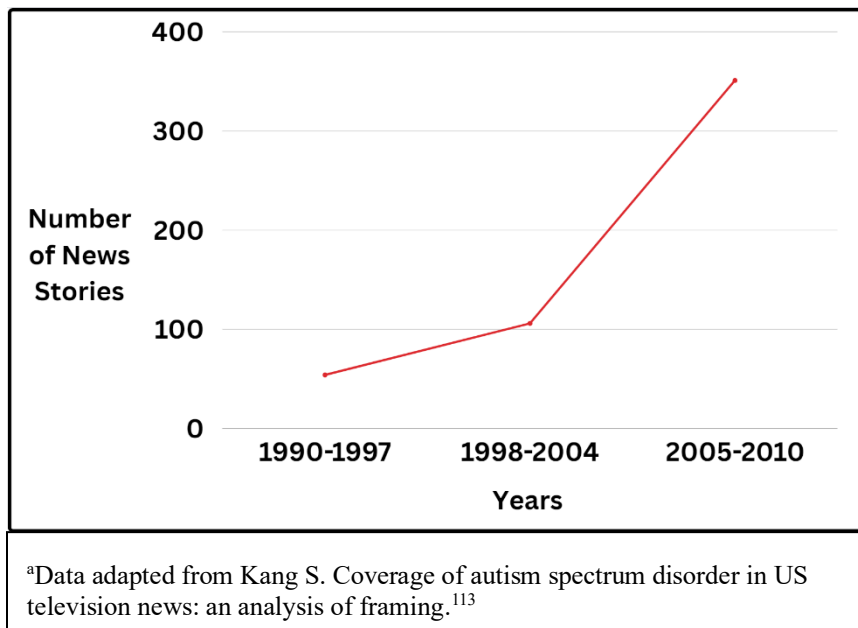
The Slatkins' connection to Blair brought them to a gala dinner for the completion of the Human Genome Project (HGP), where they met Tom Insel, a doctor and entrepreneur who was also then-director of the National Institutes on Mental Health (NIMH).¹¹⁸ Insel guided their consideration of finding a cure with the suggestion of significantly advancing autism research through genomic science.¹¹⁸ The Slatkins and the Hilfigers eventually joined forces with Bob and Suzanne Wright of Autism Speaks, billionaire hedge-fund manager Jim Simons, and his wife, Marylin.^{118,119} The Slatkins, Wrights, and Simonses were each separately devoted to autism causes.¹¹⁸ Yet, they also worked with Tom Insel to plan and hold an autism think tank in 2005 at the prestigious Columbia University, with Insel as a speaker.¹¹⁸ They invited world-class scientists and offered six privately-funded \$120,000 research grants and public-private partnerships were discussed.¹¹⁸ As stated by Laura Slatkin in 2006, "Conversations took place [at the think tank] that shaped the future of autism."¹¹⁸ The Kennedy influence noted in the fashion and lifestyles of both Deeda Blair¹³⁵ and Laura Slatkin¹³⁷ suggests that naming the 2006 *Combating Autism Act* was inspired by JFK's 1963 proposal to *Combat Mental Retardation*.

As Chief Executive Officer of the NBC television network, Bob Wright was able to directly influence the public's attitude toward autism through network news and programming.¹¹⁹ NBC ran a week-long autism series, and Bob and his wife, Suzanne, appeared on the Today

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Show.^{119,117} They further raised awareness on a global scale, lighting the Empire State Building in New York City with blue Autism Awareness Day (April 2) and encouraging other venues worldwide to do the same.¹¹⁹ Autism coverage was blooming on a broader scale, as well. The number of US television network news stories about autism in the period from 1990 to 1997 more than doubled between 1998 and 2004, and most of the latter covered issues regarding personal and children's experiences and autism's causes.¹¹³ Additionally, the blockbuster 1988 film *Rain Man*¹³⁸ introduced autism to many Americans for the first time.

Figure 5: The Number of US Network News Stories on Autism^a



The Rise of Self-Advocacy

Naturally, children with autism grow up. Children diagnosed with autism in the 1990s, especially after 1994 when DSM®-IV widened diagnostic criteria to include people with intact verbal abilities, were maturing in the early 2000s. They began to offer self-advocate perspectives on the needs of people with autism, which did not always align with autism parents' views. As with autism parents, the internet facilitated their networking, but for autistic people's challenges

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with social communication disorders, it also brought the crucial benefit of reducing their trouble with speaking and interacting face-to-face.²⁵ Though they had made connections, their voices were underrepresented until Ari Ne’eman formed the Autistic Self Advocacy Network (ASAN) in 2006.²⁵ The slogan from broader disability empowerment movements, “Nothing about us without us,”¹³⁹ became their call to action. Nevertheless, due to the timing, politicians concerned with the CAA’s²⁹ elevation to the governmental agenda heard the perspectives of parents of autistic children more than they heard those of autistic people. This shifted quickly after 2006, and ASAN has played a more prominent role in shaping political will around the CAA’s²⁹ subsequent reauthorizations.

The DSM®-5,⁶ 2014

The DSM®-5⁶ was the first edition to use the term NDDs and recognize the relationship between the six categories. Therefore, in 2006, when the CAA²⁹ was passed, the overlapping symptom burden and its consequences to the broader population with NDDs were not yet understood. Since 2014, it is becoming increasingly evident. Yet, CARES³⁰ has continued to invest heavily in research, education, and services supporting people with ASD and their caregivers without policy consideration for the broader population with NDDs. The same is true for the entitlements under IDEA²⁷ and Medicaid for ASD.⁴ Concurrently, millions of other children impaired by ADHD^{20,140} and other NDDs and their families have struggled to gain policy traction while their experiences are shrouded from the public and policymakers due to stigma and structural inequities, leaving research, parent, educator, and healthcare provider training, as well as supporting infrastructure, underfunded. Furthermore, families have been left isolated, often bearing sole financial responsibility for any help they seek. Notably, children with

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hidden NDDs that co-occur with ASD receive ready access to their diagnosis and treatment under IDEA.²⁷ At the same time, those without ASD encounter barriers to financial help, knowledge-building, and care access.

Within this context, the six key informants who participated in this analysis lobbied, researched, educated on, advocated, and provided care for children, adults, and families with NDDs for a collective 189 years.

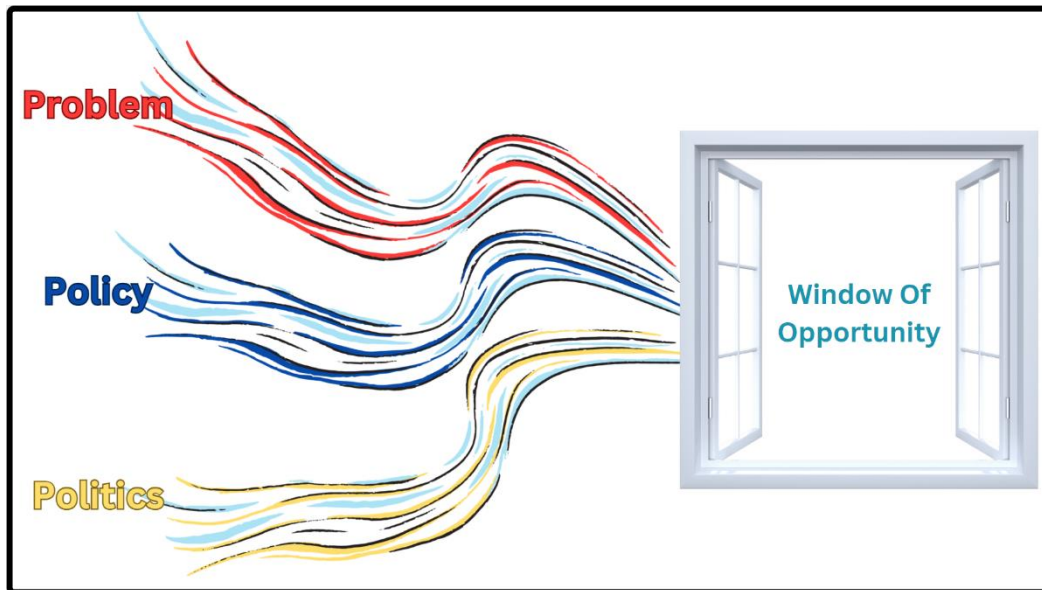
Methods

Conceptual Framework

The MSF provides a structure for comprehending the rationale behind autism policy in 2006, which is essential to navigating policy equity and coherence for the entire population with NDDs in 2023 and beyond. Further, applying the MSF to this work can be illuminating for public policy analysts, students, advocates, and other policy specialists by helping to reveal the translation of theory into actual policy development.

