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# Trapped Children: Popular Images of Children with Autism in the 1960s and 2000s

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**Abstract** The lay public inherits much of its information about disability and mental illness through the media, which often relies on information from popular scientific works. Autism, as it was defined during the dominance of psychogenic paradigms of mental illness, generated certain tropes surrounding it, many of which have been popularized through media representations. Often inaccurate, these tropes have persisted into contemporary times despite a paradigmatic shift from psychogenic to biological explanations and treatments for mental illness. The current article examines images and articles of children with autism from the 1960s and the early 2000s in major news media and scientific literature to highlight the persistence of themes of fragmentation and the imprisonment of children with autism. While these themes have persisted in psychological and media literature, narratives of people with autism and their families often present a different perspective. This results in two divergent 'realities' of autism being disseminated into the general public.

**Keywords** Autism · Media · Disability · Mental illness · Neurodiversity

## Introduction

> I am quite certain that public knowledge of mental illness does not come from professional journals through which mental health professionals share their research and ideas with one another.[1]

Neither, psychologist Otto Wahl argues in *Media Madness*, is it derived from mental health newsletters or college classes in psychology. "It is far more likely," he continues,

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[1] O. Wahl, *Media Madness: Public Images of Mental Illness* (New Brunswick: Rutgers University Press, 1995), 2.

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"that the public's knowledge of mental illness comes from sources closer to home, sources to which we all are exposed on a daily basis—namely, the mass media."[2] The reach of the scientific and professional communities, he argues, are no match for the oft inaccurate and demeaning stereotypes the public encounters in films, novels, plays, newspapers and magazines. These portrayals, more than any other, shape and determine public perception of human difference.

In a pattern of cyclical influence, imagery of human difference in popular media both reflects and influences the general public's understandings of mental illnesses and disabilities. Popular images can impart messages of recovery, dangerousness, ability level, and severity, influencing how people interact with those diagnosed with or exhibiting cognitive and physical disabilities.[3] The strength of media influence on public perception and action requires close scrutiny of the relationship between representations of human difference and the experiences of those characterized. Inasmuch as representations reflect a particular reality,[4] they can also develop a life of their own, diverting from the path of the actual behaviors, personalities, abilities and lives of people with mental illness or disability, creating a 'false reality' of difference. Many in the autism community concerned about the misrepresentation of people who are 'on the spectrum,' attribute faulty depictions to a lack of "autistic voices" informing the public of their realities and the ways they would like to be portrayed.[5] With the recent rise of diagnoses and fears of an autism 'epidemic,' Autism Spectrum Disorders (ASDs) are seen in popular media more than ever, disseminating and promoting a distinct representation to the general public about autism and those diagnosed.[6]

Since the mid-20th century, there has been an exponential increase in autism-related research centered on biological and behavioral presentations and variations.[7] This information has covered and impacted an enormous range of issues related to heritability, treatment and educational options as well as descriptions of presentations and experiences. In addition, memoirs and autobiographies about autism are being published at an astonishing rate, creating a genre of "autistic autobiography."[8] Most of these works fall under what Arthur Frank describes as "quest narratives," illness stories characterized by both an overcoming and acceptance of the condition and an ability to use the strengths of

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[2] Ibid., 3.

[3] Wahl, *Media Madness.*

[4] Images and representations are always subject to social construction and cannot truly depict reality; however, I use the word 'reality' to discuss what is intended to be understood as truth and actuality seen in images and representations.

[5] P.C. Durbin-Westby, "'Public Law 109–416 Is Not Just about Scientific Research': Speaking Truth to Power at Interagency Autism Coordinating Committee Meetings." *Disbility Studies Quarterly* 30, No. 1 (2010), http://www.dsq-sds.org/article/view/1070/1245 (accessed March 23, 2010).

