

IN A DIFFERENT KEY

EXPLORING FURTHER

A concise catalogue of books, articles and programs offering more detail, deeper insight and subject matter expertise around issues raised by the documentary



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Being Autistic: Defining/Describing

It is surprisingly difficult to define or describe autism succinctly. The exact nature of autism, as well its boundaries, has been debated in good faith for decades, literally from the start, when Dr. Leo Kanner admitted to being uncertain exactly what criteria should count toward the diagnosis that he himself created. The uncertainty derives primarily from the fact that an autism diagnosis is based entirely on a person's behaviors, and how they are perceived, which allows significant room for social and subjective interpretation. As a result, definitions can prove extremely flexible, elastic and mutable. The record shows that even the American Psychological Association, whose defining Diagnostic and Statistical Manual is seen to be authoritative, has in fact changed how it defines autism multiple times over the decades. A brief account of this evolution can be found in the book *In A Different Key, the Story of Autism*, in Part VII, Chapter 35. A link to the current DSM definition is included below. Yet another way to approach understanding of what it means to be autistic is to read accounts written by autistic people themselves, and by those who know them best.

Kanner's Definition.

Child psychiatrist Dr. Leo Kanner is credited with publishing the set of medical histories (1943) that proved seminal in establishing the diagnosis of autism (although others in the era had independently been noticing some of the behaviors he described and theorizing their significance). His descriptions of the behavior patterns he observed thus stood as the first widely publicized attempt to "define" autism, and were enormously influential.

- "Autistic Disturbances of Affective Contact." *Nervous Child* 2 (1943): 217–50.
- "Follow-up Study of Eleven Autistic Children Originally Reported in 1943." *Journal of Autism and Childhood Schizophrenia*. 1, no. 2 (1971). 1,2: : 119--45.

The Diagnostic and Statistical Manual, fifth edition, 2013.

The DSM-5 is the standard reference book that healthcare providers use to diagnose mental and behavioral conditions. In order to meet the diagnostic criteria for autism a child must have specific deficits in several areas. DSM-5 defines these criteria. Published by the American Psychological Association, the DSM typically requires a subscription to access, but through an arrangement with the US Centers for Disease Control, anyone can access the DSM's criteria for Autism Spectrum Disorder through [this link: https://www.cdc.gov/ncbddd/autism/hcp-dsm.html](https://www.cdc.gov/ncbddd/autism/hcp-dsm.html)

"Uniquely Human"

A unique book, by Dr. Barry Prizant, one of the longest-tenured autism experts in the field today. His book makes an argument for understanding autism in a new way, one that depends on his own work with autistic people devoted to respecting what they say *they* want and need. Co-authored with Tom Fields-Meyer. *Uniquely Human*, by Dr. Barry Prizant, 2015.

Being Autistic: Defining/Describing (continued)

Autistic Autobiographies

One of the best way to learn what being autistic means is through books by autistic authors. Those listed here are only a starting point.

- ***Look Me in the Eye, My Life with Aspergers***, by John Elder Robison, 2007. John Elder Robison's autobiography is a best-selling account of being autistic. John also tells his personal story in the film *IN A DIFFERENT KEY*.
- ***Thinking in Pictures: My Life with Autism***, by Temple Grandin. Dr. Grandin was one of the first autistic authors anywhere to write about the experience of being autistic. Her story has been told many times, including by Hollywood, but this is her own account of it.
- ***Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome***, by Stephen Shore, 2003
Shore is a professor at Adelphi University and a leading advocate in the autism community

Concepts: Neurodiversity

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John Elder Robison puts its succinctly in *In A Different Key*. “Neurodiversity,” he explains, “is the idea that some amount of neurological diversity is a normal, healthy part of humanity.” The term also describes an influential movement led primarily by autistic people to retire the so-called “medical model of autism, to instill autistic pride, and to insist on full inclusion and empowerment of autistic people as self-advocates.

Neurodiversity Outlined

Discussion: *What is Neurodiversity?*

<https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>

Organizations/Initiatives

- Landmark College’s Center for Neurodiversity aims to advance understanding of the benefits of a neurodiverse society.
<https://www.landmark.edu/center-for-neurodiversity>
- The College of William and Mary’s Neurodiversity Initiative seeks first to serve the campus community and ultimately to be a model for other campuses.
<https://www.wm.edu/sites/neurodiversity>

Books

- *Unmasking Autism: Discovering the New Faces of Neurodiversity*, 2022. By Devon Price
- *The Power of Neurodiversity: Unleashing the Advantages of Your Differently Wired Brain*, 2011, by Thomas Armstrong
- *Divergent Mind: Thriving in a World That Wasn't Designed for You*, 2021, by Jenara Nerenberg

Concepts: Profound Autism

The term “Profound Autism” is a relatively recent coinage intended to recognize the challenges of a subgroup of people on the autism spectrum who are intellectually disabled, minimally verbal and in need of 24/7 supervision. The concept has been developed and promulgated in response to a lack of media and scientific attention to the needs of people in this group, although it is estimated that they constitute up to 48 percent of all people assigned a diagnosis of Autism Spectrum Disorder.