As Kingdon⁴³ developed the MSF, his central inquiry regarding public policy was, “How does an idea’s time come?” In answering that question, he describes three streams of influence, problem, policy, and politics, flowing concurrently but with separate impacts on an issue’s outcome.⁴³ As the streams flow, issues become visible, and policy alternatives are coupled with them.⁴³ The policy community generates successive alternatives for a particular issue according to reactions to previous ones and feedback from events in each stream.⁴³ Influential actors include the policy and political entrepreneurs who craft viable policy solutions for the issue and sponsor its elevation to the government agenda.⁴³

Figure 6: A Visual Representation of the Multiple Streams Framework⁴³



The Problem Stream

The problem stream is where people's daily conditions become subjects of change.⁴³ Policy issues are defined here, and solutions may or may not yet be apparent when they are. Factors such as crises, programmatic feedback, and other focusing events that grab the public's attention and align its sentiments may spark the human sense of injustice, mobilizing advocates to seek a re-balancing through policy.⁴³ A prime example of a focusing event is the 1911 Triangle Shirtwaist Factory fire that killed 146 workers due to inadequate jobsite conditions and led to the public outrage that still drives the mission of the Occupational Safety and Health Administration (OSHA) today.¹⁴¹

The Policy Stream

Kingdon's policy stream is the domain of policy communities, made up of non-partisan specialists in a given field both in and outside of government who understand the problem and

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work to find viable solutions to match with it.⁴³ This is most often conducted iteratively until a policy entrepreneur, a specialist devoted to a given policy issue, finds a solution that resonates with the public and a political entrepreneur, usually a political figure willing to sponsor its elevation to the legislative agenda.⁴³ Alternatively, a focusing event in the problem stream can cause political entrepreneurs to sense a policymaking opportunity and seek immediate and viable policy alternatives from a policy community.⁴³ The pool of ideas from which the policy community works is referred to by Kingdon⁴³ as the “primeval soup” in a nod to biologists’ conceptualization of the evolution of life from molecules floating around in earth’s early oceans, linking and breaking apart and linking again until the perfect combination was achieved.ⁱⁱ Two of Kingdon’s⁴³ observations are particularly relevant to the policy stream for the CAA.²⁹ First, policy innovation is often more about combining solutions with issues in novel ways rather than inventing entirely new solutions.⁴³ Second, fragmented policy communities tend to create dissonance, while tightly knit policy communities generate more harmonized policies.⁴³

The Political Stream

The political stream is the realm of the national mood, advocacy groups, and the government’s reactions to their pressure.⁴³ Consensus-building is the central activity here.⁴³ It is where politicians sense the balance between support and opposition to a policy proposal and where that proposal becomes a bill or gets thrown back into the primeval soup to simmer a while longer.⁴³ Politicians will naturally align if they sense overwhelming support for a proposal.⁴³ If they sense division between constituent groups, they usually seek to balance their support.⁴³

ⁱⁱBiologists actually refer to this as the “primordial soup,” attributed to Alexander I. Oparin et al’s heterotrophic theory of the origin of life. However, out of enormous respect for Kingdon’s insight and expertise in crafting the MSF and discussions of it since, “primeval” will suffice.

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Interestingly, Kingdon⁴³ points out that politicians may support a proposal even when they perceive an unfavorable balance of support for it. In those cases, politicians conduct an internal calculus of the costs and benefits of sponsoring the bill.⁴³ In most cases, several negotiations occur between policy and political entrepreneurs before a proposal becomes a bill.⁴³ Importantly, one person can be both the policy and political entrepreneur, advocating for a proposal and possessing the political capital to influence its introduction to colleagues and elevate it as a bill for legislative consideration.⁴³ Turnover of political parties or pivotal staff roles can affect support for a policy proposal, as can jurisdictional power struggles between governments (e.g., federal and state) or government entities (e.g., Department of Education and Department of Health and Human Services).⁴³ The importance of the political stream as a driver of high legislative agenda status must not be underestimated, even in the face of definitive data or scientific evidence supporting a policy proposal.

Window of Opportunity

Finally, Kingdon states that only when the three streams converge does a window of opportunity open through which public policy may be elevated to the decision agenda, the short list of issues to be decided by a legislature.⁴³ Policy and political entrepreneurs are instrumental in opening windows.⁴³

Literature Review

A comprehensive literature search and review, structured after Sutton et al's¹⁴² Framework Synthesis Review, was conducted. Documents included peer-reviewed journal articles, congressional records, policy analyses, monographs, news and magazine articles and editorials, and miscellaneous grey literature. Topics reviewed included diagnostic definitions,

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scientific research, and expert perspectives, including self-advocates,' on NDDs and their best treatment practices, relevant federal policy, and historic disability-related events affecting the public. The literature review developed knowledge in four domains. First was the Multiple Streams Framework,⁴³ its components, like policy and political entrepreneurship, and how they apply to autism and NDD policy in the US and other nations. Boolean search terms included “Kingdon multiple streams,” “multiple streams framework AND autism AND 2000 (or other years)”, and similar. Searches were conducted on Google Scholar and the UNE Library’s multi-database search prompt. Second, literature was gathered to understand the historical and contextual factors, emphasizing the social and political environment and public mood around autism and disability policy during the late 20th century and early 2000s. Terms like “autism,” “ADHD,” “mental disorders AND stigma,” “History of [Autism OR ADHD],” “autism policy,” “adhd policy,” “SPCD policy,” “Institutionalization,” “Mental Health AND Disorders,” “Developmental Disabilities AND 20th Century”, etc. were employed. The third domain of knowledge sought in this review was on the NDDs of interest, namely ASD, ADHD, and SPCD, their prevalence, and their impact on the individuals and families experiencing them. Search terms included the names of each condition alone and in combination, and “DSM®,” “ICD,” and search terms like “US Cost Burden AND Autism” and “US Cost Burden AND ADHD” were used. Literature on these conditions collected during previous research was also utilized. The fourth domain was legislative and judicial records concerning the federal policies mentioned in this paper, such as the CAA,²⁹ CHA,¹²⁸ and IDEA,^{27,108,111} and hearings held about or relevant to them.

Searches were conducted using the UNE Library, Google Scholar, Google, and, and results were limited to articles and books published in English and produced during the years

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2018-2023 for current diagnostic and prevalence information and during the years 1970 to present for Multiple Streams⁴³ historical perspectives, records, and analyses. Information on historical disease and contextual views was sought from the late 1800s until now. Finally, snowball sourcing was conducted from relevant citations in the literature and key informant references to people, events, further literature, and popular media. Sources came from multiple academic databases, including MDPI, Elsevier, Eric, NIH, and Springer Publishing, as well as the National Archives, Library of Congress, Presidential Library collections, and interlibrary loan.

Key Informant Interviews and Qualitative Analysis

Semi-structured interviews (SSIs) were conducted with six key informants (KIs) with a collective total of over 189 years in disability and special education policy, research, advocacy, and professional school instruction. SSIs consist of a scripted set of open-ended questions designed to elicit responses rich with information relevant to the research question. The interview protocol, participant inclusion and exclusion criteria, and Participant Information Sheet were reviewed by the University of New England's Institutional Review Board. KIs had to be over 18 years old with substantial expertise in disability or special education policy or an adjacent field impacted by the CAA.²⁹ Further, at least one had to be autistic or the parent of an autistic child.

Four of the six KIs were employed in their fields of expertise contemporaneously with events leading to the CAA's²⁹ adoption, one since the 2000s and one since the early 2010s. One KI is autistic. The interview protocol was written so that its questions could be adapted depending on the KI's field of expertise but would remain relevant to the conditions leading to

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the CAA.²⁹ Interviews were recorded on the Zoom software platform and transcribed into a text document. Pseudonyms were assigned and substituted for KI names to protect the confidentiality of all KIs; then, all transcripts were uploaded to Atlas.ti software, version 23, for content analysis. Content analysis was conducted on interview transcripts using methods and guidance from Erlingsson and Brysiewicz.¹⁴³ Transcripts were examined for quotations relevant to the research questions. Each quotation was labeled with factual, descriptive one- or two-word codes. When all transcripts were coded, codes were reviewed and condensed by dropping those with low use frequencies or merging redundant codes. Then, related codes were placed into categories describing “who,” “what,” “where,” or “when.”¹⁴³ Themes were then developed from within and between the categories. Themes answer questions such as “why,” “how,” “in what way,” and “by what means.”¹⁴³ The Atlas.ti platform facilitates the manual work of analyzing transcript contents, its organization, and the overall analysis of results from multiple sources. For instance, Atlas.ti counts the number of times a code is used in a project and refers to this as “groundedness.” The more grounded a code, the more thematic it is. Additionally, the number of links a code has to other codes is called “density.” Codes with a high density strongly relate to the research question and should be considered influential. In this project, categories with a density score of 10 or more were deemed influential regarding the research question and included in the analyses of streams. Themes from the transcript analysis were triangulated with data from the literature review where congruence existed to add context and depth to the Discussion and Implications sections.

