



*Autism in Love*



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# Using This Guide

Indie Lens Pop-Up is a neighborhood series that brings people together for film screenings and community-driven conversations. Featuring documentaries seen on PBS's *Independent Lens*, Indie Lens Pop-Up draws local residents, leaders and organizations together to discuss what matters most, from newsworthy topics, to family and relationships. Make friends, share stories, and join the conversation. Can't attend in person? [Find Independent Lens on Facebook](#) for information on our online Pop-Up events.

This discussion guide is designed as a tool to facilitate dialogue, and deepen understanding of the complex topics in the film *Autism in Love*. It is also an invitation to not only sit back and enjoy the show, but to step up and take action. This guide provides important context on the issues raised in the film, and can serve as a springboard for further research. It raises thought-provoking questions to encourage viewers to think more deeply and spark conversations with one another. We present suggestions for areas to explore in panel discussions, in the classroom, in communities, and online. We also include valuable resources and connections to organizations on the ground that are fighting to make a difference.

**For information about the program, visit [pbs.org/indielenspopup](https://pbs.org/indielenspopup)**

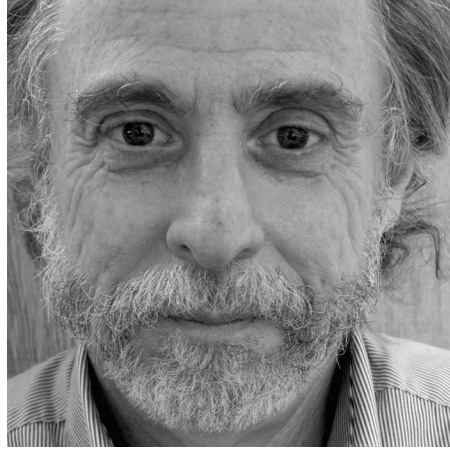


# From the Filmmakers



**Matt Fuller**

Director/Producer, *Autism in Love*



**Ira Heilveil**

Executive Producer, *Autism in Love*



**Carolina Groppa**

Producer, *Autism in Love*

*Autism in Love* represents a labor of love for its filmmakers. The initial idea for the film came as the result of an inquiry into a paradox and the desire to explore what some might consider a prevalent myth. The myth is simply that people who have been diagnosed with autism are incapable of forming deep, loving relationships. The paradox is that the word “autism” means “focused on one’s self,” and yet truly being in an intimate relationship with another person seems to require deep knowledge of the other. How can someone be focused on him- or herself and yet know someone else so well that the relationship can be truly intimate?

The task was set out to create a film that, while it is inevitable that the director’s perspectives will enter into the final product, will be fundamentally honest. In true documentary fashion, no attempt was made to manipulate any of the interactions or scenes in the film. Equally important, we wanted to create a film that, to the greatest extent possible, explored the phenomenon of love through the eyes of the people who were labeled as “autistic.” While we interviewed so-called “experts” in the field, we chose not to use any of that footage because they weren’t the people whose stories we wanted to tell.

From the perspective of the executive producer, I want to individually add that beyond the initial concept and parameters mentioned above, this is truly a “Matt Fuller film.” I believe that what makes this documentary so powerful is that beneath and behind every scene are the relationships that were formed between Matt and the subjects of the film. While Matt crafted an extraordinary final product, it was ultimately his kindness and patience that led to the subjects’ willingness to reveal to him their innermost struggles. Developing that kind of trust is by no means an easy thing to do.

While those of us involved in the creation of this documentary hoped that on the surface it would help all of us to better understand what lives behind the label of autism, we secretly hoped that by getting a glimpse into the lives of others who struggle with love those of us who are currently called “neurotypical” would also learn something about ourselves and about our own struggles with intimate relationships. Ultimately, the question we hope that you will be better informed to answer is this: Are any of us really that different?

—Ira Heilveil, Ph.D. (Executive Producer), Matt Fuller (Director and Producer), Carolina Groppa (Producer)

# The Film



People with autism face many difficulties, and one of those is in the area of romantic relationships. Here, autism creates a distinct disadvantage, as this developmental disorder jeopardizes some of the core characteristics of a relationship — communication and social interaction. However, people diagnosed with autism can, and do, experience romantic love. ***Autism in Love*** explores the lives of four adults as they face the challenges their condition presents in pursuing and managing romance in their lives.

Lenny is a young man living with his single mother in Los Angeles. He very much wants to have a girlfriend, a “serious” girl with whom he would have a traditional relationship in which he is the major breadwinner. But for such a relationship to happen, he says he needs to find a good job. He recognizes that his autism is an impediment to fulfilling his desires, and, consequently, he feels very down on himself. His anger rises to the surface as he expresses his frustration about being different from others who have gone to college, shutting him off from potential friendships. He wishes he wasn’t autistic. His depressed state led to concerns that he might harm himself, and he spent a brief time in a mental health facility in 2013. His pain is palpable as he breaks down in tears talking about how difficult it is to live with his condition. Toward the end of the film, he secures a job bagging groceries at Ralph’s, a Los Angeles supermarket chain, but his emotional state remains tenuous.

