



CENTER FOR  
DEVELOPMENT  
& DISABILITY

# Moving Targets:

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THE EFFECT OF SHIFTING AUTISM PERSPECTIVES ON  
FAMILIES

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# Science:

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“Statements about autism that are made without scientific evidence could cause more problems than they solve.”

Psychology Today, September 2025

# Where We've Been:

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Leo Kanner – 1943, refrigerator mothers

Bruno Bettelheim – 1967, “the Empty Fortress”

Kanner recanted his premise in 1969, said that autism was “innate”.  
Bettelheim never changed his position that mothers were the cause of autism.

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# What is Asperger's Syndrome?

## An Autism Spectrum Disorder

- Autism affects individuals in different ways, but general symptoms include impairments in speech or communication skills that are usually recognizable from an early age.
- The disorder can affect the individual's motor skills as well, and those affected are usually less likely to make eye contact and may have a fixation on specific parts of objects.
- Individuals with autism sometimes lack interests in developing relationships with their peers as well, and can sometimes lack the desire to engage in make-believe play.

## How is it different from classic autism?

- Asperger's syndrome is, in many ways, a milder form of classic autism.
- Whereas those with autism do not attempt to create relationships, children with Asperger's syndrome attempt to have interactions with others, though they may have difficulty understanding conventional social rules.
- Asperger's syndrome does not usually affect language and communication skills as severely as classic autism. In fact, those with Asperger's usually have a good handle on language skills without a speech delay.

**1994:** Asperger's Syndrome is added to the DSM IV, expanding the autism spectrum to include milder cases in which individuals tend to be more highly functioning

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**1998:** A study published in *The Lancet* suggests that the measles-mumps-rubella (MMR) vaccine causes autism. This finding was quickly debunked.

**2000:** Vaccine manufacturers remove thimerosal (a mercury-based preservative) from all routinely given childhood vaccines due to public fears about its role in autism--even though, again, the vaccine-autism link has been debunked.



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**2013:** The DSM-5 folds all subcategories of the condition into one umbrella diagnosis of autism spectrum disorder (ASD). Asperger's Syndrome is no longer considered a separate condition. ASD is defined by two categories: 1) Impaired social communication and/or interaction. 2) Restricted and/or repetitive behaviors

### Autism Spectrum Disorders (ASD)

- A. Persistent deficits in social communication and social interaction  
B. Restricted, repetitive patterns of behavior, interests, or activities

	<b>Social Deficits</b>	<b>Restricted Behaviors</b>
<b>Severe</b> (Level 3)  Requiring very substantial support	<ul style="list-style-type: none"> <li>- Severe deficits in verbal and nonverbal social communication</li> <li>- Severe impairments in functioning</li> <li>- Very limited initiation of social interactions</li> <li>- Minimal response to social overtures from others</li> </ul>	<ul style="list-style-type: none"> <li>- Inflexibility of behavior</li> <li>- Extreme difficulty coping with change</li> <li>- Restricted/repetitive behaviors markedly interfere with functioning in all spheres.</li> <li>- Great distress/difficulty changing focus or action.</li> </ul>
<b>Moderate</b> (Level 2)  Requiring substantial support	<ul style="list-style-type: none"> <li>- Marked deficits in verbal and nonverbal social communication</li> <li>- Social impairments apparent even with supports in place</li> <li>- Limited initiation of social interactions</li> <li>- Reduced or abnormal responses to social overtures from others.</li> </ul>	<ul style="list-style-type: none"> <li>- Inflexibility of behavior</li> <li>- Difficulty coping with change</li> <li>- Restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts.</li> <li>- Distress and/or difficulty changing focus or action.</li> </ul>
<b>Mild</b> (Level 1)  Requiring support	<ul style="list-style-type: none"> <li>- Without supports in place, deficits in social communication cause noticeable impairments.</li> <li>- Difficulty initiating social interactions</li> <li>- Clear examples of atypical or unsuccessful response to social overtures of others.</li> <li>- May appear to have decreased interest in social interactions.</li> </ul>	<ul style="list-style-type: none"> <li>- Inflexibility of behavior causes significant interference with functioning in one or more contexts.</li> <li>- Difficulty switching between activities.</li> <li>- Problems of organization and planning hamper independence.</li> </ul>

### Social (Pragmatic) Communication Disorder

Meets the social deficits criteria of ASD, but not the restricted behaviours criteria

# Levels of Support – Social Communication (DSM-5)

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## **Level 1: requiring support**

Without supports, deficits in social communication cause noticeable impairments; e.g., atypical or unsuccessful responses to social overtures

## **Level 2: requiring substantial support**

Marked deficits in verbal and nonverbal social communication, apparent even with supports

## **Level 3: requiring very substantial support**

Limited initiation and minimal response to social overtures

# Levels of Support – Restrictive, Repetitive Behavior (DSM-5)

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## **Level 1: requiring support**

Causes significant interference with functioning in one or more contexts

## **Level 2: requiring substantial support**

Appear frequently and interfere with functioning across a variety of contexts

## **Level 3: requiring very substantial support**

Extreme difficulty with change, markedly interfere with functioning in all spheres

# Where we are now:

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2025:

Diversity, Equity, and Inclusion are no longer guiding values/principles of our federal government

The idea of an autism registry

Reexamination of a link between vaccines and autism

Tylenol

Leucovorin

Autism as “a tragedy”

Changes at NIH and CDC

2026:

Changes to the Autism interagency coordinating council

Removal of the list of questionable autism treatments from the CDC web site

Families as paid caregivers cited as an example of “Medicaid fraud.”