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Figure 7: Visual Representation of the Qualitative Analysis Process

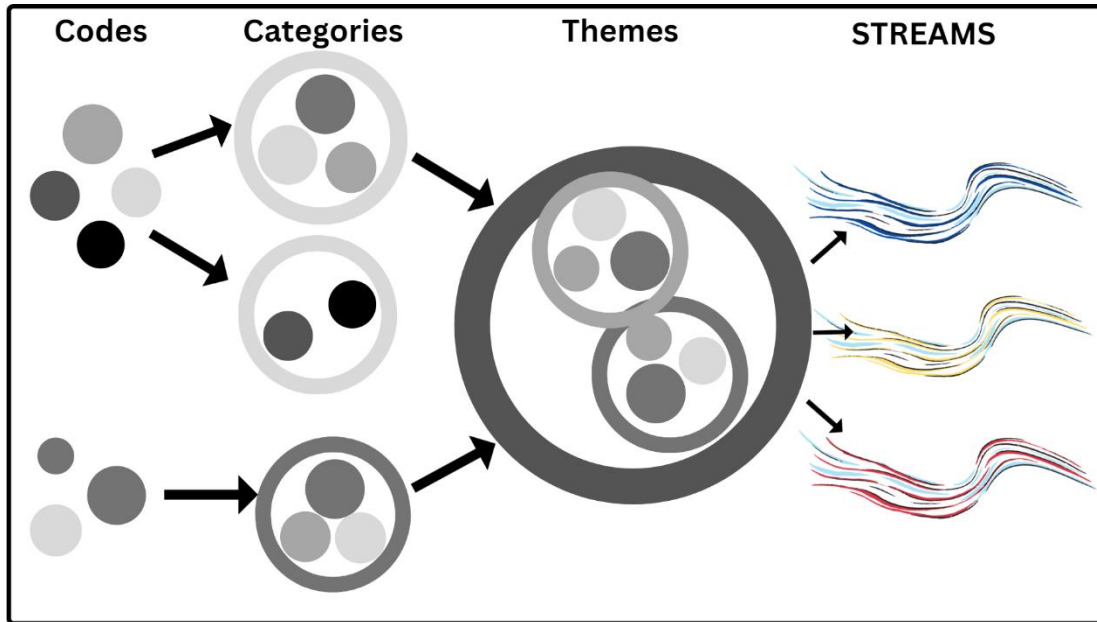


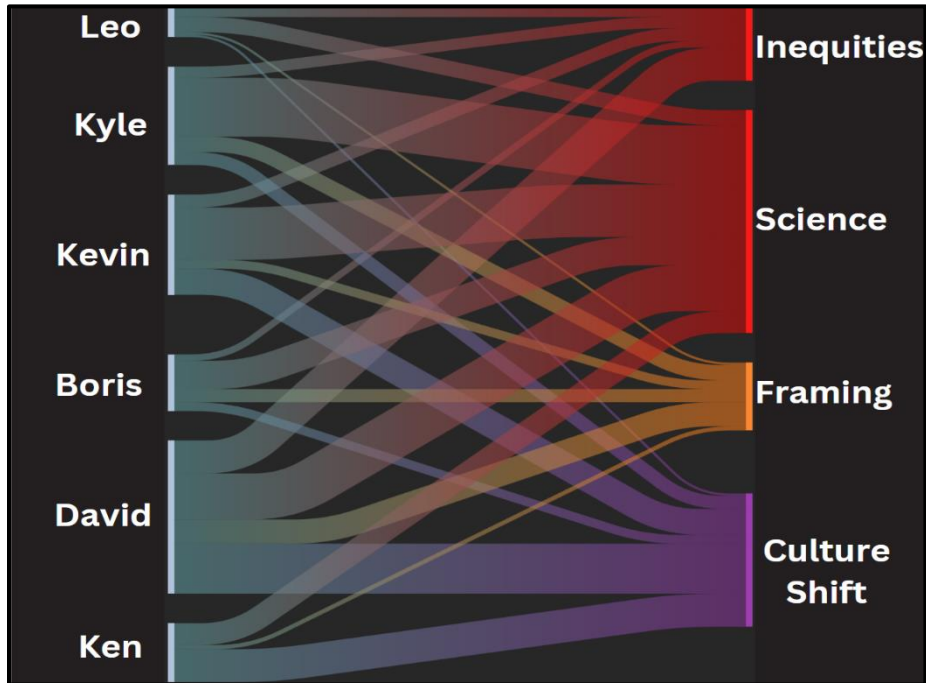
Figure 8: Excerpt of Qualitative Analysis from Key Informant Transcript

Quotation Content	Codes	Categories	Themes
Got some examples of that, you know, sort of as hard as we fought for the big bucket for children with special health care needs, children with mental health needs never exactly been included there.	System complexity, barriers MH Stigma Science 1990-early-2000s	CULTURE SHIFT, FEAR	1) The U.S. values productivity and solutions that involve the market. 2) Visible disabilities are favored over hidden ones (e.g., impairments from mental disorders). 3) Disparities to healthcare access and treatment arose from reliance on differing policies and each ones' qualifying criteria and jurisdictional status. (e.g., states' Medicaid programs and private health insurance coverage)
Other public policies all slice and dice the children into categories that don't rationally make sense that don't have a logic to the nature of health, and and the categories of conditions that overlap in ways that are confusing and that create barriers to families and children getting adequate services, access to care and becoming entitled to services that they should be entitled to	Parents preferred Autism Dx to ID Dx: System complexity, barriers Treatment often depends on insurance coverage Equity Federal agency turf wars Federalism IDEA Parents preferred SLD to ID Science 1990-early-2000s zip code	CULTURE SHIFT	
it was valued by the President because of what it did. You know it was valued by providers who there was a market of providers who had the tools to do the direct interventions for orthopedic conditions. I'm gonna save you. It wasn't even about children whose lungs had a problem. It wasn't about children who had hearing problems. It was about children whose limbs muscular, skeletal, orthopedic conditions were a challenge.	Disparities Visibility US preference for downstream solutions US productivity culture	CULTURE SHIFT	

Analysis

The Problem Stream

Figure 9: Sankey Diagram of Key Informant Contributions to Each Problem Stream Category



Categories

Four problem stream categories surfaced in the data analysis of KI transcripts: Science, Culture Shift, Inequities, and public message framing, labeled “Framing.” Two of these categories intersected with other streams: Culture Shift with the policy stream and Framing with the political. Some of the representative codes nested within these categories included *DSM®*, *evidence-based*, *disability = visible*, *mental health stigma*, *zip code*, *Medicaid waiver*, *parent stress*, *financial pressure*, *evolution*, *Applied Behavioral Analysis (ABA)*, *autism envy*, *autism myopia*, *family advocates*, *media including internet*, and *disaster frame* (which merged with the codes, *autism epidemic*, *vaccine-autism connection*, *the worst thing*, etc.).

Themes

The following problem stream themes arose from the six KI transcripts.

National Culture Shift (Categories: Culture Shift, Inequities)

- A national policy shift in the 1960s significantly reduced institutionalization and placed people with disabilities in the home and community who had not been there previously, making them visible to the public.
- People's disabilities stemming from a range of health conditions were labeled by healthcare providers and educators as "mental retardation" and left largely undifferentiated well into the 1990s. The public was even less well informed about mental disabilities, advocating for their disabled family members, and the social-emotional tools for life in an inclusive society.
- Emotional and financial stress was building on families caring for autistic children.

The fragmented scientific and medical community (Categories: Science, Culture Shift)

- A fragmented scientific and medical community was still working to overcome social norms around mental illness and validate the definition of autism and the existence of ADHD as developmental disorders.

Education and IDEA^{27,108,111} (Categories: Inequities, Culture Shift)

- Parents of autistic children desired a separate IDEA¹⁰⁸ category for their children, an advocacy effort that aligned with the efforts of parents of children with SLDs to have children with autism removed from the SLD category. In 1990, IDEA¹¹¹ was revised accordingly, and public awareness of autism diagnoses and a sense of its prevalence began to rise.

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- Parents of autistic children saw hope in Applied Behavioral Analysis (ABA) and IDEA's¹¹¹ promise of FAPE and, therefore, filed lawsuits and pushed for autism diagnoses.

Narratives about autism (Categories: Framing, Inequities, Science)

- Media and the Department of Education (DoE) portrayed autism as an “epidemic” of a mysterious disease that devastated families and portended broader societal disaster.
- Powerful autism advocates, including celebrities, CEOs, and political figures, launched fear-based publicity campaigns conveying two main messages: that vaccines caused autism and that autism was the worst thing that could happen to a family.

Discussion

Autism arose as a policy issue in the mid-1990s because of publicly available prevalence and cost data, increasing public fear, and the emotional and financial strain on families and schools doing their best to care for autistic children. Discord in autism science until the 1980s and the lag between research, dissemination, and diagnosis delayed distinguishing people with MR, or ID, from those with other developmental disabilities. Additionally, a lack of pediatric psychiatrists and financial barriers delayed diagnosis further for many. As discussed by KI Ken, even into the 1990s, children carried the generic label of MR. Autism diagnosis was initially elusive to all but the most tenacious and financially sound families, but then came a diagnostic breakthrough – the ADOS⁸² and ADI.⁸³

Fortuitously, IDEA's¹¹¹ 1990 reauthorization began the nation's first systematic autism surveillance just as diagnosticians were being trained on the ADOS.⁸² Autism was now visible. Prevalence and cost data readily flowed to the public from IDEA's mandated reporting. Further, the IDEA¹¹¹ revisions included more assessments and services for students with a classification

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of autism rather than MR or ID, including a battery of health assessments, vocational skill-building, and assistive technology.^{23,24} KI David recalled that behavioral interventions such as task analysis and occupational training that had been developed in the 1970s and 1980s became educational options for children with developmental disabilities, especially those without a MR or ID designation. This resulted in increasing demand for delayed diagnosis of MR and specialized services tailored to each learner's intellectual ability, which had previously been assumed to be low for all developmentally disabled students. As a result of this, autism became a preferred diagnosis to optimize their children's chances of reaching their potential.^{23,24,iii}

Even before ABA became a potential "cure" for young autistic children, schools' financing of FAPE, instead of their previous standards of safeguarding and custodial care, stressed their budgets. Judicial clarifications of Constitutional protections for children with disabilities had translated to FAPE for all students, regardless of the severity of their impairments. Like President Kennedy's plan, this was another critical leap towards health and economic equity for the nation and another missed opportunity to adapt successfully through augmentative policies. Instead, the DoE, states, and local schools were left to solve such a momentous frameshift's social and budgetary problems. 1990 Was a trifecta of puzzlement for the DoE as it began adjusting to the IDEA¹¹¹ revisions, applying those revisions to an ever-increasing autistic population, and responding to desperate parents' hope and sense of urgency for their children's early treatment with ABA. On balance, the public was left to interpret bewildering differences in educational determinations for children with similar disorders in different locales and with different genders, races, and impairments. Consequently, disparities

ⁱⁱⁱ This has also been observed and discussed contemporarily by the author in clinical settings and with early intervention professionals.