[6] Recent works include: G. Berks-Abbot, "Mark Haddon's Popularity and Other Curious Incidents in My Life as an Autistic," *Autism and Representation*, ed. M. Osteen (New York, Routledge, 2008), 289–296; A. D. Baker, "Recognizing Jake: Contending with Formulaic and Spectacularized Representations of Autism in Film," *Autism and Representation*, ed. M. Osteen (New York, Routledge, 2008), 229–243; P.C. Durbin-Westby, "'Public Law 109–416 Is Not Just about Scientific Research': Speaking Truth to Power at Interagency Autism Coordinating Committee Meetings;" S. Murray, *Representing Autism: Culture, Narrative, Fascination,* (Liverpool: Liverpool University Press, 2008); M. Osteen, "Autism and Representations: A Comprehensive Introduction," *Autism and Representation*, (New York, Routledge, 2008), 1–48.

[7] S. Baron-Cohen,*The Essential Difference: Male and Female Brains and the Truth About Autism*. (New York: Basic Books, 2003); A. Feinstein, *A History of Autism: Conversations with Pioneers,* (New York: Wiley-Blackwell, 2010).

[8] I. Hacking, "Autistic autobiography," *Philosophical Transactions of the Royal Society B, 27* (2009).

autism to better one's life.[9] Narratives are ontological tools that tell society what it means to be part of a particular identity or state of being. Master narratives, the dominant portrayals that guide cultural judgements of others, are publicly taken as reality and, as such, should be built from stories that are accurate and faithful to a person's experiences.[10] When considering the varied scientific, media, and autobiographical accounts of autism, it is not the points at which they converge that reveals reality, but the points as which they part and even conflict.

I am concerned here with two major issues: (1) how autism, as a condition without any physical signs, is portrayed in static images to the public and the messages these images convey, and (2) the ways in which science, the media, and personal narratives construct differing representations—and consequently, realities—of autism as a contemporary diagnostic category and identity status. Comparing images in the popular American media from the 1960s and the early 2000s,[11] I ask: are there differences in the images that reflect a new reality of autism in 2000 from the growing library of scientific findings and/or autistic narratives and, if so, what does this new reality tell the American public about autism? I argue that, while research findings have led to deeper understandings of autism as a condition and how best to intervene, the core assumptions about autism have been maintained. These assumptions continue to be portrayed in popular representations, creating a scientific reality of autism. Meanwhile, an increase in autistic autobiographies has been challenging these core assumptions outside of science, developing an opposing reality. The result are two distinct representations of an autistic reality—one that relies on long-lasting, deficit-focused definitions of the condition and one that responds to phenomenological accounts that question these definitions. The realities constructed in these texts and images influence how people respond to and understand autism and people labeled as autistic. As such, this essay also aims to extract the meanings held in these images to place them in conversation with changing scientific and advocacy paradigms.

## Representations and imagery of autism

Photographs, frequently taken as exact replicas of actuality, are assumed to be without bias or deception, serving as a powerful source of information for the public. Disability scholar Rosemarie Garland-Thomson argues that photographs of people with disabilities perpetuate assumptions of reality, yet are, in fact, more indicative of cultural expectations of disability experience. These false realities are easily achieved through the photographic process that "arrests time, freezes motion, and prunes away space, which are the coordinates and the context of 'real life.'"[12] In other words, the limited scope and purposeful editing of photographs eliminate the space necessary for viewers to gain a frame of reference representative of reality. Through purposeful editing, posing and framing, these images reflect and perpetuate familiar and acceptable notions of disability and mental illnesses.

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[9] A.W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: The University of Chicago Press, 1995), 115.

[10] J.L. Scully, *Disability Bioethics: Moral Bodies, Moral Difference,* (Lanham: Rowman & Littlefield Publishers, Inc, 2008).

[11] I am focusing on the 1960s as a comparison to the most recent images because at this time, autism was gaining recognition in scientific and public spheres. Additionally, the 1960s began with the dominance of the psychoanalytic paradigm. M.H. Nadesan, *Constructing Autism: Unravelling the 'Truth' and Understanding the Social* (London: Routledge, 2005)

[12] R. Garland-Thomson, "Seeing the Disabled: Visual Rhetorics of Disability in Popular Photography," *The New Disability History: American Perspectives*, ed. P. K. Longmore and L. Umansky (New York: New York University Press, 2001), 336.