Relevant data

The Prevalence and Characteristics of Children with Profound Autism, 15 Sites, United States, 2000-2016

<https://pubmed.ncbi.nlm.nih.gov/37074176/>

A discussion of the data and its significance, published the Autism Science Foundation

https://autismsciencefoundation.org/press_releases/cdc-profound-autism-statistics/#:~:text=The%20definition%20of%20profound%20autism,with%20autism%20was%2026.7%20percent

Recognition of the category

In 2021 The Lancet Commission met to address the needs of individuals with autism around the world. This meeting resulted in the commission proposing that the autism community begin using the term profound autism to identify and support children with the most severe lifetime needs and supports.

The report:

The Lancet Commission on the future of care and clinical research in autism

<https://pubmed.ncbi.nlm.nih.gov/34883054/>

Commentary:

https://autismsciencefoundation.org/press_releases/cdc-profound-autism-statistics/

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Advocacy

There are at least two national organizations dedicated to pursuing research and policy solutions for the challenges that affect people and families who live with profound autism.

- Profound Autism Alliance
<https://profoundautism.org/>
- National Council on Severe Autism
<https://www.ncsautism.org/>

Book-length portrait

The book *We Walk: Life with Severe Autism* is a collection of essays by Dr. Amy Lutz, who also appears in the film *In a Different Key*. In both the film and her book, Lutz portrays the passions and challenges of her adult son, Jonah, who requires 24/7 support. She does so with nuance, love and respect, while also exploring the complexity of issues like who should decide for those who can't speak for themselves, and similarly difficult issues that arise around profound autism.

Support checklists

A set of guidelines specifically to support profoundly autistic people has been created by the September 26 Project (created in honor of autism activist Feda Almaliti and her profoundly autistic 16-year-old son Muhammed, who died in a house fire on that date in 2020).

- **Fire Safety** <https://www.september26.org/fire-safety>
- **Wandering Prevention** <https://www.september26.org/wandering-prevention>
- **Emergency Preparedness** <https://www.september26.org/natural-disaster>

Intersectionality: Race and Autism

Early diagnosis of autism spectrum disorder is critical for children to have their best chance at the most successful life. The gaps between racial, ethnic and sociodemographic disparities are closing, but currently children of color still suffer from more negative outcomes because of lack of understanding and services.

Studies

Epidemiology

- The US Centers for Disease Control reports the national rate of autism diagnosis on a biennial basis, and breaks the data down by race. The results can be found here: <https://www.cdc.gov/ncbddd/autism/data.html>

Analysis

- A deeper breakdown of the numbers, in a 2022 study: *Racial and Ethnic Differences in Rates and Age of Diagnosis of ASD*. <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2797991>
- A 2021 study that seeks explanations for disparities: *Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8500365/>

Work of Stephanie Keeney Parks

Anthropologist Stephanie Keeney Parks, who appears prominently in the documentary *In A Different Key*, has brought the expertise of her field to the question of race disparities in autism diagnosis. Some of her findings are included in her masters thesis, *Parenting Autism: An Exploratory Study of The Culture and Experience of African-American Parents of Children Diagnosed with Autism*. It can be found here: <https://researchworks.creighton.edu/esploro/outputs/graduate/Parenting-Autism-An-Exploratory-Study-of/991005932504202656>.

Intersectionality: Autism, Girls and Women

Even since Dr. Leo Kanner first described autism in his groundbreaking set of case histories in 1943, a distinctly lopsided ratio of roughly 4-to-1 has persisted of boys-to-girls in getting the diagnosis. There is uncertainty over why this ratio exists, and whether it is in fact primarily an artifact of perception and definition. But its prevalence has had numerous consequences in the way autistic girls and women are recognized and supported.