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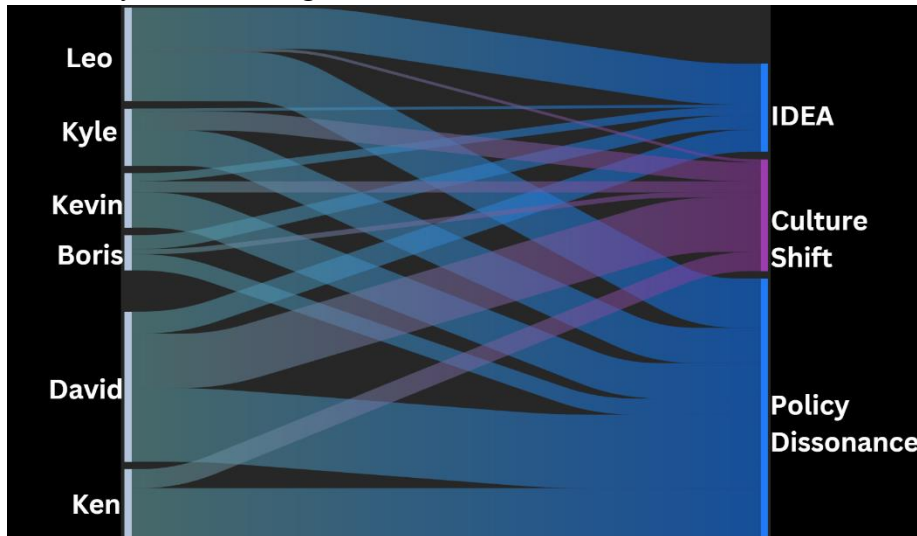
resulted, and unease built both inside and outside of school systems as families grappled with the injustices, burdens, and stigma of being autistic and caring for autistic children. A national focusing event came with increasing attention to an impending financial crisis for America's schools based on DoE data trends showing an autism epidemic and per-pupil costs of educating autistic children that were significantly higher than legislators had anticipated when EAHCA¹⁰⁸ was first adopted and far greater than appropriations had ever been.¹¹⁶

In the mid-1990s, the public was hearing and seeing stories about autism with increasing frequency. Network news stories and popular press pieces carried narratives of a mysterious disease that seemed to trap children within themselves and heroic warrior parents who were fighting to save them. Moreover, different advocacy groups arose whose missions and messages evoked a range of emotions, with fear being the primary one. The burgeoning internet accelerated the broadcast of advocates' messages, including misinformation. Starting in 1998, the false vaccine-autism link spread rapidly, and its promoters capitalized on parents' fears about autism and their love and protective instinct for their children, creating an ongoing focusing event. The public's faith in science and trust in the government was shaken by conspiracy theorists' narratives, resulting in a separate health and policy problem: decreased vaccine uptake. Finally, the 1998 CDC investigation into a suspected autism cluster in Brick, NJ, was a minor focusing event that drew the public's attention to one community's experience with autism and left an open question about its causes and whether their communities and children could be next.

While the public was focused on autism, it remained resistant to recognizing ADHD as anything other than a problem related to parents' failure to apply appropriate discipline techniques and "big pharma's" manufacturing of a market for stimulant medications.^{89,94}

The Policy Stream

Figure 10: Sankey Diagram of Key Informant Contributions to Each of the Policy Stream Categories



Categories

Three policy stream categories were detected: Policy Dissonance, Culture Shift, and IDEA. Culture Shift intersected with the problem stream, as mentioned above. Codes within the Policy Dissonance category included *functional disability*, *conflicting entitlement programs*, *conflicting diagnostic/qualifying schema*, *IDEA does not match DSM®*, *IDEA: Other Health Impaired (OHI) category = aggregate data*, *transition services*, *slice and dice*, *US productivity culture*, and *shifting disability definitions*. IDEA codes included *Education of All Handicapped Children Act of 1975*, *care coverage*, *financial pressure from care costs*, and some of the IDEA codes co-nested under Policy Dissonance. The category, Culture Shift, revolved around deinstitutionalization, with codes such as *DD Act*, *the disability rights movement*, *FAPE*, the *ADA*, *supportive services and technology*, *cure*, and *prevention*.

Themes

The following policy stream themes arose from KI's.

The Primeval Soup and Wellness vs. Productivity (Categories: Policy Dissonance, Culture Shift)

- The deinstitutionalization of people with mental disorders, begun in the early 1960s, posed issues that necessitated public policy adjustments to assist with equipping families and communities with the education and resources to care for people with disabilities. Ideals of healthcare and capitalism clashed within the policy community.
- Americans, including policy experts and medical providers, tend to recognize physical and other visible disabilities over ones that cause impairments to an individual that cannot be readily seen or verified by others.
- A complex tangle of disability policies and jurisdictions arose that prioritized productivity over wellness and left gaps in coverage. Healthcare and social services were intended to make people work rather than make them well. This was true for children's policies as well. Even with a medical diagnosis, a student must be classified with impairment by their school before qualifying for services under IDEA.^{27,108,111}
- Curing and preventing autism were viewed as more favorable policy solutions than support and quality of life measures because they would squelch the upward spike in prevalence and head off the forecasted financial disaster.
- Policy solutions in the CAA²⁹ were not novel. They substantially increased funding for programs already in place and either dedicated them to autism or made it their primary focus.

The Civil Rights Lens and Blueprints for Success (Categories: Culture Shift)

- The disability rights movement provided a civil rights lens, and the Arc's successful advocacy provided a blueprint for action to later disability advocates and policy entrepreneurs.

Assistive Technology, Occupational Training (Category: Culture Shift, IDEA)

- The development of behavioral interventions, vocational training, and supportive technologies, such as communication devices, significantly influenced educational and healthcare policy for people with disabilities.

Discussion

An overarching policy dissonance provides the context for the CAA's²⁹ policy stream and solutions simmering in its primeval soup. President John F. Kennedy's 1963 statement, "The mentally ill and the mentally retarded need no longer be alien to our affections or beyond the help of our communities,"⁶⁴ set the tone for a sea change in American ideology toward people with developmental and other disabilities. Moreover, courts' affirmations of 14th Amendment rights for people with disabilities, sidestepped for decades while America emphasized industrialization and capitalism, seemed to take the nation by surprise. The logical accompaniment to these vast shifts in national executive and judicial policy would have been coordinated and timely augmentative policies to equip the public with guidance, tools, and support for adapting to the new paradigm and ensuring that the care of people with disabilities was centered on wellness and the dignity of personhood for all. Unfortunately, those augmentative policies did not materialize.

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As a nation striving to end the moral injury of institutionalization by caring for disabled loved ones in homes and communities, we had not yet reconciled the principles of inclusion and sustainability with our internalized values from hundreds of years of covetous capitalism. We as a nation had failed to acknowledge that institutionalization was a legacy of the stigmatization and incarceration of disabled people that had been intensified by America's rapacious embrace of the free market ideals of individual responsibility, competition, and prosperity. People with disabilities, especially non-obvious ones, remained stigmatized and viewed as defective and a burden. While seen as noble, caring for them was given little quarter in practical settings such as work, creating dualistic tensions for caregivers. This panoptic perspective pervaded the public and policy experts' mindsets, bounding the progress of healthcare policy in the US, especially for mental health. KI Kevin stated that within the policy community, experts who coupled health-centered policy solutions with disability issues quickly received feedback indicating that political will demanded a turn toward productivity-centered [i.e., conforming to market ideals] solutions. The result is healthcare policies that separate, label, and treat people (termed "slicing and dicing" by KI Kevin) according to productivity goals rather than aiming for wellness and a humane consumer (e.g., people with disabilities, caregivers) experience. Policies and gaps produced from this mindset created extreme pressure for families, educators, and health care providers in a society founded on and indoctrinated into an avarice mindset.

Federal health and disability policy shifts stemming from the 1960s meant many solution ideas were already simmering in the primeval soup when autism prevalence emerged as a policy problem in the mid-1990s. For the policy community, the Civil Rights Act of 1964¹⁰⁰ had provided a fresh lens through which to look for solutions for people with mental disorders.^{25,102} Further, in the 1970s and 1980s, courts consistently steered legislative policy solutions toward

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their rulings.¹⁴⁴ Policy protections for people with autism had grown before it was even recognized as a policy issue, but it was legislatively limited to what contemporary political will would support. The DD Act¹⁴⁵ provided a model of benefits, including research, centers of excellence, and advocacy councils, that translated well to the issue of autism.