Garland-Thomson explains that photographs provide the public with a safe space on which to gaze at disability from a distance, avoiding the impropriety of public staring.[13] Scholar Stuart Murray notes that this process is somewhat altered when viewing images of neurobiological impairments such as autism, emphasizing the scenic context that is used to convey the condition in the absence of physical markers.[14] The process of viewing a photo of autism is, he states, not one of "seeing" but one of "witnessing, a bringing to bear on the individual photograph of an amorphous and often contradictory set of ideas that stand for what we know of autism at the present time."[15] As autism is witnessed through representations, the public inherits an ideology of what autism is through the presentation of persistent "root-metaphors"[16] and common autistic tropes. Often, these representations rely on the subject's pose and physical context as cues to the reality of the condition. For example, children (and it is almost always children rather than adults) are seen alone, looking away to communicate the presumed withdrawal from reality. Children are often interacting with toys in different ways, portraying behavioral abnormalities. Thus, I will focus on contextual aspects in interpretations along with accompanying texts.

Similar to Murray's discussion of autistic photographs, I employ Garland-Thomson's taxonomies of "visual rhetoric"[17] to help decipher messages within the images presented. While they were created to describe images of physical difference, the categories are similarly applicable to representations of autism, which must make it into a physical difference, even though it is not. The four categories include: "the wondrous, the sentimental, the exotic, and the realistic."[18] Each rhetoric conveys a specific purpose and message for the reality, or false reality, they portray.[19] Disability representations, including those of autism, usually reflect a combination of these categories. Autism-related representations can be categorized as sentimental or exotic; however, most use overlapping and complementary strategies to maximize the meaning of the image.

Images of autism from the 1960s and the early 2000s reveal both the contextual methods employed in portraying autism as well as salient themes and tropes used to address the nature and effects of autism. Photographic evidence from popular print media reflect a distinctly divergent message from those of recent autistic narratives. Media portrayals are more closely aligned with scientific and medical constructs of autism which tell a decidedly different story than those told by people with autism and their families. In many ways, the medical and scientific realms have maintained specific characterizations of autism throughout major shifts in dominant theoretical paradigms. Scientists and psychiatrists reformulated etiological, prognostic, and therapeutic issues related to autism after the 1960s away from psychoanalysis and towards biological psychiatry. However, the central descriptions and compositions of the conditions were rarely questioned or reconsidered. As such, new theories began to explain the old definitions. The popular media followed suit, highlighting the same features that were considered to be the most unique or interesting to the public. The persistent messages and

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[13] R. Garland Thomson, *Staring: How We Look,* (Oxford: Oxford University Press, 2009), 165.

[14] ASDs are diagnosed by professionals from observations of behaviors making static images of autism reliant on contextual cues to portray the condition.

[15] Murray, *Representing Autism.*

[16] S.L. Gilman, *Seeing the Insane* (New York: John Wiley & Sons, 1982), xii.

[17] Ibid., 339.

[18] Briefly, the wondrous portrays the subject in exceptional situations that connote overcoming the disability to perform almost supra-human tasks. Sentimental images are those that evoke pity from the viewer: exotic images sensationalize the disabled while allowing the (non-disabled) viewer to view, or stare, at a distance for the purposes of entertainment and spectacle. Finally, the realistic category attempts to normalize the disability while simultaneously portraying it as a condition the viewer would want to avoid.

[19] Garland-Thomson, "Seeing the Disabled."

values are imparted in the images through context, subject features, and body and facial positions and matched in the paradigmatic verbiage within the text of the article, which shifted from psychoanalytic to biomedical language. While images and photographs of autism have maintained long-standing tropes of representations, such as focusing on children who are alone,[20] they have evolved with changes in American society to maintain political and professional correctness.[21] Despite this update, there remain several underlying themes the photographs convey about the experience of autism that, despite conflicting evidence, continue to subsist. The current article will focus on the two prominent themes evident in representations from both eras: fragmentation and the imprisonment of the normal child.[22]