Lindsey and Dave are a couple in their 30s who met at an autism conference. They have been involved in a relationship for eight years, during which one or the other has felt hesitant about making a long-term commitment. Intelligent and articulate, they explore their relationship on camera, identifying the challenges they face, their feelings for one another, and the nature of love. Lindsey, who is artistically inclined, eloquently expresses her feelings about being autistic, whereas Dave, the scientist, explains his “formula” for what attracts him to

another person, comparing the stages of a relationship to the electromagnetic spectrum. They both display the maturity and self-awareness that helps build a strong relationship, and by the end of the film, concerns about commitment seem to be resolved. Evidence of their readiness to take their relationship to the next level comes in a touching scene, as Dave proposes and Lindsey accepts.

Stephen is a middle-aged man who lives in St. Paul, Minnesota. Stephen's speech is succinct, precise, and sometimes repetitive, and his answers to questions are to the point and without elaboration. For 20 years, he was married to Gita, who died of cancer in 2013. In an interview before she died, Gita explains that Stephen is the right mate for her because they complement each other. Unlike Stephen, she is very verbal, and he accepts her as she is, despite her mild learning disability. She can tell he loves her by his eyes and the way he looks at her. The camera provides a glimpse of the sadness in Stephen's face when he is asked about Gita after her death. Stephen works at jobs involving repetitive, low-skill tasks and lives in the apartment he shared with Gita, but he maintains close contact with his elderly parents, who still care for him to some degree.

### Selected Individuals Featured in *Autism in Love*



Lindsey

Dave



Lenny



Stephen

## BACKGROUND ON THE SUBJECTS

**Lenny:** Around the time Lenny was 11 years old, his mother Kathy discovered the key characteristics of autism while searching medical journals at a local library. Up until then, he had been misdiagnosed by several physicians. Kathy immediately had Lenny evaluated by a Regional Center (a nonprofit private corporation that contracts with the California Department of Developmental Services to provide services and support for individuals with developmental disabilities), where he was diagnosed with autism. With welfare as her primary income, Kathy was unable to subsidize any therapy or support to help manage his autism. Although Lenny was a client of a Regional Center, he was shifted back and forth between the center and schools for years, both institutions insisting support was the responsibility of the other. Due to this neglect, Lenny received no support or services for his autism until he was 14 years old. After he graduated from high school and “aged out” of entitlement-based public education, he was left on his own to navigate the world as an adult with autism.

**Lindsey:** She was born in Tokyo, Japan, and received her official autism diagnosis at age 2 at the University of California Los Angeles (UCLA) during a visit to the United States. By age 4, she began to develop expressive language and was involved in several years of occupational therapy, speech therapy, and other early intervention programs (along with her autistic brother, who requires more intense support). She eventually earned a BA degree in music technology and photography at the College of Santa Fe, in New Mexico. She works at a nonprofit organization, the Washington, D.C., chapter of the Autism Society of America and devotes her free time to her many interests, including traveling, sexuality research, Japanese culture, photo documenting, and composing music on her 1909 Steinway.

**Dave:** He is a meteorologist with the National Weather Service, a career that grew from an intense childhood interest in the weather, especially thunderstorms. He earned his BS and MS degrees in meteorology at North Carolina State University. His interests include autism advocacy, handyman work, bicycling, kayaking, and traveling. He received early intervention services from Child Development Resources in Williamsburg, Virginia, in the early 1980s and received an official autism diagnosis from the TEACCH (*see “Treatment,” page 8*) program in Chapel Hill, North Carolina, in 1983.

**Stephen:** After surviving the concentration camps in Transnistria (now an autonomous region between Romania and Moldova), Stephen’s parents emigrated from Romania to the United States with their two daughters. They settled in St. Paul, Minnesota, where Stephen was born. Two pioneers of autism research, Bernard Rimland and O. Ivar Lovaas, who were visiting the University of Minnesota, diagnosed Stephen. At the time, there was very little information available about autism. Dr. Lovaas trained several graduate students in behavioral therapy, and they worked with Stephen for a number of years. Stephen and Gita’s relationship resulted from the matchmaking efforts of their parents. The two families knew each other and thought Stephen and Gita (who had some intellectual challenges) would make a good couple. So they were introduced and quickly fell in love.

### Other Individuals from the Film

In addition to the four featured individuals, others who appear on screen include:

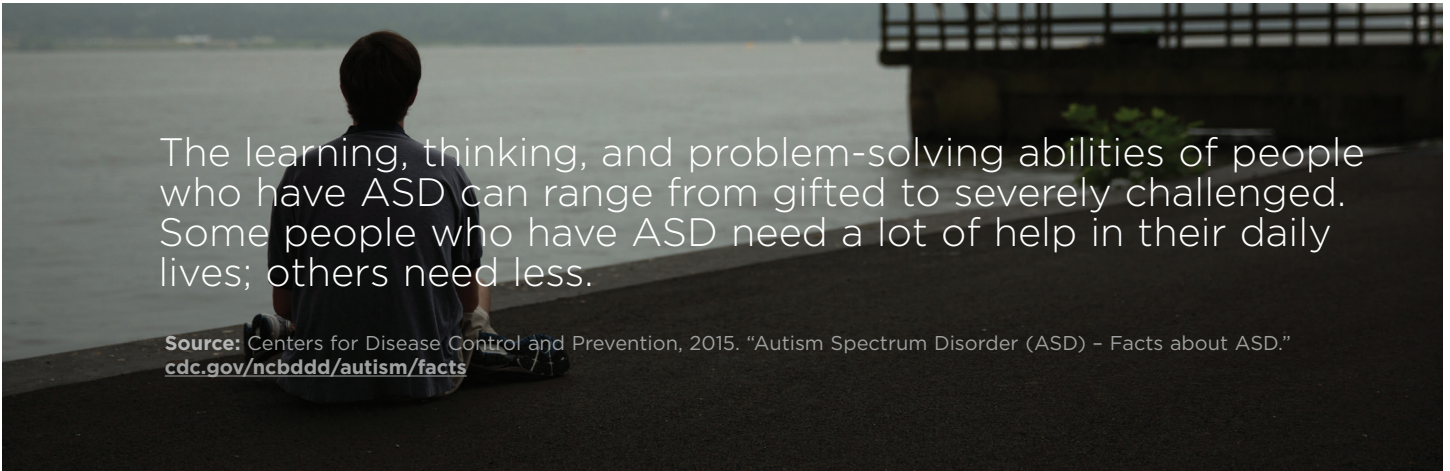
Kathy – Lenny’s mom

Gordon – Lindsey’s father

Edith and Max – Stephen’s parents

Gita – Lenny’s late wife

# Background Information



The learning, thinking, and problem-solving abilities of people who have ASD can range from gifted to severely challenged. Some people who have ASD need a lot of help in their daily lives; others need less.

Source: Centers for Disease Control and Prevention, 2015. "Autism Spectrum Disorder (ASD) - Facts about ASD." [cdc.gov/ncbddd/autism/facts](https://www.cdc.gov/ncbddd/autism/facts)

#### Source:

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#### Source:

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"If you've met one person with autism — you've met one person with autism. —DR. STEPHEN SHORE

## The Autism Spectrum and the Spectrum of Love

The individuals featured in *Autism in Love* fall along different points of the autism spectrum. They also represent a spectrum of love, illustrating the ways we find it, the different stages of a romantic relationship and what it's like to be in one, and the intense longing a person can feel when looking for love. Although the film's focus is on people with autism, many of the insights and challenges it brings to light will be familiar to anyone who has searched for romantic love.

## What Is Love?

The film provides this definition of love: "A profoundly tender, passionate affection for another person; the unselfish, loyal, and benevolent concern for the good of another."

## What Is Autism?

The film provides this definition of autism: "A developmental disorder, present from early childhood, characterized by difficulty in communication and forming relationships with other people and in using language and abstract concepts. Now considered an autism spectrum disorder (ASD)."

*The words autism and autistic stem from the Greek autos, meaning "self."*

According to the Mayo Clinic (2014), "Autism spectrum disorder (ASD) is now defined by the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* as a single disorder that includes disorders that were previously considered separate — autism, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified.

"The 'spectrum' in autism spectrum disorder refers to the wide range of symptoms and severity. Although the term 'Asperger's syndrome' is no longer in the DSM, some people still use the term, which is generally thought to be at the mild end of of autism spectrum disorder."



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- » National Institutes of Health, National Institute of Neurological Disorders and Stroke, 2015. "Autism Fact Sheet." [ninds.nih.gov/disorders/autism/detail\\_autism](http://ninds.nih.gov/disorders/autism/detail_autism)
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- » Centers for Disease Control and Prevention. "Vaccines and Autism: A Summary of CDC Conducted or Sponsored Studies." [cdc.gov/vaccinesafety/pdf/cdcstudieson-vaccinesandautism.pdf](http://cdc.gov/vaccinesafety/pdf/cdcstudieson-vaccinesandautism.pdf)
- » Mayo Clinic, 2014. "Autism spectrum disorder - Causes." [mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/causes/con-20021148](http://mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/causes/con-20021148)

## SYMPTOMS AND DIAGNOSES

The following is adapted from resources from the National Institutes of Health, 2014 and 2015.

The symptoms of ASD and the combination of symptoms differ from individual to individual. This makes it difficult to diagnose the severity of the disorder. Some of the common signs of ASD in young children are:

- Infrequent response to their name
- Poor eye contact
- Delayed language development
- Lack of emotional expression
- Repetitive movements such as rocking, hand-flapping, and head-banging
- Abnormal interests or intense fixation on an object or activity

This is only a partial list of symptoms that may be indicative of ASD. If a doctor or parent is concerned about a child's developmental progress, the child may receive a hearing test, a complete physical and neurological examination, and a screening test for ASD based on diagnostic guidelines provided by the DSM-5.

The Autism Society writes, "There are many differences between a medical diagnosis and an educational determination, or school evaluation, of a disability. A medical diagnosis is made by a physician [or psychologist] based on an assessment of symptoms and diagnostic tests.... An educational diagnosis is made by a multidisciplinary evaluation team of various school professionals. The evaluation results are reviewed by a team of qualified professionals and the parents to determine whether a student qualifies for special education and related services under the Individuals with Disabilities Education Act (IDEA) (Hawkins, 2009)."

## CAUSES

ASD has no single known cause. Because the symptoms and severity of the disorder vary, there are probably multiple causes. Generally, causes fall into two main categories (Mayo Clinic, 2014):

**Genetic:** Research has identified a number of genes associated with ASD. Some studies of people who have ASD have found irregularities in several regions of the brain, and others suggest abnormal levels of certain neurotransmitters. These neural differences may stem from atypicalities in genes that control brain growth in early fetal development. Genetic differences may be sporadic or inherited, as twin and family studies have suggested. Epigenetics is also becoming a significant area of research. This research is not solely focused on the genes that a person possesses; it is also focused on the factors that control gene expression (turning off and on) of those genes that also may play a role (Autism Speaks).