# Caregiver Stress

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Autism caregivers experience significantly higher stress, with up to 80% reporting being "stretched beyond their limits". Parents of children with autism often experience higher stress than those raising typically developing children or children with other disabilities, with 75.9% reporting at least mild burden and 33.8%–34% experiencing high or severe caregiving burden.

Pub. Med.

# Caregiver Stress

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## Key Statistics and Findings

- **High-Stress Levels:** Caregivers report significantly higher stress than parents of typically developing children and those with other disabilities.
- **Mental Health Impact:** Approximately 45% of mothers and 48% of fathers reported symptoms consistent with an anxiety disorder, according to, while other studies show 49.6% of caregivers experience overall high psychological distress.
- **Caregiver Demographics:** Most primary caregivers are mothers, who often experience higher levels of stress compared to fathers.
- **Child Factors:** A negative correlation exists between child sensory processing issues and caregiver burden; specifically, 63% of this burden is predicted by the child's sensory, behavior, and developmental scores.
- **Financial Burden:** The need for specialized care often forces parents to change employment or quit, causing financial strain.

# Intolerance of Uncertainty

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Intolerance of uncertainty is a cognitive and emotional tendency where an individual finds the inability to predict future outcomes stressful, unbearable, or threatening .

Key Characteristics and Behaviors:

Need for control to avoid unpredictability

Over preparation/research to prevent unforeseen consequences

Reassurance seeking – asking for confirmation from others

Avoidance – Avoiding situations where outcomes are not guaranteed

Catastrophizing – fearing worst case scenarios



National Institutes of Health (.gov) +3

# Value Based Care

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Value based care is a healthcare delivery model that shifts the focus from the volume of service (fee for service) to the quality of patient outcomes. Providers are incentivized to deliver better care, improve, population health, and lower costs. This approach prioritizes prevention, chronic disease management, and coordinating care to improve patient experience.

Key components and Benefits:

Quality over quantity

Improved outcomes

Reduced costs

Coordinated Care

Improved Experience

**CMS.gov**

Centers for Medicare & Medicaid Services | CMS (.gov) +8

# Value Based Care in Autism

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“If we ameliorate caregiver stress, we support the individual with autism.”

“If we support the individual with autism, we ameliorate caregiver stress.”



# Autism Culture:


## Language & Beliefs

- **Cure Autism Now (CAN)**
- **Defeat Autism Now (DAN)**
- **Orthomolecular treatment – B6 magnesium**
- **Gluten Free – Casein Free Diet**
- **Sensory Integration**
- **Facilitated Communication**
- **Auditory Integration Training**
- **Secretin**
- **Facilitated Communication – spelling**
- **Telepathy**
- **Picture Exchange Communication System**
- **Social Stories**
- **Hyperbaric Oxygen**
- **Applied Behavior Analysis (ABA)**
- **Red Wine and Cilantro**
- **Camel's Milk**
- **Stem Cell therapy**
- **Fecal Implants**
- **Leucovorin**
- **Magnetic e-resonance therapy (MeRT)**

# Suspension of Disbelief

Suspension of disbelief in autism treatment involves navigating the tension between scientific, evidence-based approaches and often unproven or "magical" cures. Effective support focuses on individual needs rather than forced compliance, requiring skepticism to avoid pseudoscientific therapies. Proper treatment emphasizes supporting neurodiversity rather than merely modifying behaviors

Autism Spectrum News



Autistic culture is **culture built around the ways of speaking, thinking, and acting that come naturally to autistic people, or which have been created in Autistic communities.** Autistic culture is the culture created by and for autistics.

<https://www.stairwaytostem.org/educators/autism-101-autism-cultural-responsiveness-for-improved-interaction>

# Autistic Community Autism Community

**Autistic vs. Autism Community:** The "autistic community" refers specifically to people on the spectrum who share a culture, identity, and advocacy goals. The "autism community" is broader, often including parents, professionals, and supporters.

# Perspectives from Autistic Adults:

My family had me in early autism therapy because they didn't accept me for who I am.

My family didn't recognize that I had autism so I missed out on early treatments that could have been helpful for me.

# Science:

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Psychology Today, September 2025

We don't receive wisdom, we must discover it for ourselves after a journey that no one can take for us or spare us.

Marcel Proust

.... there ain't no journey that don't change you some.

David Mitchell

What a long, strange trip it's been.

Robert Hunter/ Jerry Garcia