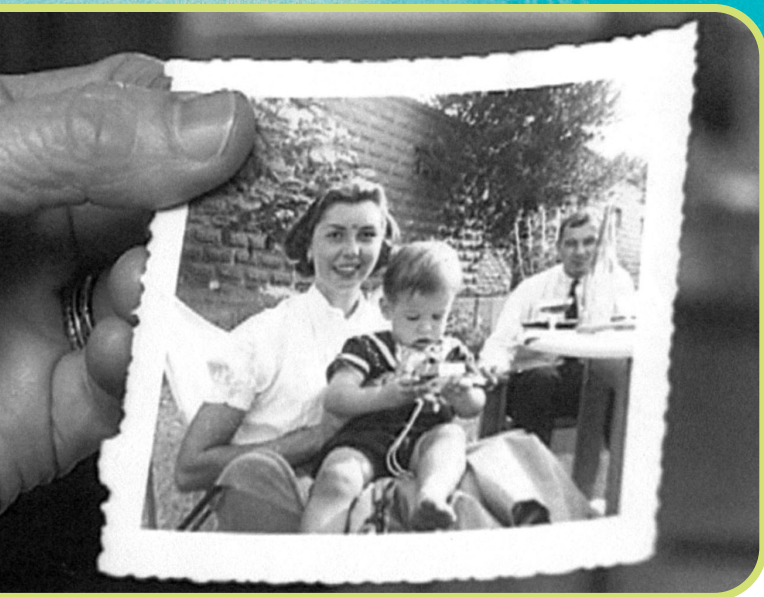


# Refrigerator

## Mothers



*Premiering*

on P.O.V. July 16, 2002  
at 10:00 PM EST on PBS.

**itvs** community connections project



## FILMMAKERS' STATEMENT

### SIMPSON:

I am often moved to investigate and document the courage of people when their artistic, spiritual or political journeys lead them into uncharted waters. What drew me to REFRIGERATOR MOTHERS was the sense that these women harbored stories of unfathomable sorrow and strength. On top of having to deal with their children's sometimes extreme behavior, these parents were blamed for causing autism through some tragic flaw of their own. The fact that so many parents did survive the blame, guilt and grief is a testimony to their strength and to the nearly unbreakable bond at the heart of familial love.

### HANLEY:

I was inspired to make REFRIGERATOR MOTHERS after my own experience with mother blame a few years ago. When I sought help from our pediatrician for my three-year-old son's failure to speak and his strange, self-isolating social behaviors, the doctor blamed what he presumed to be my overanxious, overbearing mothering and advised me to leave my son alone. My son was diagnosed months later with pervasive developmental disorder/autism. In the '50s and '60s, when blaming mothers was all the rage, what must it have felt like to be burdened not only with one's own feelings of guilt, but with the reproach of an entire professional community for having caused this mystifying and troubling disorder in one's own child? Through this film, I hope to honor a generation of mothers who truly went it alone and whose children had little or no access to treatments that I believe have assured my child a bright and productive future. I wanted to recognize the contributions made by these mothers, many of whom laid the groundwork for activism and advocacy in autism. Even today, many healthcare professionals remain uneducated about autism and its symptomatic behaviors. As a result, they often apply the remnants of blame when approached by parents like me who are desperately seeking help for their children. I hope this film helps raise awareness of this growing disorder and reminds us of the beauty and humanity of autistic people.

### QUINN:

With REFRIGERATOR MOTHERS, I saw an opportunity to show one facet of the tragic human consequences of experts who rely solely on their own beliefs and limited observation, allowing a sense of arrogance to eclipse common sense. Kartemquin's mission is to tell stories from the point of view of the people and families who are confronted by the challenges of life in our American democracy. The story of how these mothers overcame someone else's mistake is an inspiration and lesson for us all.

*Refrigerator Mothers*  
By David E. Simpson,  
J.J. Hanley and  
Gordon Quinn  
  
A Kartemquin Educational  
Films production.