**Environmental:** Research is currently looking into whether such factors as viruses, air pollutants, and complications during pregnancy contribute to autism. Vaccines have been at the center of a controversy linking them with autism (see "*Controversies and Disagreements*"), but no reliable research study has shown such a connection. The American Academy of Pediatrics (2014) and the Centers for Disease Control and Prevention report that there is no link between ASD and vaccines.

## TREATMENT

The notion of treatment for autism is a controversial one, and some individuals in the autism community question whether autism should be treated at all. (See “*Controversies and Disagreements.*”)

At present there is no cure for autism, but a variety of techniques are used to help people function effectively in their environments and to support families in raising autistic children. Many argue that the ideal treatment plan is one that best meets the needs of the individual. Some options for treating ASD are:

**Therapies and interventions.** These address the range of social, behavioral, and communication difficulties associated with ASD. Among the approaches to treating ASD are the following:

- **Applied Behavior Analysis** “focuses on the principles that explain how learning takes place. Positive reinforcement is one such principle. When a behavior is followed by some sort of reward, the behavior is more likely to be repeated. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning” (Autism Speaks, “Applied Behavior Analysis”). Some examples include:
    - **Discrete Trial Training** is a specific approach based on principles from applied behavior analysis and can be applied at any age. This approach uses one-on-one teaching to help the person who has ASD learn new skills by breaking down a whole skill into small parts and teaching each part of the skill until the whole skill is learned. The goal with this approach is to get the child close to normal developmental functioning (Autism Speaks, “Discrete Trial Training”).
    - **Verbal Behavior Therapy** supports an individual to learn language by connecting words with their purposes. The individual learns that words can help achieve desired results (e.g., to receive an object or something from someone). The individual learns how to use words to make requests and communicate ideas, rather than focusing on words as just labels. “To put it another way, this intervention focuses on understanding why we use words” (Autism Speaks, “Verbal Behavior Therapy”).
  - **Early Start Denver Model** (ESDM) is a relationship-based intervention and involves the parents and families of young children. ESDM uses a data-based approach and empirically supported teaching practices, fusing behavioral, relationship-based, and a developmental, play-based approach into an integrated whole that is completely individualized and yet standardized (UC Davis Mind Institute).
  - **TEACCH** (Treatment and Education of Autistic and Related Communication Handicapped Children) focuses on improving a person’s adaptation and skills, but does not expect children to achieve typical development with treatment (National Institutes of Health, 2014).
- Other interventions** include outpatient and school-based approaches to teaching important functional skills. Support for people who have ASD and their families includes the following:
- **Social skills groups** include peers who have ASD, and sometimes those who do not, to learn and practice social skills together with help from skilled therapists (Interactive Autism Network, 2011).

#### Sources:

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- » UC Davis Mind Institute. "Early Start Lab - What is the ESDM?" [ucdmc.ucdavis.edu/mindinstitute/research/esdm](http://ucdmc.ucdavis.edu/mindinstitute/research/esdm)

• **Family therapy** can help support parents, siblings, and other family members as they navigate through living with a child who has ASD. It can also teach family members to interact with that child in ways that promote his or her social skills and communication (Interactive Autism Network, 2012).

• **Individual or group psychotherapy.** These approaches help a person who has ASD and his or her caregivers to manage symptoms of anxiety, depression, behavioral rigidity, and other problems that are common for people who have ASD (Interactive Autism Network, 2012).

• **Assistive and augmentative communication therapy (AAC)** consists of a variety of strategies, including use of sign language and other tools to help a person communicate effectively when they are not skilled at using verbal communication (Autism Consortium, 2012).

#### MEDICATION

Certain medications may be prescribed to treat specific symptoms experienced by many people who have ASD, but there are no medications that treat autism itself. For example, antidepressants may be used for anxiety, depression, and obsessive-compulsive disorder, and antipsychotic drugs may be given for severe behavioral problems. Impulsivity and hyperactivity may be treated with medication used for attention deficit disorder (National Institutes of Health, 2015; Mayo Clinic, 2014).

#### OTHER TREATMENTS

• **Dietary interventions**, such as eliminating dairy products or foods containing gluten, have been cited anecdotally as helpful for some children, but parents are cautioned to consult their pediatrician to make sure the child's nutritional needs are being met (National Institutes of Health, 2015). Some classify dietary interventions as alternative therapies (see below).

• A number of **alternative therapies** exist, but there is little or no scientific evidence to support their effectiveness. Although some of these may be helpful in combination with the therapies and interventions described above, many professionals recommend that parents be careful about adopting any unproven treatments.

# PIONEERS

In the history of autism as a known disorder, three major figures stand out.

## EUGEN BLEULER

**(1857–1939)** was a Swiss psychiatrist whose work focused on schizophrenia. His study of schizophrenics led to the introduction of two terms describing major symptoms of the condition: *ambivalence* – the coexistence of mutually exclusive contradictions within the psyche – and *autism*, a term he introduced in 1911 referring to the loss of contact with reality, frequently through indulgence in bizarre fantasy. Autism was once considered a symptom of schizophrenia, but under our current understanding of both conditions, autism is completely unrelated to schizophrenia. The term *autism* was later adopted by Leo Kanner and Hans Asperger to describe children with affective disorders and the inability to engage in social relationships.