The evolution of autism science had also contributed to potential policy solutions. Bernard Rimland's⁶⁹ neural theory spawned biological research as a policy alternative to couple with autism.²⁵ Bauman and Kemper's⁷⁸ 1985 discovery of specific brain abnormalities linked to autism clinched the attractiveness of cure-focused research as a policy solution.¹²⁸ The locus of cause became the brain and its biological and environmental determinants rather than individuals' moral, emotional, or intellectual failures, making policy solutions seem more straightforward.

Data made autism visible. The IDEA¹¹¹ revision of 1990 provided autism policy entrepreneurs with crucial data to guide analysis of the issue and potential solutions. Starting in 2001, the wave of state mandates for private insurance coverage of ABA signaled to federal policymakers that autism and its costs were an urgent policy issue. Policymakers had Kennedy's plan as a backdrop, sensing that combating the problem resonated with the public more than adapting to it did. *Cure* and *prevent* alternatives translated to substantial forecasted cost savings both for the government and individuals. Further, research had already been successfully coupled with autism as part of the CHA¹²⁸ and it aligned with *cure* and *prevent* goals. Additionally, translational research to optimize ABA methods offered the possibility of curbing its high costs while still aiming for a cure. Kingdon⁴³ points out that a policy issue must be coupled with a

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viable solution to rise to the government's decision agenda, and the CAA's²⁹ coupling of research with autism is a prime example of this.

Multiple policy entrepreneurs affected the CAA's²⁹ success in various ways. Reviewing Representative Burton's attempts at being a policy entrepreneur reveals that while he was unsuccessful at elevating his solutions, he nevertheless played a cardinal MSF role in the adoption of the CAA.²⁹ Burton attempted to maximize the opportunity presented by autism as a policy issue by embracing the vaccine-autism link as a *cure* solution, believing that eradication of thimerosal from childhood vaccines would prevent future cases.¹³⁴ His misadventures based on fraudulent data still served to create an awareness of autism and receptivity for a future well-timed solution in both the policy community and the greater public.²⁵ Kingdon⁴³ refers to this as "softening up." Meanwhile, Representative Smith continued to devote substantial time and energy to the issue of autism, forming the congressional autism caucus and sponsoring the ASSURE section of the 2000 CHA.¹²⁸ Both Burton and Smith fit Kingdon's⁴³ criteria for policy entrepreneurs by holding authoritative decision-making positions, having political capital, and being persistent in pursuing autism policy solutions. Burton's invention of the anti-vaccine solution rather than recombining past solutions with the issue of autism made his policy harder to elevate beyond his realm of authority. Alternatively, for the CHA,¹²⁸ Smith proposed programs for autism modeled on those already in place for other conditions, or he emphasized focusing existing programs primarily on autism. Smith's strategy was familiar, easy to understand, and foundational for the CAA.²⁹

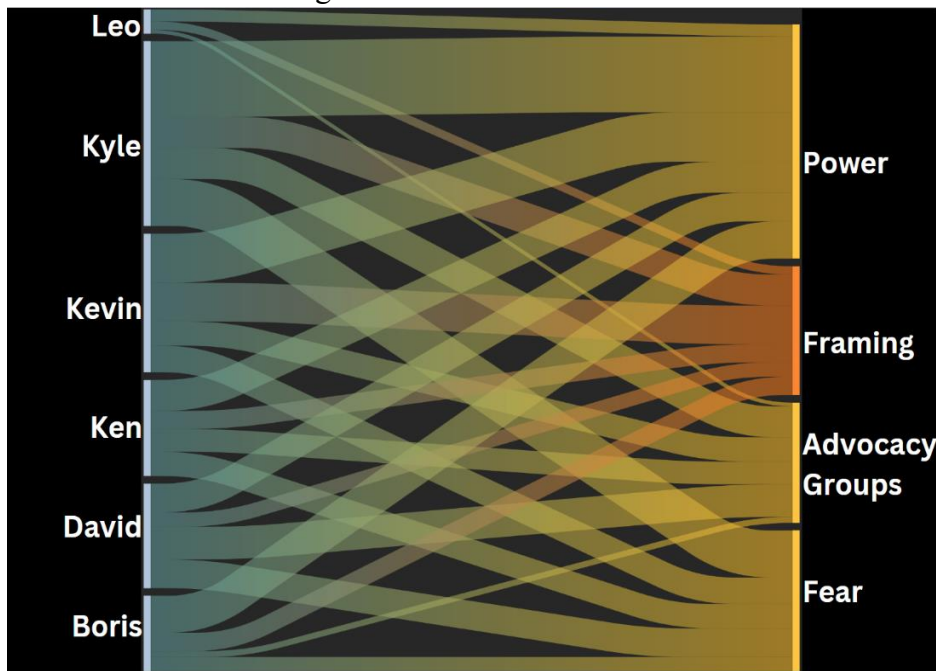
The *combat* mindset was, therefore, encouraged in the policy community, and entrepreneurs emphasized aligned solutions rather than ones that optimized life for people with

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autism and their caregivers. The healthcare complexities and administrative and financial burdens regularly faced by parents of autistic children today continue to reflect these policy priorities. As autism policy progressed, ADHD and other NDDs were eclipsed, remaining invisible to policymakers, or worse, a third-rail issue that did not have a nucleus of political will behind it.

The Politics Stream

Figure 11: Sankey Diagram of Key Informant Contributions to Each of the Politics Stream Categories



Categories

Four categories were revealed: Power (i.e., wealth, access), Fear, Advocacy Groups, and Framing. Framing, as mentioned previously, intersected with the problem stream. Codes within these categories included *Bob and Susan Wright, autism parents, powerful people (race, money, access), political will, competition, federal agency turf wars, combat, cure, singular, public fear*

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of and fascination with autism, mental health stigma, message framing > science, and false vaccine-autism link, Autism Speaks, Autism Society of America, Association of University Centers on Disability (AUCD), self-Advocates, competes for resources, and media including internet.

Themes

Themes in the political stream that arose from KIs included the following.

Mental Health Stigma and Political Will (Categories: Power, Framing)

- American stigmatization of mental disorders and skepticism about entitlement programs for people whose disability is not apparent pose challenges to garnering the political will needed to elevate policies in this field to the decision agenda. Grasping this is crucial to the political maneuvering of policies because message framing shapes political will, and political will eclipses science in agenda-setting. Sound data must always have political will behind it to be elevated to the decision agenda, but political will can promote an issue regardless of the data behind it. Therefore, separating certain mental disorders such as ID and autism from other mental illnesses irrespective of the DSM® has been a successful strategy for aligning political will with policymaking objectives.

“Powerful” Autism Parents (Categories: Power, Advocacy Groups, Framing)

- A group of people, referred to repeatedly in interviews as “powerful” autism parents, had extraordinary financial and social capital and began to advocate for autism in the early 2000s.

The Inter-Agency Coordinating Committee (IACC) (Category: Power)

- The IACC was unique and extraordinarily powerful because it was an executive branch committee dedicated to only one health disorder – autism.

Many Voices (Categories: Advocacy Groups, Framing)

- Numerous private autism advocacy groups had formed, each with their own views and priorities on autism to add to the broader advocacy of the DD Act’s University Centers of Excellence on Developmental Disabilities, Education, Research & Service (UCEDDs) in each state. This resulted in the fragmentation of the developmental disability community and heightened competition for resources between disability groups and government agencies.

Media Coverage and Public Mood (Categories: Fear, Framing)

- Media coverage led to a public fear of and fascination with autism.
- The suspected autism “cluster” in Brick, New Jersey, caused more public concern and urgency in the search for answers about autism.
- Congressional hearings on autism and the false link to vaccines created fear and vaccine hesitancy in the public that persists today.

Self-Advocacy’s Late Arrival (Categories: Advocacy Groups)

- Autistic self-advocates had an internet presence but were few and were just beginning to organize in the late 1990s to early 2000s.

Discussion

Political influences leading to the CAA²⁹ came from a range of sources. Pressure was applied to legislators from advocacy groups, agencies with a stake in autism policy, and autism

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parents. Autism advocacy groups enjoyed the advantage of The Arc's successful advocacy model. It provided a blueprint for building momentum toward an analog to the DD Act of 1975,¹⁰⁷ specifically for autism. The network of UCEDDs funded by the 2000 reauthorization of the DD Act,¹⁴⁵ called the Association of University Centers on Disability (AUCD), was a significant and unified national voice for evidence-based policy regarding people with developmental disabilities, including autism. However, autism-only advocacy had been growing, and the steep rise in autism prevalence and its stressors on families spun off organizations like CAN, NAAR, ASA, Autism Speaks, Generation Rescue, and others. Each now had a voice and a slightly or vastly different aim. They did not always align with one another, AUCD, or even the truth. Some groups eventually aligned strategically, but there were numerous bids for political priority through their interactions within and outside government.^{25,26}

The "squeaky wheel" often draws the political will for successful policy bids, as Kingdon⁴³ points out, which was certainly the case around autism. All of the KIs mentioned a select core of autism parents being central to the passage of the CAA,²⁹ using adjectives including "powerful," "influential," "rich," and "privileged" to describe them. The KIs knew of the Wrights, who started Autism Speaks, but other names were not recalled. Parent and grandparent advocates urgently wanted answers about autism and help with the emotional and financial costs of caring for their autistic children, and they were persistent in their pursuits. The Slatkins, Hilfigers, Simonses, and the Wrights added their voices to the large and loud group of autism advocates, but instead of focusing on complicated matters, they brought a public appeal in the form of American ideals. They were affluent, successful in business and Wall Street (i.e., the market), had tremendous social networks, and were white. Further, they wanted what the nation wanted: to fight, to eradicate autism. They did not push for supporting people with autism, which