THE FILMMAKERS



## REFRIGERATOR MOTHERS

In the 1950s and '60s, at a time when society thought a woman's most important job was to raise happy, well-adjusted children, mothers of children diagnosed with autism faced a life-long struggle with guilt and grief. When parents noticed the various symptoms of autism—the child's failure to develop speech, his or her self-isolation and repetitive behaviors—they went to doctors, often psychiatrists, to understand what was wrong with their children and to get help. The experts explained their child's characteristic symptoms not as biologically based, but as a reaction to something in the psychological environment. Suspicion naturally fell on the mother who was home all day with the child. These mothers were subjected to an inquisition into their personalities, their mothering skills, their marital relationships and their supposed emotional coldness. Along with the diagnosis of autism for their children, these mothers received a diagnosis of their own: "refrigerator mothers."

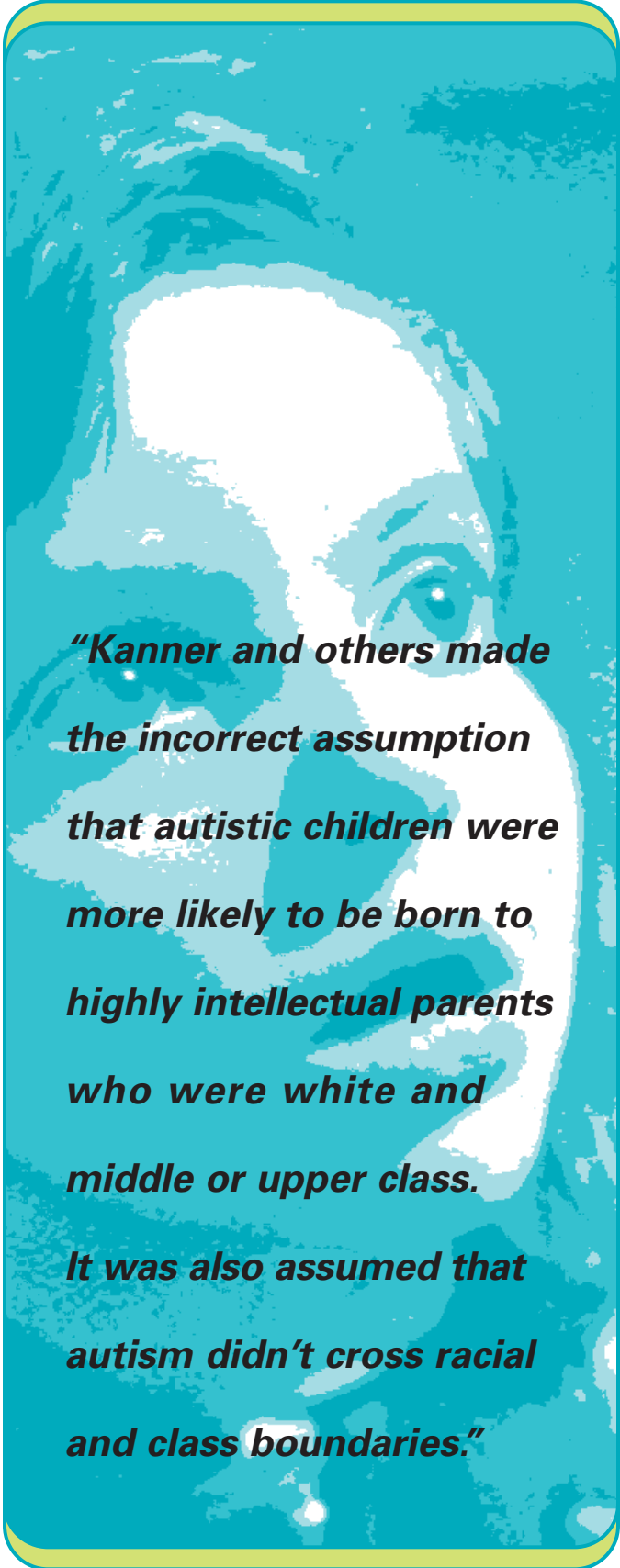
## WHAT IS AUTISM?