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### Sources:

- » The New York Times, 1981. “Obituaries – Dr. Leo Kanner, 86, Child Psychologist.” [nytimes.com/1981/04/07/obituaries/dr-leo-kanner-86-child-psychologist](http://nytimes.com/1981/04/07/obituaries/dr-leo-kanner-86-child-psychologist)
- » Simons Foundation Autism Research Initiative, 2007. “Leo Kanner’s 1943 paper on autism.” [sfari.org/news-and-opinion/classic-paper-reviews/2007/leo-kanners-1943-paper-on-autism-commentary-by-gerald-fischbach](http://sfari.org/news-and-opinion/classic-paper-reviews/2007/leo-kanners-1943-paper-on-autism-commentary-by-gerald-fischbach)

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## LEO KANNER

**(1894–1981)** was a psychiatrist who was the first to describe “infantile autism,” a spectrum of clinical conditions manifested by extremely socially detached children. He differed from Bleuler in that he did not consider autism an early form of schizophrenia. Born in Austria and educated in Germany, Kanner immigrated to the United States in 1924. In 1930, he founded the Johns Hopkins Children’s Psychiatric Clinic, the first such clinic in the country. Based on his clinical work, he wrote *Child Psychiatry* in 1935, the first English language textbook on the topic. His “Autistic Disturbances of Affective Contact” published in 1943 is a seminal paper that is one of the bases for the modern study of autism.

## HANS ASPERGER

**(1906–1980)** was an Austrian physician. “In 1944, he observed four children in his practice who had difficulty integrating socially. Although their intelligence appeared normal, the children lacked nonverbal communication skills, failed to demonstrate empathy with their peers, and were physically awkward. Their speech was either disjointed or overly formal, and their all-absorbing interest in a single topic dominated their conversations. Dr. Asperger called the condition ‘autistic psychopathy’ and described it as a personality disorder primarily marked by social isolation” (National Institutes of Health, 2014). He referred to some children with this condition as “little professors” because they could talk about their favorite subject in great detail. Asperger’s work remained largely unknown until after his death, when English translations became available.

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**Source:**

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## DEFINITIONS

**NEUROLOGICAL DISORDERS** are diseases of the central and peripheral nervous system — in other words, the brain, spinal cord, cranial nerves, peripheral nerves, nerve roots, autonomic nervous system, neuromuscular junction and muscles. These disorders include epilepsy; Alzheimer’s disease and other dementias; cerebrovascular diseases, including stroke, migraine, and other headache disorders; multiple sclerosis; Parkinson’s disease; neuroinfections; brain tumors; traumatic disorders of the nervous system, such as brain trauma; and neurological disorders resulting from malnutrition (World Health Organization, 2014).

**MENTAL DISORDERS** are psychiatric illnesses, or diseases that appear primarily as abnormalities of thought, feelings, or behavior, producing either distress or impairment of function (World Health Organization, 2014).

**NEURODIVERSITY** is a concept in which neurological differences are to be recognized and respected as any other human variation. These differences can include those labeled with dyspraxia, dyslexia, attention deficit hyperactivity disorder, dyscalculia, autistic spectrum, Tourette’s syndrome, and others. For some autistic people, neurodiversity is viewed as a concept and a social movement that advocates for viewing autism as a variation of human wiring, rather than a disease. As such, neurodiversity activists reject the idea that autism should be cured, advocating instead for celebrating autistic forms of communication and self-expression and for promoting support systems that allow autistic people to live as autistic people (National Symposium on Neurodiversity at Syracuse University).

**THEORY OF MIND** can be summed up as a person’s inability to understand and identify the thoughts, feelings, and intentions of others. Having difficulty recognizing and processing the feelings of others is sometimes referred to as “mind-blindness.” Some believe that theory of mind deficits can be used to explain the social and communication impairments that define ASD (Autism Speaks; Indiana University Bloomington, Indiana Resource Center for Autism).

### FACTS FROM THE CENTER OF DISEASE CONTROL AND PREVENTION (2014)

*Note:* Facts surrounding autism and its prevalence are debated, are often considered controversial, and change from year to year.

- About one in 68 children has been identified with ASD, according to estimates from the Centers for Disease Control and Prevention’s Autism and Developmental Disabilities Monitoring (ADDM) Network.
- ASD is reported to occur in all racial, ethnic, and socioeconomic groups.
- ASD is almost five times more common among boys (one in 42) than among girls (one in 189).
- Prevalence of autism in children in the United States increased by 119.4 percent from 2000 (one in 150) to 2010 (one in 68).

**Source:**

- » Centers for Disease Control and Prevention, 2014. “Autism spectrum disorder (ASD) - Data & statistics, prevalence.” [cdc.gov/ncbddd/autism/data](https://www.cdc.gov/ncbddd/autism/data)

**Awareness of [autism spectrum] disorder and improved screening methods have contributed to the increase in diagnoses in recent years.**

# Controversies and Disagreements

The diagnosis and treatment of ASD is marked by several controversies, which stem from four perspectives on autism identified by Dr. Thomas Insel, director of the National Institute of Mental Health. According to Dr. Insel (National Institutes of Health, 2013), a kind of community, or “kingdom,” has grown up around each of these perspectives, with distinct assumptions, literature, and organizations, and this has created confusion for families seeking to find help and support for a loved one with the disorder. Each group holds to its own views, with different implications for dealing with ASD. Here is a summary of those perspectives:

## ILLNESS

This kingdom, “largely populated by clinicians, researchers, parents, and some people with autism, views autism as a brain disorder in which the language of medicine applies, with a focus on improving diagnosis and interventions, and cure as the ultimate goal.” Rather than seeing autism as a disability needing improved services and supports, “the illness kingdom focuses on biomedical approaches to reduce the need for services and supports.”