## Fragmentation

The representation of fragmentation provides a metaphor for both the person and the family. People with autism are portrayed and perceived as not being "whole" people,[23] and autism is depicted as a tragedy that will break up a family and its individual members. Most written descriptions of autism impart this message and supplement the notion that with intense intervention, the child and family can be whole and functional again. Perceptions of autism's ability to fragment the self arises from psychogenic literature of the mid-twentieth century, especially that from the work of self-proclaimed autism expert, Bruno Bettelheim.[24] Many of psychoanalysts of the 1960s wrote about the damaging effects of poor or cold parenting[25] that could lead to the development of childhood autism and they often recommended the child be removed from the home, resulting in a broken, or fragmented, family.[26] Fragmentation of psyche was evident in psychoanalysis of the mid-twentieth century. However, later scientific articles that focused on biology described fragmentation via a break down in "normal" development,[27] fragmentation of neurological functioning,[28] or as

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[20] Murray, *Representing Autism.*

[21] Such as including more ethnic and age diversity.

[22] Another commonly misrepresented theme is that of an extreme unawareness of others, often referred to a lack of "theory of mind". This misconception has been explored in other works including: D. Smukler, "Unauthorized Minds: How 'Theory of Mind' Theory Misrepresents Autism." *Mental Retardation* 43, No. 1 (2004): 11; R. Savarese, *Reasonable People: A Memoir of Autism and Adoption: On the Meaning of Family and the Politics of Neurological Difference* (New York: Other Press, 2007).

[23] This message is also expressed through the widespread use of a puzzle piece to represent autism, which some see as an inappropriate metaphor for the condition and those diagnosed. Smukler, "Unauthorized Minds."

[24] B. Bettelheim, *The Empty Fortress: Infantile Autism and the Birth of the Self,* (New York: Simon & Schuster, 1967); see also, H.H. Eveloff, "The Autistic Child," *Archives of General Psychiatry*, 3 (1960): 66.; E. Schloper, "The Development of Body Image and Symbol Formation Through Bodily Contact with an Autistic Child," *Journal of Child Psychology and Psychiatry and Allied Disciplines* 3 (1962): 191.; K. Soddy, "The Autistic Child," *The Practitioner* 192 (1964): 525.

[25] Leo Kanner first equated parents to coldness and refrigeration, but it was Bruno Bettelheim who promoted the use of the term, "refrigerator mothers" to describe the cold, detached mother that caused autism in children (Bettelheim 1967). He published much of his work in popular magazines and and newspapers, widely influencing public perception of autism at that time. R. Pollak, *The Creation of Dr. B: A Biography of Bruno Bettelheim* (New York: Simon & Schuster, 1997).

[26] Bettelheim, *The Empty Fortress*; Eveloff, "The Autistic Child."

[27] For example see H. Clancy, A. Dugdale, and J. Rendle-Short, "The Diagnosis of Infantile Autism," *Developmental Medicine and Child Neurology* 11 (1969): 432.; S. R. Lewis and S. Van Ferney, "Early Recognition of Infantile Autism," *The Journal of Pediatrics* 56, No. 4 (1960): 510.; L. Sahlmann, "Autism of Aphasia?" *Developmental Medicine and Child Neurology* 11 (1969): 443.

[28] For example, see Clancy, *et al.*, "The Diagnosis of Infantile Autism"; J. K. Wing, "Epidemiology of Early Childhood Autism," *Developmental Medicine and Child Neurology* 5 (1963): 646.

a partially damaged child with "islets of normal, near normal or exceptional intellectual function or skill."[29] In other words, having a fragmented skill set or biology.[30] Whether the model placed the etiology and effect outside the individual (as in psychoanalysis) or internally (as in the biological model), professionals were convinced that people or more specifically, children, with autism were somehow broken or incomplete because of the condition. The media easily inherited this portrayal.

A June 25, 1967 article by Bruno Bettelheim in *The Chicago Tribune*, "The Children Who Never Were," characterized these notions of fragmentation with a full-page image of the darkened and broken child discussed throughout the article (Fig. 1). The image is so obstructed with darkness and cracks that it is difficult to see the child's face, communicating that autism is so overpowering, so completely breaking a child's selfhood, that he almost is unrecognizable as a person.