Autism is a lifelong developmental disability affecting learning, verbal and non-verbal communication and social interaction. An incurable but treatable neurological disorder, autism occurs in all racial, ethnic and social groups. Though autistic children share many characteristics, there is no single cause for the disorder. Genetics may be a factor; other factors may include viral infections (before or after birth), environmental toxins or delivery complications.

Like any biological disorder, autism varies in severity, from mild to mentally and physically disabling. Children with mild autistic symptoms may fixate on a favorite subject, resist any change in routine or speak inappropriately or in loud monotones. With severe autism, a family may have a child who can't speak, hurts himself, flaps her hands or limbs, screams instead of sleeping at night or is upset by the slightest sensory stimulation. Because of this wide range, diagnosticians often refer to the disorder as Autism Spectrum Disorder, or ASD. Autistic people with high IQs and normal speech may still struggle with rigid routines, abnormal responses to sensory perceptions, behavioral overreactions and social isolation. One trait that all people with autism share to some degree is an inability to interpret other people's behavior.

Before the 1940s, children who would now be called autistic were labeled emotionally disturbed, schizophrenic or mentally retarded. When psychiatrist Leo Kanner first described these children's symptoms in 1943, he named the syndrome Early Infantile Autism, because it usually appeared in the first three years of life.

Kanner made his diagnosis under particular circumstances that help explain the origin of the "refrigerator mother" theory. At that time, Kanner observed a small sample of children from educated families typically from the academic community. Because of the limited size and selectiveness of his study, Kanner and others made the incorrect assumption that autistic children were more likely to be born to highly intellectual parents who were white and middle or upper class. It was also assumed that autism didn't cross racial and class boundaries. Though Kanner thought the children's inability to relate to others was probably innate, he also stressed the coldness and intellectual nature of their parents, especially their mothers. Later, psychiatrists, overwhelmingly psychoanalytically trained, embraced a psychological cause for the disorder and the "refrigerator mother" theory became the reigning psychiatric orthodoxy.



***"Kanner and others made the incorrect assumption that autistic children were more likely to be born to highly intellectual parents who were white and middle or upper class. It was also assumed that autism didn't cross racial and class boundaries."***

## THE ROLE OF BRUNO BETTELHEIM

Bettelheim became a renowned University of Chicago professor and child-development specialist who built much of his reputation on the “refrigerator mother” theory. His theory likened the lives of autistic children to prisoners in concentration camps—where Bettelheim had been held captive for months during World War II. He popularized his theory on national television talk shows and through his well-received book, *The Empty Fortress*. His treatment for autism was to remove the child from all parental influence and place him or her in the Sonia Shankman Orthogenic School at the University of Chicago, which Bettelheim directed.

Other proponents of the “refrigerator mother” theory took it one step further than Bettelheim, advocating that the mothers themselves needed treatment. This added considerable emotional distress to already burdened families.



## SOCIAL CHANGES

Bernard Rimland, a psychologist whose son was diagnosed with autism, presented the first solid argument that autism is a biological condition. In the early 1960s, his book *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* questioned the myth that unloving parents caused autism. With a small group of parents, Rimland went on to found the National Society for Autistic Children, now the Autism Society of America (ASA). He currently directs the Autism Research Institute in San Diego, which collects data from parents all over the world.

Rimland’s book and his emphasis on advocacy created the first cracks in Bettelheim’s theory and the power it held in the psychoanalytic community. Mothers who had been persuaded by professionals that they were at fault now felt a glimmer of hope. Today, because of the movement that Rimland and others started, parents of autistic children no longer face an uphill struggle to convince doctors that they are not responsible.