## IDENTITY

This kingdom, founded by young adults with autism who can live independently, views autism as a “difference in need of accommodation, not a disorder in need of cure.” These self-advocates, “rather than seeking to become ‘neurotypical’... advocate for acceptance or inclusion.... They see causal explanations as irrelevant and view treatment as coercive conformity.... Their focus is on community supports, educational and occupational services, and civil rights.”

## INJURY

This kingdom is focused on “the purported role of vaccine injury as a cause” of autism. It was “founded by parents who report marked regression in their previously interactive, communicative toddler after the 18-month vaccination series.” They feel that “mainstream science and medicine have failed them and [they] have turned to alternative treatments based on detoxification, diet, or oxidative stress.” Assuming that autism has been caused by injury, they advocate for prevention to stop the soaring prevalence of autism.

## INSIGHT

This is the kingdom of social neuroscientists who “assume that the study of people with social and communication deficits is a remarkable opportunity to understand the social brain.” These scientists use “tools from cognitive science, neuroimaging, and neuroanatomy to map brain pathways for social information such as face recognition or theory of mind. They feel their studies are critically important even when they do not reveal a cause or a cure for autism.”

These nonoverlapping perspectives have created a good deal of divisiveness within the autism world. Dr. Insel calls for finding common ground so that all of these communities can work together, starting with the need for better services.

### Source:

- » National Institutes of Health, National Institute of Mental Health, 2013. “Director’s blog: The four kingdoms of autism.” [nimh.nih.gov/about/director/2013/the-four-kingdoms-of-autism](http://nimh.nih.gov/about/director/2013/the-four-kingdoms-of-autism)

# Adults with Autism

What happens when children with autism become adults with autism and want to have lives of their own? As with romantic relationships, they can face some serious challenges. Becoming an adult in American society means learning to live independently, finding employment, and being responsible for your own needs at a level that matches one's cognitive and functional ability levels. If they have been fortunate enough to have good support services and strong parent advocates through elementary and high school, many young people who have ASD can have a good start toward independence in their adult lives. But some children miss out on getting good services, often through a lack of financial means or familial support or because of inadequate school or community resources. Even if they have received an educational classification of autism and been provided services mandated by the Individuals with Disabilities Education Act (IDEA), that entitlement-based help ends once they graduate. The need for services, however, continues beyond the school years, and those are much harder to find. Adult services are usually available based on eligibility, including consideration of a person's functional ability levels on specific tests, unlike public education's entitlement-based services

## Sources:

- » Autism Society. "Adulthood." [autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood](https://autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood)
- » Autism Society. "Employment." [autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/employment](https://autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/employment)
- » Autism Society. "Residential/Housing." [autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/residentialhousing](https://autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/residentialhousing)
- » Autism Society. "Social/Relationships." [autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/socialrelationships](https://autism-society.org/living-with-autism/autism-through-the-lifespan/adulthood/socialrelationships)

## Importance of Independence

Not all cultures embrace the idea of grown children moving away from home, but in American culture, this is a hallmark of independence. Whether going away to college or having their own apartment, young people are expected to develop skills at the level of their cognitive ability in managing finances, caring for personal possessions, structuring their time, and dealing with the other mundane tasks of daily life. The ability to attend to these tasks is considered a sign of competence and maturity.

Three main areas where people who have autism often need support in the transition to adulthood are (Autism Society, "Adulthood"):

**Living arrangements.** Depending on how well an individual is able to manage everyday tasks, he or she may live in a supervised group home with several other people; a supervised apartment, either alone or with another person; or completely independently with little or no support from outside agencies. All of these arrangements depend on the availability of services and facilities in the community (Autism Society, "Residential/Housing").

**Employment.** Even if they do not live independently, having meaningful work is very important for everyone, including for people who have autism. Being employed is linked to feelings of self-esteem, and the structure of work contributes to the comfort and predictability of day-to-day life. For someone with autism, successful employment takes advantage of the individual's skills and abilities. People who have ASD may engage in competitive employment, the most independent situation, in which they may need only minor accommodations; supported employment, which provides a system of supports that enables the person to work; and secure or sheltered employment, which is in a facility-based setting and sometimes is accompanied by skills and behavior training (Autism Society, "Employment").

Thirty-five percent of young adults aged 19–23 who have autism have not had a job or received education after leaving high school.

**Social relationships.** Because of the nature of ASD, people who have the disorder have a hard time finding friends. Although it is assumed that people with autism prefer to be alone, loneliness can be a problem. Thus, having support in finding and developing friendships is a critical element in quality of life and involves not only honing communication skills, but also identifying ways to meet others with shared interests (Autism Society, "Social/Relationships").

## Source:

- » Pediatrics, 2012. "Postsecondary education and employment among youth with an autism spectrum disorder." [ncbi.nlm.nih.gov/pmc/articles/PMC3362908](https://pubmed.ncbi.nlm.nih.gov/pmc/articles/PMC3362908)

# Topics and Issues Relevant to *Autism in Love*

A screening of *Autism in Love* can be used to spark interest in any of the following topics and inspire both individual and community action.