In the image, the boy's eyes are focused on something away from the camera and viewer—a facial posture typical of images of people with autism. He is also pointing at his mouth, seeming to draw attention to the location of the most recognizable point of autistic fracturing—broken communication. The caption, "What is missing in the autistic child is the conviction that he can change a course of events once it has been set in motion," conveys both Bettelheim's theoretical perspective and the belief that the child is not complete.

The accompanying article lays out Bettelheim's etiological and therapeutic paradigm based on psychoanalytic processes. Several phrases suggest that children with autism are incomplete persons, such as there is an "absence of goal-directed action;" and that one must "succeed in freeing the child to take purposeful action again." Words such as "absence" and "again" convey something missing that can be regained, and that once skills of "purposeful action" are returned to the child, she will return to completeness. Bettelheim's children have lost the ability to interact purposefully with the environment creating two people—the broken child who is currently presented, and the actual child who can be rebuilt with good intervention.

The darkness and disarray of the image lead readers to feel both the brokenness and the confusion inherent in a condition such as autism. Not only is the child in need of repair but there also seemed to be pieces missing in the image and in the child. Resembling a puzzle to be put together, this image falls within the categories of exotic and sentimental visual rhetoric, allowing viewers to witness the total darkened fracturing of this child from a strange and chaotic disorder—unique, mysterious and sad.

Since the 1960s, there has been a definite shift in the scientific and medical literature away from a psychogenic focus to a solidly biological and genetic paradigm. There are numerous recent articles looking for the genetic basis of autism as well as those which explore specific neurological mechanisms.[31] While generating a host of helpful research, these fields have perpetuated the notion that autism results from brokenness in

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[29] Clancy et al., "The Diagnosis of Infantile Autism", 439

[30] U. Aurnhammer-Frith, "Emphasis and Meaning in Recall in Normal and Autistic Children," *Language and Speech* 12 (1969): 29; M. K. DeMyer, N. A. Mann, J.R. Tilton, and L.H. Loew, "Toy-Play Behavior and Use of Body by Autistic and Normal Children as Reported by Mothers," *Psychological Reports* 21 (1967): 973; E. A. Frommer, "Autistic Children." *Public Health* 80 (1966): 279; E.M. Ornitz, "Disorders of Perception Common to Early Infantile Autism and Schizophrenia," *Comprehensive Psychiatry* 10 (1969): 259.

[31] For example, see G. Dawson, S. Webb, G.D. Schellenberg, S. Dager, S. Friedman, R. Aylward, and T. Richards, "Defining the Broader Phenotype of Autism: Genetic, Brain, and Behavioral Perspectives," *Development and Psychopathology*, 14 (2002): 581; U. Frith, *Autism: A Very Short Introduction,* (Oxford: Oxford University Press, 2008); J.R. Hughes, "Update on Autism: A Review of 1300 Reports Published in 2008," *Epilepsy & Behavior* 16 (2009): 569; D.K. Kinney, D.H. Barch, C. Bogdan, S. Napoleon, and K. M. Munir. "Environmental Risk Factors for Autism: Do They Help Cause De Novo Genetic Mutations That Contribute to the Disorder?" *Medical Hypotheses* 75, No. 1 (2010): 102.

**Fig. 1** The broken and dark nature of this image of a young child visually demonstrates Bettelheim's descriptions of the fragmentation of children with autism

chromosomal, brain-based, or other biological pathways. Using a medical model, these works depict autism in terms of characteristics that are damaged and need to be fixed. Additionally, parental resources on coping mechanisms, such as those found on the internet[32] and even some advocacy pieces,[33] highlight high-divorce rates and familial stress associated with autism. In contemporary times, the notion that autism fragments a family has replaced the notion that autism results from a broken family. The theme of fragmentation remains in these representations despite major shifts in cultural and scientific paradigms of childhood and psychiatry. The external, psychoanalytically-driven brokenness projected onto the child was replaced by an internal, biomedically-shaped brokenness projected onto the family.