However, remnants of mother blame are sometimes felt by families seeking help for their children. The family pediatrician is typically the first professional that parents approach with their suspicions. Pediatricians, who have little experience with autism, may tell mothers that the problem lies with them. This failure to recognize the neurological basis of autism can postpone critical early intervention treatments that can make an enormous difference in the development of an autistic child.

While initial studies from the 1960s estimated four or five cases of autism in 10,000 people, it is now recognized as much more prevalent. The Centers for Disease Control and Prevention (CDC) estimate the number of those affected at 20 in 10,000. Diagnostic improvements and a broader definition of autism have often been used to explain this increase; however, there is strong evidence that the rate of autism is dramatically increasing.

Within the past few years, research into the causes and treatment of autism has increased, thanks primarily to the advocacy of families that have been affected by autism and to the many dedicated professionals who have made it their primary study. Behavioral interventions (i.e. Applied Behavioral Analysis, Lovaas Behavioral Intervention and the TEACCH Program) are effective in improving the social functioning for many autistic children. Because of this early training and the increase in children being diagnosed with ASD, the number of children with autism who attend public schools has steadily risen. Many individuals with autism can make eye contact, show affection and smile, although autism may affect the range of response. With appropriate treatment, some behaviors associated with autism can change or diminish over time and people with autism can learn to compensate for their disability.

Each person with autism is different, with a unique personality and set of challenges. Some adults with autism live and work independently, some need support for daily pressures and others depend heavily on family and professionals. No longer automatically relegated to institutions as they were in the dark ages of treatment, adults with autism are now speaking for themselves, writing their own books and providing valuable insight into the challenges of this disorder.

## DISCUSSION QUESTIONS

### BEFORE VIEWING THE PROGRAM:

What do you know about autism? Do you know anybody who has autism?

Until the 1970s, mothers of autistic children were often referred to as “refrigerator mothers.” What does this mean to you? Why do you think mothers, rather than fathers, were labeled this way?

If a doctor told you that your behavior was responsible for your child's illness, what would you do?

### AFTER VIEWING THE PROGRAM:

What did you learn about autism? How did it affect your ideas about autism?

With whom did you most identify with in the film and why?

Why do you think so many experts were willing to believe an unproven theory? Why wasn't that theory questioned for so many years? What did it take to overturn the idea that mothers were at fault? What safeguards can the professional community take before endorsing a particular point of view?

Where do you interact with people with disabilities in your community? What are ways you can offer support to people with disabilities and their families? What services are available to them in your community?

What are effective ways that people with disabilities can have their voices heard and ideas represented in your community?

## DISCUSSION POINTS

- In REFRIGERATOR MOTHERS, “mother blame” comes from an external source. How is this different than the internal blame that parents may feel about their child's condition?
- In the film, Robert Coles makes the following statements. What do you think he means by them and how do they relate to your experiences with the medical profession?
  - “Our patients should be our teachers.”
  - A “collaboration of peers” is a good model for treatment.
  - The psychiatric establishment of the 1950s and '60s was a “closed, totalitarian system.”

- Although the percentage of autistic children seems to be increasing, there has been little growth in the number of facilities or services for autistic adults. What can be done to raise societal awareness of the issues that people with disabilities face? What steps can be taken to improve their housing opportunities?
- In the film, Dorothy tells how doctors at the University of Illinois thought her son Steven was not autistic because her family didn't fit the mold of “white, upper middle class, and very, very bright.” How do doctors' perceptions of their clients influence their decision-making?
- Richard Pollack, author of *The Creation of Dr. B*, explains that in the 1940s and early '50s psychoanalysis was a popular concept, and that Bettelheim gained acceptance because his theories on autism fit neatly into the psychoanalytic model. What medical or psychological theories that are popular now may be questioned twenty or thirty years from now?