Articles

- Scientific American. *Autism: It's Different in Girls*, 2016. Maia Szalavitz.
<https://www.scientificamerican.com/article/autism-it-s-different-in-girls/>
- New York Times. *What Autistic Girls Are Made Of*. August 8, 2016.
<http://www.nytimes.com/2007/08/05/magazine/05autism-t.html?ei=5090&en=c14e426fd46d527a&ex=1343966400&adxnnl=1&partner=rssuserland&emc=rss&adxnlnx=1187881435-Dm0mCDI67wJugwa949lu9w&pagewanted=all>
- Spectrum News. 2016. *Women with autism hide complex struggles behind masks*
<https://spectrumnews.org/opinion/viewpoint/women-autism-hide-complex-struggles-behind-masks/>
- New York Times. 2020. *My Daughter and I were diagnosed with autism on the same day*
<https://www.nytimes.com/2020/04/15/parenting/autism-mom.html>

Books

- *Aspergirls*. 2010. Rudy Simone. A collection of essays written by autistic women.
- *Pretending to be Normal: Living with Aspergers Syndrome*. 2014. Liane Holliday Willey
- *Girls Growing Up on the Autism Spectrum: What Parents and Professionals Should Know About the Pre-Teen and Teenage Years*. 2009. Shana Nichols

The Work of Amy Gravino

Amy Gravino features prominently in the documentary *In A Different Key*. She is a certified Autism Specialist and President of ASCOT coaching. She is an international speaker and autism sexuality advocate, and frequent lecturer on issues related to girls and women on the spectrum. The link following presents a 2016 talk she delivered at New York University in 2016, titled *The Girl Behind the Curtain: A Journey Inside the Nooks and Crannies of Autism*. <https://steinhardt.nyu.edu/metrocenter/asdnest/amy-gravino-asd-girls>

Challenging Contexts: Autism and Policing

Studies on Autism and Policing

Numerous studies have explored this challenge, and assessed programs that attempt to address it, going back to the early 2000s. Some of the more recent studies include:

- 2020, “**A Systematic Review of Law Enforcement Training Related to Autism Spectrum Disorder.**”
Available at: <https://journals.sagepub.com/doi/abs/10.1177/1088357620922152?journalCode=foab>
- 2021, **Interactions between Individuals on the Autism Spectrum and the Police**
Available at: <https://academic.oup.com/policing/article-abstract/15/2/950/6008004?login=false>
- 2019, **Measuring Police Officer Self-Efficacy For Working With Individuals With Autism Spectrum Disorder**
Available at: https://uknowledge.uky.edu/cgi/viewcontent.cgi?article=1097&context=edp_etds
- 2023, **The training of New Jersey emergency service first responders in autism awareness**
Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5363970/>

In addition, the topic has frequently been addressed through user-friendly articles published by the Organization for Autism Research, a scientifically based research organization founded to apply research to questions important to autistic people and their families, as well to disseminate information to the autism community. The link below is one of many articles that can be found on their site regarding autism and law enforcement training.

- 2006, **Autism Spectrum and Law Enforcement Training | OAR**
Find at: <https://researchautism.org/oaracle-newsletter/autism-spectrum-and-law-enforcement-training>

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Examples of Legislative Responses

- A federal, bipartisan law enforcement de-escalation training act was signed into law in 2022.
<https://www.congress.gov/bill/117th-congress/senate-bill/4003/text>
- Utah has joined other states in requiring autism awareness training. Here's what Utah's training covers: Lawmakers in Utah, like many places around the country, now require new police cadets to have autism training.
<https://www.ksl.com/article/50166554/law-now-requires-autism-awareness-training-heres-what-utah-police-will-learn>

Programs and Tools

There are several well-regarded individual consultants available to bring training to departments across the US. It is recommended to do individual research in this regard.

In addition:

- The Autism Program at Johns Hopkins All Children's Hospital has developed a training program, with more information available here: <https://www.hopkinsmedicine.org/all-childrens-hospital/services/autism-center/autism-training-for-first-responders>.
- A comprehensive guide created for law enforcement officers contains much useful information. It can be downloaded here: <http://mopca.com/wp-content/uploads/Autism-Guide-for-LE-v2.pdf>
- VirTra (a private firm) has partnered with the Southwest Arizona Research and Resource Center to develop an innovative 3-D interactive simulation trainer focused on interactions with autistic citizens. More information can be found here: www.virta.com.

Challenging Contexts: Autism and Poverty

More than half of autistic children live in low-income households and one in four was living in poverty (2022 data). These circumstances have extreme negative impact on their families' access to services and support, including for the crucial "early intervention" period, which has direct consequences for health and other outcomes. These challenges are as intractable as poverty itself, and require addressing at the social policy level.