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would have had less political will behind it. Laura Slatkin's 2006 sentiments about her seven-year-old autistic son, published in a prominent magazine just three months before both houses of Congress passed the CAA,²⁹ "We worry all the time, How are we going to take care of David when he's twenty or thirty?"¹¹⁸ "We can't talk about it; it's too painful."¹¹⁸ "Autism is so devastating,"¹¹⁸ both framed autism as "devastating," reinforcing the national mood, and encapsulated American political will. When an issue is too complex or emotionally charged, Americans tend to pull away from the hard work of thinking and feeling about it. Instead, we focus on actions we can take immediately and push commitment to solving the complex issues into a vague future. Though Laura Slatkin's social and financial circumstances were distinct from most Americans, she was relatable in this comment. Named "Autism's Angels"¹¹⁸ by one author and "The Autism Cabal"¹⁴⁶ by another, this group of parents and grandparents were the nucleus of power referred to by the KIs. They accessed Tom Insel and coordinated with him to develop the research plan and funding method to cure autism that translated to the CAA.²⁹

As legislators and Congress considered autism issues, executive branch agencies added their influence in hearings and congressional reports to maintain or grow their jurisdiction's DD funding.^{25,26} Tasked with health services leadership and infrastructure, the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), CDC, and Substance Abuse and Mental Health Services Administration (SAMHSA) all had a stake. Relevant to political negotiations, all five KIs who worked in autism policy or programs mentioned the IACC's influence. It provided a distinctive presence for autism in political consensus-building. KIs Kevin and Boris both considered how the IACC seemed to stand out among complementary HHS committees that traditionally covered broad categories of other health disorders, such as the Advisory Committee on Heritable Disorders in Newborns and

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Children, which advises the secretary on HHS actions regarding all congenital health conditions rather than just one. The NIH-oriented mission of the IACC was apparent in the first version of the CAA²⁹ passed by the Senate, which authorized funds to flow directly to the NIH for research on autism's causes.¹⁴⁷ Before its bicameral adoption, however, the House revised its language to ensure that funds would first pass through HHS and to allow the NIH to determine research trajectories as science progressed rather than being locked into etiological research.²⁹

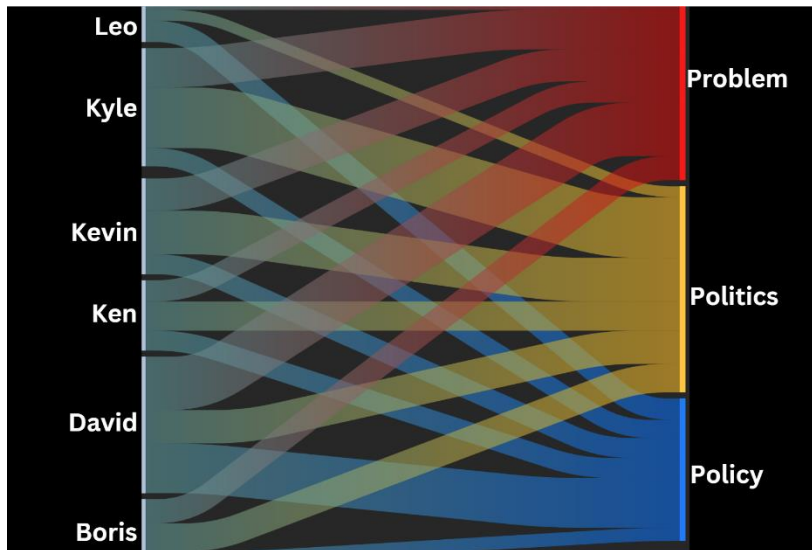
Though legislators put stock in the credibility of scientists, they required the will, political and their own, to elevate and adopt policy. The public was consistently left with open questions about what caused children to become autistic, whether it could happen to their children, and whether they could stop autism, with fear as the underlying theme. As a natural reaction to fear, the nation was primed for a fight-or-flight response, and because fleeing was not a viable option, fighting was the only viable solution. Furthermore, a map to the decision agenda already existed in President Kennedy's earlier plan and Smith's ASSURE section of the CHA.¹²⁸ As the mid-2000s approached, the stigma around autism had been reduced by the diffusion of IDEA's¹¹¹ 1990 classification of autism as a learning disability separate from other mental disorders. Popular media portrayals of autistic people as savants and their families as protagonists furthered autism's intrigue. Simultaneously, ADHD had been framed in news stories as little more than a discipline problem, and ADHD medications were controversial, explained by one New York Times writer as an exploitation of the public by pharmaceutical companies with a contrived diagnosis.¹⁴⁸ It raised connotations of bad parenting, bad kids, and bad business. Politically, autism had a much lower bar to clear than ADHD would have had if it had been considered as part of the CAA.²⁹

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The national mood,⁴³ or broad social consciousness, around autism was one of fear and fascination, made so largely by the narrative tactics deployed by the influencers. The political will to cure and treat autism by funding scientific research was the logical outcome of over a decade of consistent fear- and devastation-based message framing and lived experiences of autism by a growing population of US citizens. Consensus-building was facilitated, and it enjoyed non-partisan support because autism affected all Americans either directly or indirectly. Even so, the CAA²⁹ took slightly more than a year and a half to be adopted from the time it was introduced.

A Window Opens: Discussion

Figure 12: Sankey Diagram of Key Informant Contributions to Cumulative Stream Data



The pivotal moment for the CAA²⁹ came when Deeda Blair connected the Slatkins to Tom Insel. She possessed a personal ambition to improve mental health science and knowledge of biotechnology that shaped her ideas on the possibilities for both autism advocates and the NIH offered by the recently completed HGP. Autism was coupled with a viable solution (research for

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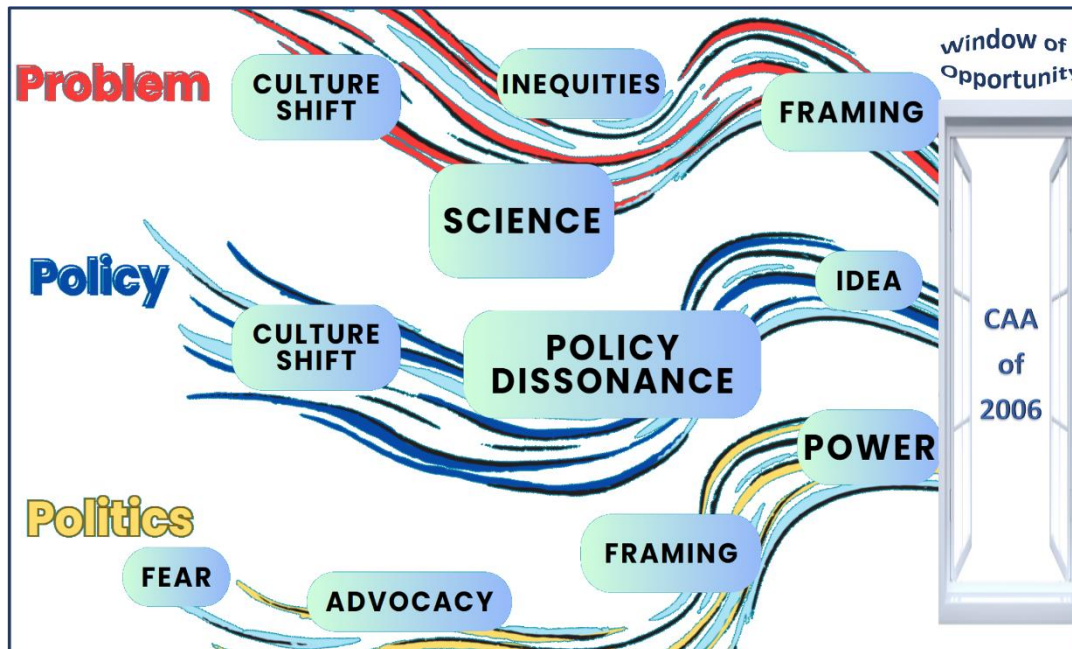
a cure), and a consensus was developing. The problem, policy, and political streams were converging. Blair's linking of the Slatkins et al to Tom Insel and his entrepreneurial acumen in tying autism research to genomic research supercharged the policy solution and political will for the CAA²⁹ by capitalizing on public awe and wonder. Awe and wonder inspire unity and the desire for understanding, respectively.¹⁴⁹ As an entrepreneur, Insel knew this either instinctively or tacitly. Without explicitly focusing on autism, the innovation of the HGP nevertheless worked to unite political will around knowledge-seeking for it. Insel's credibility as a scientist and his position at the NIMH had already attracted world-class geneticists to seek autism's cause when he reported to the Senate subcommittee in June 2006 that genomic science could accelerate research and potentially identify biomarkers for mental illness.¹⁵⁰ Definitive proof of mental disorders was something yearned for by politicians and the public, skeptical of their authenticity, and the prospect of attaining them was alluring. Coupling it with consideration of the CAA²⁹ was masterful. Not only was Insel a business entrepreneur, but he was also the consummate policy entrepreneur.