## DISCUSSION POINTS FOR FAMILIES OF CHILDREN WITH AUTISM

Some adults with autism live independently, with a support system. Others take advantage of supervised group living. Have you thought about what you will do when your child reaches adulthood? Are there programs that meet your needs?

What expectations do you place on professionals (psychologists, psychiatrists, teachers) when it comes to treating or diagnosing your child's behavior?

What kind of support do you receive from your family and friends in raising your child?

How has the presence of an autistic child in your family affected your other children's development?

Autism often drains families emotionally, physically and financially, yet autism research receives only a fraction of the funding for other major illnesses. Why do you think autism is perceived differently than other childhood diseases such as leukemia, cerebral palsy and epilepsy?

How do you help educate the public about your child's needs? How can parents best advocate for their autistic children's needs?

## RESOURCES

### AUTISM NETWORK INTERNATIONAL

P.O. Box 35448  
Syracuse NY 13235  
www.ani.autistics.org

An international support and advocacy organization run by and for autistic people. ANI supports civil rights, self-determination, respect and dignity for autistic people, not interventions designed to make autistic people "more normal."

### AUTISM RESEARCH INSTITUTE

4182 Adams Ave.  
San Diego CA 92116  
Tel: 619.281.7165  
Fax: 619.563.6840  
www.autismresearchinstitute.com

Founded in 1967 by Bernard Rimland, Ph.D., the Autism Research Institute houses the world's largest database of detailed case histories of autistic children. The Institute conducts research and disseminates the results of research on the causes and efficacy of various treatments of autism.

### THE AUTISM SOCIETY OF AMERICA

7910 Woodmont Avenue, Suite 300  
Bethesda, Maryland 20814  
Tel: 800.3AUTISM  
Fax: 301.657.0869  
www.autism-society.org

The "voice and resource of the autism community," the ASA offers support to the autism community in the areas of education, advocacy, public awareness and research.

### CURE AUTISM NOW

5455 Wilshire Blvd.  
Suite 715  
Los Angeles, CA 90036-4234  
Tel: 888.8AUTISM  
Fax: 323.549.0547  
www.cureautismnow.org

An organization of parents, physicians, and researchers, dedicated to promoting and funding research with direct clinical implications for treatment and a cure for autism.

### THE DOUG FLUTIE, JR. FOUNDATION FOR AUTISM

P.O. Box 767  
Framingham, MA 01701  
Toll Free: 1-866-3AUTISM  
www.dougflutiejrfoundation.org

Provides grants to organizations that aid families affected by autism, funds education and research into the causes and consequences of childhood autism and serves as a clearinghouse and communications center for new programs and services developed for children with autism.

### FIRST SIGNS, INC.

P.O. Box 358  
Merrimac, MA 01860  
(978) 346-4380  
www.firstsigns.org

National nonprofit organization dedicated to educating physicians and parents about the early identification and intervention of autism and other developmental disabilities.

### NATIONAL ALLIANCE FOR AUTISM RESEARCH

99 Wall St.  
Research Park  
Princeton, NJ 08540  
Tel: 888.777.NAAR  
Fax: 609.430.9163  
www.naar.org

NAAR's mission is to fund, promote and accelerate research and science-based approaches that seek to determine the causes, prevention, effective treatments and ultimately, a cure for autism spectrum disorders.

### TASH

29 W. Susquehanna Ave., Suite 210  
Baltimore, MD 21204  
Tel: 410-828-8274  
www.tash.org

TASH is a collaborative membership association that actively promotes (through advocacy, research and education) the full inclusion and participation of people with disabilities in all aspects of community life.