Reports and Studies

- *National Autism Indicators Report: The Intersection of Autism, Health, Poverty and Racial Inequity*. 2022. A collaboration between UCLA Health's Department of Medicine and the AJ Drexel Autism Institute, this report examines "how demographics alone, and in combination with other social characteristics of children, are associated with differences in the rates of health and healthcare outcomes they experience." <https://drexel.edu/autismoutcomes/publications-and-reports/publications/NAIRIntersection/>
- *Almost one-third of autistic children in the United States live in poverty*. 2020. <https://www.spectrumnews.org/news/more-than-half-of-autistic-children-in-united-states-live-in-poverty/>
- *Study: Autism Spectrum Disorder Among US Children (2002–2010): Socioeconomic, Racial, and Ethnic Disparities*. 2017. <https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2017.304032>
- Article about the above study: *Autism prevalence and socioeconomic status: What's the connection?* 2017. <https://news.wisc.edu/autism-prevalence-and-socioeconomic-status-whats-the-connection/#:~:text=Children%20living%20in%20neighborhoods%20where,kids%20from%20more%20affluent%20neighborhoods>
- *How low-income parents are working to help their children with autism*. 2019. The Independent. <https://www.independent.co.uk/news/health/autism-poverty-low-income-how-parents-children-spectrum-chicago-a8744496.html>

Challenging Contexts: Bullying in School

As Amy Gravino points out in the documentary *In A Different Key*, all children can face bullying but autistic children are especially susceptible, and the long-term impacts can be profound. The effects have been tied to higher suicide rates, especially among females. But programs exist that can mitigate bullying.

Prevalence of bullying of autistic children

- Two-Thirds of kids with autism have been bullied, according to a survey conducted by the Interactive Autism Network (IAN), a project of Kennedy Krieger Institute.
<https://medicalxpress.com/news/2012-03-two-thirds-kids-autism-bullied.html>
- *Youth with autism spectrum disorder and the transition to adulthood*, 2023. This paper on transitions to adulthood includes information on bullying and its impact. <https://psycnet.apa.org/record/2022-91981-028>

Impacts of Bullying

Article from Children's Hospital of Pennsylvania. 2022.

<https://www.chop.edu/news/health-tip/bullying-and-children-autism-how-help-your-child>

Impact on Suicide Risk

- Paper: *A 20-year study of suicide death in a statewide autism population*. 2019.
<https://pubmed.ncbi.nlm.nih.gov/30663277/>
- Paper: *Suicide ideation and attempts in children with autism*. 2013.
<https://www.sciencedirect.com/science/article/abs/pii/S1750946712000931>

Mitigating Bullying

Article: *A Good Influence*, 2012.

<https://www.spectrumnews.org/opinion/a-good-influence/>

Challenging Contexts: Autism and Employment

Regular employment confers many benefits for all of us: financial, psychological and social. Autistic people, however, face persistent challenges in both attaining and retaining jobs. Data suggests that close to 90 percent of autistic people who could participate gainfully in the economy are either unemployed or underemployed. At least some part of this gap can be bridged if employers make greater efforts to accommodate autistic employees. This would create a win-win outcome, as autistic workers are known to be reliable and effective, and some bring with them unique skills and insights.

Data

- *Outcomes of Young Adults on the Autism Spectrum* (2015) A short presentation extracted from the National Autism Indicators Report, this paper points out that autistic people have the “lowest employment rate across disabilities.” <https://drexel.edu/autismoutcomes/publications-and-reports/publications/employment-outcomes-of-young-adults-on-the-autism-spectrum/>
- Statistics on the absence of services to support employment are presented in *Unrealized Cross-System Opportunities to Improve Employment and Employment-Related Services Among Autistic Individuals* (2023). <https://onlinelibrary.wiley.com/doi/abs/10.1111/1468-0009.12666>

Employment Support Programs

The programs listed below have demonstrated success in offering support to both sides of the equation: autistic employees and their employers.