The promise of utilizing genomics to find a cure for autism was the solution for which the autism policy community had been waiting. Representative Chris Smith and the Congressional Autism Caucus were already open to a "cure" solution. Still, they had not possessed the specific tools to create an entirely separate autism policy in 2000, when they had worked on the CHA.¹²⁸ Now they did, and Senators Rick Santorum (R-PA) and Chris Dodd (D-CT) drove the CAA²⁹ onto the decision agenda and through the window of opportunity opened by the work of Tom Insel and the group of extraordinarily influential parents and grandparents of autistic children. The CAA²⁹ was introduced to the Senate on April 19, 2005, and was passed by both chambers on December 7, 2006. President George W. Bush, who had formed a friendship with the father of an

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autistic boy in 2003¹⁵¹ and whose own father had been a strident ally for people with disabilities,¹⁵² signed the CAA²⁹ into law on December 19, 2006.

Figure 13: A Visual Representation of the Multiple Streams Framework with Major Qualitative Research Categories



Implications

American political will favored familiar solutions and entrenched values over the reconciliation of new and old mindsets. Attitudes grounded in the 17th-century promotion of market economics and early 19th-century industrialization endured through a seismic US culture shift in the mid-20th century, and the resulting political will bounded the policy decisions that led to the CAA.²⁹ Results from this analysis have implications for US mental health policy and equity, the Autism CARES Act,³⁰ the MSF, and other key research findings and conclusions.

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US Health Policy

First, to meaningfully drive equitable US health policy, Americans must face the stigmatization of mental illness within our culture and its origins and then reconcile the tension between our historical indoctrination into a greed-driven mindset and our innate desire to be morally good. In her book on political decision-making, Deborah Stone¹⁵³ states that a society creates its “signature” by defining human value and dignity within its culture. Market-driven cultures are inherently competitive, rewarding people who achieve and punishing those who don’t.¹⁵³ Further, market forces create pressure to serve popular tastes, often at odds with commitments to broad community- and trust-building.¹⁵³ This aligns with Roy Grinker’s⁵⁶ conclusions about capitalism and its resultant utilization of institutionalization and medicine as a means to productivity. Stimulant medications for ADHD are an example of this. They neither cure the disorder nor provide constant relief from symptoms for the person taking them. Their value lies in their ability to improve the output (e.g., behaviors, grades, job performance) of the person with ADHD, thereby reducing their stigmatization. The individual’s life outside of being productive remains devalued in finding a solution, harming both the individual and the society that compels this behavior. Are we as a nation aiming for health as a function of productivity or vice-versa?

America, having been entrenched in the market economy for centuries, birthed a culture that simultaneously defined and stigmatized mental disorders based on productivity rather than wellness, making those judged to be less productive invisible. Further, those with mental disorders that are not readily apparent to others but nevertheless result in health and economic inequities for the individuals with them have been marginalized. The contemporary social scientist Brené Brown¹⁴⁹ defines invisibility as the unacknowledged, ignored, or diminished

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humanity and relevance of an individual or a group, and she asserts that it is one of the most painful human experiences.¹⁴⁹ She goes on to reveal that empathy is a tool only truly available when we are open to experiencing another's pain. In addition, recent research¹⁵⁴ has shown that people with a scarcity mindset are significantly less able to respond empathetically to others' pain. This evidence suggests that because American market ideals sharpen our competitive nature and are based on a scarcity mindset, they reduce our capacity to empathize with the pain created by our imposition of invisibility on others who do not conform to them. The resistance to social support, also known as entitlement programs, in federal policymaking is a hurdle that must be overcome to advance public policy and address the invisibility we impose on people with mental disorders. Brown¹⁴⁹ further explains that resentment is related to hidden envy that we tend to experience when we fail to set boundaries or ensure our needs are met. Therefore, Americans who have accepted the distorted market mindset of constant growth and played their part in its continuance without question by tamping down their pain and impairments may harbor envy at the thought of giving resources to others that they believed could only be attained through silent suffering.

America's quest for equity in its people's health and economic outcomes must meet and merge with its entrenched capitalism. Rather than tying human value to productivity, creating a sustainable market economy must attend to valuing the contributions of all and ensuring care without inflicting moral injury on people who cannot contribute and on those who care for them. Kennedy's plan to recognize the dignity of people with mental retardation was a significant step toward American self-awareness and equity. Grinker⁵⁶ observed that the modern neurodiversity movement helps destigmatize people with NDDs by focusing on their abilities in the workplace rather than their disabilities. Realigning America's market values with its moral values and

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tempering its scarcity mindset must be prioritized to promote empathy, the critical component of political will needed to elevate coherent and meaningful health policies. Public health practitioners and policymakers must work dualistically to couple maximally supportive solutions with the policy issues posed by NDDs while simultaneously building empathy in the public to ensure the political will needed for a window of opportunity to open. Health behavior and social marketing theories can be utilized to inform tactical decisions and drive success. Preventing the accumulation of further morbidities and balancing the economic burden of care for those with severe impairments by giving those with less severe impairments an equitable chance to reach their full potential depends on the successful deployment of this strategy.

The CAA²⁹

Two main implications come to light concerning policy for ASD. First, a reckoning between parent advocates of “severe” autism and other parent and self-advocates is needed and inevitable. The former favors further isolation of policy attention, partitioning ASD 3 from ASD categories 1 and 2 (and all other NDDs) through the creation of a stand-alone DSM® category.¹⁵⁵ Believing that their circumstances are not being represented by the DSM® or in policymaking, this bloc of parents has formed their own organization, the National Council on Severe Autism (<https://www.ncsautism.org/>). Alternately, autistic self-advocates and parents champion neurodiversity, and especially the rights of all autistic people. They drive for policy that allows all people with autism to live their fullest lives with the support and care they need across the lifespan. Self-advocates want to feel secure being authentic, seen, and included in society. They want to access healthcare and work, receiving the support they need for their symptoms without experiencing bias from caregivers and colleagues.

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The most obvious common ground for both groups lies in their desperate desire for solutions that provide agency and as much self-reliance as possible for autistic transition-aged persons (i.e., 15-26 years old) and adults. Currently, when IDEA²⁷ no longer covers young adults with ASD, they experience a substantial loss of benefits. Further, only about 10% of autistic adults are employed.²⁶ This leaves both groups, parents and self-advocates, anxious about their futures as they navigate complex housing, healthcare, and financial issues. Kingdon⁴³ points out that a policy community's unity corresponds to its resultant policy stability and congruence. Therefore, to maintain the policy success the ASD community has enjoyed, it should be motivated to align. Otherwise, they risk instability and the potential for the advances of one community to have profoundly negative consequences on the other.

The present analysis indicates another commonality for both groups in recognizing and addressing the source of their scarcity mindset. Determining together what steps may be taken to build a more solid foundation of political will on which to base autism policymaking, especially policies for transition-age and adult programs and services, will provide a roadmap to attaining them. Both groups can then work together toward desired goals.

Policy for other NDDs

This analysis reveals the colossal impact on policymaking of readily available data and diagnostic tools. First, the DSM®-5⁶ has orphaned certain NDDs, reducing their diagnostic and treatment equity. The etiologies of ADHD and SPCD are currently attributed to environmental factors and the same cluster of genetic variants linked to ASD.³¹ However, rather than representing this full genotypic spectrum of linked disorders, the DSM®-5⁶ dissociates the phenotypes of ADHD and SPCD and bestows the term “spectrum” only on ASD. Further, it

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separated SPCD from ASD, leaving its treatment as a stand-alone diagnosis in children without ASD in question as a learning disability under IDEA²⁷ or a medical necessity. It will nevertheless be treated in children with ASD. The effects of delineating clear diagnostic criteria that are consistent with scientific evidence and have established treatment standards cannot be understated. It improves policy equity through the reduction of structural bias.

Second, the data inequity that IDEA²⁷ perpetuates for ADHD, SPCD, and other NDDs matters. ADHD is three to four times as prevalent as autism, yet it has not been regarded as an epidemic like ASD. Autism data from IDEA^{27,111} powered the ASSURE section of the Children's Health Act of 2000¹²⁸ and the CAA,²⁹ resulting in 17 years of appropriations of over three billion dollars to help people with only one of the six NDDs.^{29,156} Concurrently, populations with ADHD, SPCD, and other NDDs have been disproportionately under-represented in education data,^{27,111} health surveillance data, and research funding.¹⁵⁷ Without representative data, these people and their experiences are hidden from policymakers, and their needs remain underserved. As a result, they and their families bear an undue burden of financial, emotional, and health costs accumulated from perpetuated biases, stigmatization, and impediments encountered from an early stage throughout their lives.^{11,15, 17,158,159,160,161,162} On a socio-economic scale, by withholding policy protections from these populations, America risks exacerbating downstream mental health problems instead of tapping the potential of the population with NDDs and their caregivers.^{17,162,163,164,165} Without including other NDDs in policy protections, the opportunity to benefit from this population's improved civic and occupational engagement capacity is lost. Economically, sustaining policy benefits for the most severely impaired must be logically balanced with contributions from people with fewer support needs. Enlarging the latter's contributions can be achieved by investing in their support.

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Public health practitioners and policymakers must endeavor to ensure surveillance data equity regardless of the jurisdiction from which the data are derived. The significant role of IDEA^{27,111} in the reporting of accurate and consistent autism data, on which the CDC relies for decision-making, neglects to build the same evidence base for related NDDs, including ADHD and SPCD. This is a major disadvantage in case-building for advocates attempting to surface NDD issues and policymakers seeking solutions. Advocates, public health practitioners, and policymakers seeking to prevent the accumulation of mental health co-morbidities and poor long-term outcomes for this population must endeavor to build data equity and curate the evidence base to propel their work.