In planning a screening, consider finding speakers, panelists, or discussion leaders who have expertise in one or more of the following areas:

**AUTISM SPECTRUM DISORDER (ASD)**

**LOVE, RELATIONSHIPS, AND DATING**

**DEVELOPMENTAL PSYCHOLOGY  
NEUROLOGY**

**SPECIAL EDUCATION**

**INTERPERSONAL COMMUNICATION**

**SUPPORT SERVICES FOR PEOPLE WITH AUTISM**

**JOB TRAINING AND MENTORSHIP PROGRAMS**

# Sparking Discussion

## **Audience Conversation Starter**

Whether you are hosting or joining an Indie Lens Pop-Up event, we recommend that you ask everyone in the audience and yourself the following pre- and post-screening questions. Encourage participants to talk with one another about their responses! For example, ask participants to turn to a person sitting near them to share their answers for two minutes, then invite a few people to share with the entire group.

### **Before watching the film:**

What is your definition of love?

### **After watching the film:**

In the film, Dave shares his “formula” for love: 25 percent looks, 25 percent personality, 50 percent how the other person treats you. What is your formula for love?

### **Sample Discussion Questions**

1. What new insights has this film given you regarding autism or anyone you know on the autism spectrum? Does it counteract any of the stereotypes in our society of people who have autism? In what ways?
2. What does the film teach about love? Are there differences between different types of love, for example, parental love, romantic love, platonic love? Describe some of those differences.
3. Consider that the word *autism* has stems in the Greek word for “self” and has connotations of being self-focused. Do you think that someone can be self-focused and at the same time love someone else?
4. In the film, Lindsey asks whether someone can love you without understanding you. Separately, Dave states that it’s impossible for someone to love you without understanding you. How would you respond to Lindsey’s question? Do you agree with Dave? Explain.
5. Compare Dave and Lindsey’s relationship and communication to that of two people who are not autistic. How are the relationships different? How are they the same?
6. Lenny wonders what the viewers will think about him crying. What was your reaction to that scene? What do you think are some of the greatest obstacles that Lenny faces in finding romantic love? What are your ideas for things that could help support him?
7. Do you think it matters that Gita herself is not autistic, but is in a relationship with Stephen? Do you think this difference between Gita and Stephen plays any role in their relationship together? Gita mentions that they complement each other. In what ways do you think this is true?
8. The conditions and skills of the individuals in the film put them at different points on the autism spectrum. Do you see any commonalities among them? How does seeing these different individuals help you have a better understanding of ASD?
9. How do you think the backgrounds of and resources available to each person in the film affects his or her journey with autism? What about with love? And having a career?
10. Opinions differ on the diagnosis and treatment of autism, and feelings often run high on these two matters. Why do you think there is controversy on whether and how people who have ASD should be diagnosed and treated (if at all)? What are your own thoughts on these matters, and are they at all informed by the film?



# Suggestions for Action

1. What resources are available to support people in your community who have autism, either through local schools or through nonprofit organizations? Explore the opportunities for volunteering your time to work with autistic and other special needs individuals.
2. Invite educators of special needs children and adults as well as mainstream classroom teachers to talk to your business association, faith group, or other community organization about how they work with autistic individuals. Learn how your group can create a welcoming environment for people on the autism spectrum, and be supportive of the work of these educators.
3. The Autism Society has affiliates in all 50 states, the District of Columbia, and Puerto Rico. Contact your local affiliate ([autism-society.org/about-the-autism-society/affiliate-network](https://autism-society.org/about-the-autism-society/affiliate-network)) to find out how you can participate in

National Autism Awareness Month (April) and other activities they sponsor throughout the year. More specifics about getting involved can be found at [autism-society.org/get-involved/other-ways-to-get-involved](https://autism-society.org/get-involved/other-ways-to-get-involved).

4. Walk Now for Autism Speaks is a signature awareness and fund-raising event of Autism Speaks. Join a walk in your area or help to organize one. Autism Speaks also sponsors cycling events and triathlons. Find more information at [events.autismspeaks.org/site/apps/kd/eventcentral.asp?c=rtK2KfMSKsG&b=7800731](https://events.autismspeaks.org/site/apps/kd/eventcentral.asp?c=rtK2KfMSKsG&b=7800731).

For additional outreach and engagement ideas, visit [pbs.org/autisminlove](https://pbs.org/autisminlove). For local information, check your PBS station's website.

## Resources

Note: Each resource's description is primarily adapted from language provided on the organization's website.

[pbs.org/autisminlove](https://pbs.org/autisminlove) - This is the *Independent Lens* broadcast companion website for the film.

[autisminlove.com](https://autisminlove.com) - website for the film; follow updates about the subjects in the film.

### Basic Information

[pbs.org/pov/neurotypical/autism-history-timeline.php#.VehmeLxVikp](https://pbs.org/pov/neurotypical/autism-history-timeline.php#.VehmeLxVikp) - The timeline "A Cultural History of Autism" was created by POV as part of its resources to accompany the documentary *Neurotypical*

Each of the following websites contains definitions and information on causes, risk factors, and treatments for ASD, as well as lists of additional resources:

[nlm.nih.gov/medlineplus/ency/article/001526](https://nlm.nih.gov/medlineplus/ency/article/001526) - Medline Plus, a service of the National Library of Medicine

[ninds.nih.gov/disorders/autism/detail\\_autism](https://ninds.nih.gov/disorders/autism/detail_autism) - National Institute on Neurological Disorders and Stroke

[mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/causes/con-20021148](https://mayoclinic.org/diseases-conditions/autism-spectrum-disorder/basics/causes/con-20021148) - Mayo Clinic, one of the country's premier centers of medical care, research, and education

[cdc.gov/ncbddd/autism/facts](https://cdc.gov/ncbddd/autism/facts) - Centers for Disease Control and Prevention

[nami.org/Learn-More/Mental-Health-Conditions/Autism](https://nami.org/Learn-More/Mental-Health-Conditions/Autism) - National Alliance on Mental Illness

[kidshealth.org/kid/health\\_problems/brain/autism](https://kidshealth.org/kid/health_problems/brain/autism) - Kids Health website; explains autism in easy-to-understand language

### Research and Advocacy

[autism-society.org](https://autism-society.org) - The Autism Society is a grassroots organization devoted to increasing public awareness about the day-to-day issues faced by autistic people, advocating for appropriate services for individuals across the life span, and providing the latest information regarding treatment, education, research, and advocacy.

[autismspeaks.org](https://autismspeaks.org) - Autism Speaks is a leading science and advocacy organization dedicated to funding research into the causes, treatments, prevention, and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals who have autism and their families.

[autisticadvocacy.org](https://autisticadvocacy.org) - The Autistic Self Advocacy Network (ASAN) is a national grassroots disability rights organization for the autistic community run by and for autistic people. ASAN advocates for system changes and ensuring that the voices of autistic people are heard in policy debates and works to educate communities and improve public perceptions of autism.

## Resources for Parents

[feat.org](http://feat.org) – Based in the western United States, Families for Early Autism Treatment is a nonprofit, volunteer-driven organization that provides comprehensive information for parents in caring for and advocating for their ASD child.

[parentcenterhub.org](http://parentcenterhub.org) – The Center for Parent Information and Resources, funded by the Office of Special Education Programs at the U.S. Department of Education (OSEP), supports OSEP's Parent Center network and the role Parent Centers play in educating parents and improving outcomes for children with disabilities.

[parentcenterhub.org/repository/idea](http://parentcenterhub.org/repository/idea) – This page of the federally funded Center for Parent Information and Resources website provides comprehensive information on IDEA, including summaries of the law and its requirements, guidance on implementation, and training materials for parents and other advocates.

[autismspectrumexplained.com/autism-controversies](http://autismspectrumexplained.com/autism-controversies) – Created by the sibling of an autistic individual, Autism Spectrum Explained contains a wide variety of information about autism, including the needs of autistic people, how to interact with them, advice for parents, explanation of the controversies surrounding autism, and resources.

## Transition to Adulthood

[autismafter16.com](http://autismafter16.com) – Autism After 16 is dedicated to providing information and analysis of adult autism issues, with the emphasis on analysis.

[webmd.com/brain/autism/news/20130823/who-will-care-for-children-with-autism-when-theyre-adults](http://webmd.com/brain/autism/news/20130823/who-will-care-for-children-with-autism-when-theyre-adults) – This WebMD article describes the issues related to the transition to adulthood for people who have ASD.

[autismspeaks.org/family-services/resource-library/adults-autism](http://autismspeaks.org/family-services/resource-library/adults-autism) – Autism Speaks offers an extensive list of resources to support adults who have autism.

[articles.chicagotribune.com/2012-05-15/lifestyle/sns-rt-us-adult-autismbre84e13t-20120515\\_1\\_young-adults-asd-autism-spectrum-disorder](http://articles.chicagotribune.com/2012-05-15/lifestyle/sns-rt-us-adult-autismbre84e13t-20120515_1_young-adults-asd-autism-spectrum-disorder) – This May 2012 article from the Chicago Tribune reports on recent research into the struggles faced by young people as they transition into adulthood.

[forbes.com/sites/helainahovitz/2014/04/01/after-graduation-more-awareness-and-funding-needed-for-young-adults-with-autism](http://forbes.com/sites/helainahovitz/2014/04/01/after-graduation-more-awareness-and-funding-needed-for-young-adults-with-autism) – This Forbes article describes challenges faced by young adults who have autism and a few of the programs available to them.

## Resources for Adults with ASD

[wrongplanet.net](http://wrongplanet.net) – Wrong Planet is a web community designed for individuals (as well as their parents and professionals) with autism, Asperger's syndrome, attention deficit hyperactivity disorder (ADHD), pervasive developmental disorders, and other neurological differences. It provides a discussion forum, articles, how-to guides, a blogging feature, and more, including an article about being in love ([wrongplanet.net/positive-relationships-possible-people-spectrum-love-autism](http://wrongplanet.net/positive-relationships-possible-people-spectrum-love-autism)).

[loveandautism.com](http://loveandautism.com) – Love and Autism is an annual conference devoted to love and relationships as they pertain to those on the spectrum across the life span. The conference bridges lived experience, clinical practice, and research.

[succeedsocially.com/aspergers](http://succeedsocially.com/aspergers) – This section of the Succeed Socially website offers comprehensive descriptive information on Asperger's syndrome and how it affects adults and their interpersonal relationships.

# Credits

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Independent Television Service (ITVS) funds, presents, and promotes award-winning documentaries on public television, innovative new media projects on the Web, and the Emmy® Award-winning weekly series *Independent Lens* on Monday nights at 10 pm on PBS. Mandated by Congress in 1988 and funded by the Corporation for Public Broadcasting, ITVS has brought thousands of independently produced programs to American audiences. Learn more at [itvs.org](http://itvs.org).

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