- The Frist Center for Autism and Innovation, “connecting autism, innovation, employment and technology,” www.vanderbilt.edu/autismandinnovation
- The Precisionists, Inc. A for-profit job placement program that offers bi-directional support in the workplace, supporting both autistic employees and their employers. www.theprecisionists.com
- The Mind Institute. Launched a pilot employment support program in 2023. <https://health.ucdavis.edu/news/headlines/a-new-employment-model-for-people-with-autism-and-intellectual-disabilities-/2023/06>
- Potentia Workforce. A program offering two-way support, inspired by “embracing neurodiversity.” <https://potentiaworkforce.com/>

Autism's History

The documentary IN A DIFFERENT KEY derives much of its authority as a source for understanding autism's rich history from the Pulitzer-nominated book of the same name (full title: *In A Different Key, The Story of Autism*, 2017). For that reason, the book is highly recommended for anyone interested in knowing how we got from a time when autism was not recognized (not long ago) to the present day, when 1 in 35 children is believed to be eligible for a diagnosis. Its range is broad (covering the life of Donald Triplett, the interplay of social forces, the evolution of attitudes, the battle for civil rights of autistic people, among other topics) and therefore it is cited multiple times in the listings below, along with writing by other authors who succeed in bringing the past to life. Why does the history matter? Because it teaches so many lessons still relevant today.

The Life of Donald Triplett

Significantly more detail about Donald's life is available in the book *In A Different Key, The Story of Autism*, in these sections: Part I, Chapters 1,3 and 5-6 and Part X, Chapter 46.

In addition, a detailed profile of Donald appeared in magazine form in *The Atlantic's* October, 2010 issue: <https://www.theatlantic.com/magazine/archive/2010/10/autisms-first-child/308227/>

The iHeart podcast called "Autism's First Child" brings additional details of Donald's life across its seven episodes (while also relating stories of other autistic people today): <https://www.iheart.com/podcast/1119-autisms-first-child-95206331/>

Past Attitudes

While there is still much work to be done to achieve society's full acceptance of autistic people, history demonstrates how much worse things used to be. Society's negative assumptions regarding disability led to terrible abuses, like forced sterilization, and segregation in massive institutional settings. Knowing about this dark past is important, if for no other reason than to recognize the progress made since then, which can inspire those working on more progress still.

A vivid discussion of negative past attitudes can be found in *In A Different Key: The Story of Autism*, Part 1, Chapter 2, and Part III, Chapter 14.

Comprehensive and scholarly accounts of the impulse toward institutionalization can be found in James Trent's book *Inventing the Feeble Mind* and in Harry Bruinius' *Better for All the World: The Secret History of Forced Sterilization and America's Quest for Racial Purity*, 2006. Penguin Random House

Blaming Mothers

Psychiatry's misguided belief that autism in children resulted from bad mothering -- and the astounding harm caused by that error -- are dealt with in detail in *In A Different Key: The Story of Autism*, Part I, Chapters 7-9.

The topic is also discussed by Mitzi M. Walsh in the *AMA Journal of Ethics* <https://journalofethics.ama-assn.org/article/mothers-and-autism-evolution-discourse-blame/2015-04>

A critical profile of Bruno Bettelheim, who popularized this theory, is found in the book *The Creation of Dr. B*, by Richard Pollak.

Autism's History

(continued)

The Battle for Rights

For decades, children with intellectual and developmental disabilities had no legal right to a public school education, which not only denied them the benefits of schooling, but also encouraged widespread institutionalization. The story of the parents and advocates who fought to overcome that social failure -- and ultimately won -- is both inspiring and informative.

The book *In A Different Key, The Story of Autism*, covers personal stories of people involved in the decades-long effort by the parents of autistic people to assert their children's right to education. (They include the Lapin family, who are also seen in the film *In A Different Key*). See book Part II, Chapters 10-12; and Part III, Chapters 14-17.

An account of these battles (not autism-specific) seen from the perspective of the civil rights lawyers who took up the cause can be found in the book *What We Have Done: An Oral History of the Disability Rights Movement*. By Fred Pekla, Amherst: University of Massachusetts Press, 2012.

An ageless account of the broader disability rights campaign as led by disabled people themselves can be found in the book *No Pity: People With Disabilities Forging A New Civil Rights Movement*. By Joseph Shapiro, 1994.

A similar story of disabled people at the forefront of pushing for change is told in the 2020 documentary "Crip Camp," whose home website is at <https://cripcamp.com/>.

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History of Autism Research

In A Different Key, The Story of Autism, deals extensively with psychology's efforts to understand the nature of autism. See Part V, Chapters 25-29; Part VI, Chapter 30, Part VII, Chapter 35.

British historian Adam Feinstein's history also brings focus to the most prominent researchers and conceptualizers in the research and academic fields. *A History of Autism: Conversations with the Pioneers* explores the history of autism through conversations with leading professionals while exploring ongoing historical changes in the understanding of autism. Wiley-Blackwell, 2010.

In a similar vein: Gil Eyal's *The Autism Matrix* (2010) and Chloe Silverman's *Understanding Autism* (2011).