Policy windows open on a schedule when a law must be reauthorized, and the CARES Act's³⁰ next sunset date is September 2024. Advocates for NDD policy with a broader scope than just ASD should capitalize on this scheduled window of opportunity to raise solutions and questions that would bring relief and protection to a broader swath of Americans. Further, Kingdon's⁴³ conceptualization of policy spillover is salient here. A successful policy bid can lead to a window of opportunity for a related issue. Indeed, other NDDs are related to ASD, and now there is evidence that NDDs are upstream contributors to other major policy issues such as overdose deaths, gun violence, poor mental health, suicides, and more. Savvy policy entrepreneurs will see that there are certainly focusing events indicating problems to couple with solutions for NDDs. The solutions can be simple. Every aspect of the CAA,²⁹ research, stakeholder council, data monitoring, and parent and provider education would benefit the broader community of NDDs.

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The time has arrived for upstream prevention of seemingly intractable American health problems that lead to family trauma and generational poverty. “Punctuated equilibrium”¹⁶⁶ is a theory used to explain intermittent periods of substantial change (i.e., “punctuation”), followed by periods of stasis (i.e., “equilibrium”). Kingdon⁴³ suggests that equilibrium in policy cycles may be better-considered adaptation. The CAA²⁹ was a punctuation in mental disorder policy, and the policy community has adapted to its feedback over the past 17 years. The next reauthorization of the Autism CARES Act³⁰ presents a window for another punctuation in the development of NDD policy.

The Multiple Streams Framework

A supplement to Kingdon’s⁴³ model is suggested by the role that the HGP played in opening the policy window for the CAA.²⁹ The MSF is a probabilistic model that leaves room for randomness.⁴³ The HGP’s completion at an opportune time in the progression of autism policy was randomness that boosted the CAA’s²⁹ technical feasibility, politicians’ receptivity, and public acquiescence. With these structural requirements met, what had been only a section of the CHA¹²⁸ was substantially expanded and elevated.

Whether a pattern exists of other instances similar to the randomness in this one is an interesting question. Are there other examples of innovation appreciably clarifying a policy solution floating around the primeval soup or accelerating it in a way that inspires awe and wonder in the public, opening a window of opportunity for a solution or for scaling it up? Future research is suggested that scans for a fourth stream, an innovation stream, flowing independently of the other three and produces occasional breakthroughs that significantly improve policy solutions and create the conditions for opening a window of opportunity.⁴³ Of course, the

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innovation stream does not open policy windows by itself. It must intersect with the problem, policy, and politics streams to elevate a policy to the decision agenda.

Relevance to Other Research

Historical policy-focused analyses of the conditions leading to the CAA²⁹ were not found for comparison to this analysis. However, it has relevance to selected works studying the social and political factors contributing to the phenomenon of autism's increasing prevalence and its overall effects on politics and policy and vice-versa. In her book, *The Politics of Autism*,²⁶ Dr. Bryna Siegel, Ph.D., asserts that America's politics have wrongly prioritized basic science over translational science, depriving the contemporary autistic population and their caregivers of a broader range of evidence-based programs and practices and insurance coverage for them. She further points out the paucity of transition-age and adult support for autistic individuals as an especially troublesome omission of US policy.²⁶ Additionally, she states that the hyperfocus on autism has, in numerous ways, prevented the appropriate identification and treatment of children with other NDDs, such as ADHD, and mental health issues, such as depressive and anxiety disorders and even ID.²⁶ The present research corroborates Dr. Siegel's assertions and provides evidence of the rationale behind the politics. The consensus from key informants was that services and supports for transition-aged and adult autistic people are sorely lacking. Aging out of IDEA's²⁷ coverage is commonly called "falling off the cliff"¹⁶⁷ because of the abrupt decline in available support. The powerful nucleus of autism advocacy threw their entire stake into what was easier to envision, a cure for autism and a future with it eradicated from their lives. In doing so, they neglected to plan for an alternate outcome, and billions of dollars have funded research yielding no meaningful improvements in health, capacity, or quality of life for current autistic people and their families. Public health policymakers must avoid the irresponsible advancement

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of autism solutions that do not adequately support wellness and quality of life for people, including caregivers.

Finally, the historical cultural shift initiated by President Kennedy and its resulting steep incline in the prevalence of ASD since 1990 had social impacts that have shaped autism care. In an examination of the origins of the sharp rise in autism prevalence, Gil Eyal,⁶⁶ a sociology professor at Columbia University, astutely asks, "...why autism was rare in the past."⁶⁶ He then utilizes a social framework to determine that deinstitutionalization led to a new care model made up of parents, psychologists, and therapists who all became part of a "network of expertise"⁶⁶ that advanced diagnostic science and appropriate care standards. The current research endorses those findings and expands them by offering that the media's framing of autism, its increasing coverage frequency, and the rise of the internet as a networking and information-sharing tool contributed significantly to leveling, distributing, and connecting expertise that intensified the effects of the diffusion of the ADOS⁸² and ADI⁸³ instruments. Deinstitutionalization laid the groundwork for the funding of research that led to autism as a stand-alone diagnosis and to the multi-disciplinary approach taken for its care.

Conclusion

This analysis utilized Kingdon's⁴³ Multiple Streams Framework to explore the conditions that led the US to adopt the CAA²⁹ as a single-condition policy. Key informant transcript data indicated that the political stream played the most influential role in its passage, followed by the problem stream and then the policy stream. The literature search corroborated these results. The historical context of free market economic ideals and their distortion resulted in generations of institutionalization and maltreatment of people with NDDs, as well as moral injury to their

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families. President Kennedy's bold plan to include people with "mental retardation" in society and to fund research on it provided the necessary precursor to the CAA. America's acknowledgment of civil rights through the 1960s and 1970s further set the stage for tensions between entrenched and enlightened mindsets. Autism, defined in 1943, only became a policy issue once science parsed its diagnosis from mental retardation and developed standardized tools to facilitate diagnosis. The autism data reported by the DoE each year after 1990 were significant contributors to increasingly frequent media framing of an autism epidemic and a major focusing event, the GAO's 2005 report¹¹⁶ portending financial disaster for America's schools. In the policy stream, a culture clash between the ideals of maximum productivity and the Constitutional and moral tenets of personhood bounded policy experts' choices for a solution. Representative Chris Smith played the role of policy entrepreneur when he coupled solutions from Kennedy's plan with the issue in an autism-dedicated section of the 2000 CHA,¹²⁸ the basis of the CAA.²⁹ Dr. Tom Insel of the NIMH then worked in the political stream with a nucleus of extraordinarily wealthy and socially connected parents and grandparents of children with autism and an NIH board member, Deeda Blair, to open a window of opportunity for the CAA.²⁹ Ultimately, Insel astutely leveraged the fortuitous completion of the HGP and the awe and wonder it generated in the public to foster the political will to propel the CAA through the window.

Implications for US health policy include consideration of advancing the social model of disability to encourage the scrutiny and actions involved in removing structural and physical barriers to meaningful support of people with mental (and other) impairments. Further, disentangling the diagnoses of disorders from disabilities, as done outside the US, would promote prevention and minimize the severity of disabilities from mental disorders. The CAA was a leap toward progress on both these fronts. However, it faces at least two significant

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challenges as it approaches a scheduled window of opportunity, the next reauthorization in September 2024. First is the rift between advocates of policy benefitting only profoundly disabled autistic people and their families versus those for maintaining supports for all people with ASD. Second, policymakers will be increasingly reminded to improve policy equity according to current NDD science and a wider community of Americans with NDDs bearing substantial health and economic burdens. There is common ground for all interested parties in the sustaining economics of increasing the occupational and civic capacity of adults with NDDs and their caregivers. Finally, capitalizing on the unifying effects of awe and wonder offers intriguing prospects for building the political will to advance equitable policy solutions.

The MSF helped organize the vast amounts of complex information involved in this analysis. Results show the progression of the policy cycle for autism from the mid-1990s through 2006. Augmenting this analysis with others relevant to each of CAA's²⁹ reauthorizations, paying attention to the contributions of the IACC, the nucleus of parents and grandparents, and actors at the NIMH and in the Congressional Autism Caucus would be useful for exploring whether the 2014 DSM®-5's⁶ grouping of NDDs has caused consideration for more equitable policy for all people with NDDs at any of these junctures.

Results from this analysis are intended to contribute to the evidence that may be utilized to help policymakers optimize long-term outcomes for people with all NDDs, which would benefit the public health of all Americans. By understanding the conditions of the CAA²⁹ and how they have impacted its outcomes, we can more reliably strategize for and predict the results of future policy alternatives related to ASD and NDDs. A similar analysis of the conditions that led to the 1990 revision of the EAHCA,¹⁰⁸ now IDEA,²⁷ would provide insight into the rationale

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for treating NDDs differently under a separate but historically contingent policy. Further, studies of historical and current framing, data equity, and cultural ideals for ADHD, SPCD, and other NDDs, especially hidden ones, would characterize the barriers faced by people with them and their resultant emotional and financial burdens. Further, current health and economic outcomes associated with these populations would contribute to strategies for influencing the political will needed to enact policies that protect, support, and maximize the capacity of people with them.

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