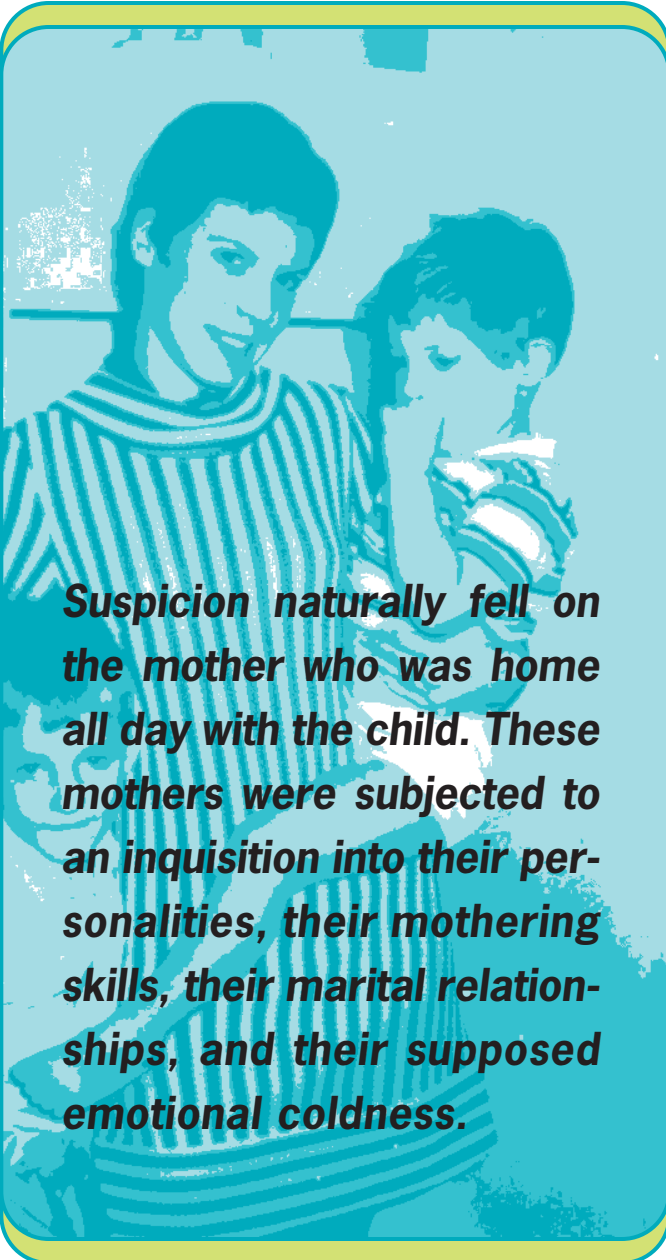


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**Suspicion naturally fell on the mother who was home all day with the child. These mothers were subjected to an inquisition into their personalities, their mothering skills, their marital relationships, and their supposed emotional coldness.**

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For more information about ITVS or to obtain additional copies of this guide, contact us at 415-356-8383; fax 415-356-8391; [itvs@itvs.org](mailto:itvs@itvs.org). Material from this guide is available on the itvs website, [www.itvs.org/outreach/toolkits.htm](http://www.itvs.org/outreach/toolkits.htm).

#### TO PURCHASE A TAPE:

Fanlight Productions: 800-937-4113 or [www.fanlight.com](http://www.fanlight.com)

#### ABOUT ITVS COMMUNITY CONNECTIONS PROJECT (CCP)

For over ten years, ITVS has fulfilled its mission of bringing powerful new voices to public television through its independent productions and national outreach efforts. In 1996, ITVS launched the Community Connections Project to maximize the use of media as a tool for civic engagement and community development. The CCP collaborates with local field organizers, national and community-based organizations and public television stations to foster dialogue, develop lasting partnerships and implement positive action.

#### ABOUT P.O.V.



*P.O.V.* is PBS's award-winning showcase for independent non-fiction film. Now in its 15th season, *P.O.V.* is a laboratory for television's potential, amplifying its broadcasts with pioneering media innovation, interaction and impact. For more information about this film and *P.O.V.* visit: [www.pbs.org/pov](http://www.pbs.org/pov)



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