As such, a 2007 article, also from *The Chicago Tribune*,[34] portrays the life history of an autistic powerlifter, Jamie, using interviews with his mother, Alice.[35] The photo accompanying this article shows the reflection of Jamie and Alice in a full-length mirror broken during one of Jamie's autistic "eruptions". Autism has split the man, his mother, and their home because of the violent and unpredictable behavior inherent in Jamie's diagnosis. This behavior, as the image suggests, has fragmented his family and his self, leaving them in a broken state. Jamie, looking somewhat sheepish yet otherwise non-disabled, is hardly

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[32] For example, see: L.J. Rudy, "Autism: Marriage and the Child with Autism," About.com, http://autism.about.com/od/copingwithautism/a/marriage.htm (accessed on May 3, 2010); Autism Speaks, "Coping," Autism Speak, http://www.autismspeaks.org/howtocope/strategies.php. (accessed on May 3, 2010); National Autistic Society, "Families: The Impact on Autism," The National Autistic Society, http://www.autism.org.uk/nas/jsp/polopoly.jsp?d=307&a=3342. (accessed on May 3, 2010).

[33] For example, the controversial video "Autism Everyday" which was created by the advocacy group Autism Speaks; Autism Speaks, "Autism Everyday," Autism Speaks, http://www.youtube.com/watch?v=FDMMwG7RrFQ. (accessed on March 29, 2010).

[34] R.W. Huppke, "Autistic Powerlifter's Quest," *Chicago Tribune*, 10 December 2007.

[35] Note that there was little information garnered from Jamie himself, reflecting a general distrust of autistic autobiography and voices. Jackie Leach Scully describes this "testimonial injustice" as a major source of disbelief of disability narratives (J.L. Scully, *Disability Bioethics: Moral Bodies, Moral Difference*) which presents a barrier to the acceptance of these representations over other misinformed narratives.

affected by the mirror's brokenness, with only his right leg being segmented by the mirror's cracks. Alice's image, on the other hand, is fragmented in several places from the mirror's cracks, suggesting that her life has been much more broken by Jamie's autism than the seemingly unaware Jamie. Looking calm but slightly resigned with her hands laced in front of her, she is a bit more difficult to see as a whole subject–autism has obscured her life and personhood. The image imparts an exotic and wondrous visual rhetoric, as it is presenting the subjects from a slight distance and focuses on the surprising and erratic strength that broke the mirror, the man, and the mother.

The article describes autism as a "mysterious disorder" and "curious in that way," further exoticizing the condition. Elsewhere, the article describes Jamie as having "fragile senses" and as being a "capable person wrapped in an autistic cocoon." Fragility implies a state of susceptibility to being broken, whereas the second statement leads readers to perceive Jamie as two fragmented people: the real Jamie and the autistic simulacrum that is exposed to the world, similar to Bettelheim's comments above. Viewers can witness such fragility in Jamie's apprehensive posture—his hands tentatively hold some paper while he looks at the mirror out of the corner of his eyes. Despite the cultural update in presenting an adult of color instead of the usual white, upper middle-class child, the image has maintained the brokenness associated with autism.

The continual imaging of autism as a condition characterized by fragmentation contradicts recent efforts of autism advocates and the neurodiversity movement.[36] Autistic memoirs, such as those by Clara Clairborne Park[37] and Temple Grandin,[38] demonstrate that autism is not, and does not have to be, a condition that splits up a family or a person's selfhood. While these stories do describe the difficulties the traits associated with autism can be for people with autism and their families, they also show that there is love and wholeness in the reality of autism. Many parents report that, although initially difficult and a source of high stress, autism has enriched their lives and that of their families, noted in many memoirs[39] and research on family experiences.[40]

The burgeoning neurodiversity movement promotes the incorporation of autistic traits into a healthy conception of one's identity. Here, the traits associated with autism add to, instead of take away from, the wholeness of the self. Perhaps the most well-known person with autism, Temple Grandin, is often quoted as saying that, given the choice, she would not change her autistic status.[41] The idea that autism completes, rather than fragments, a person is in stark contrast to the messages relayed to the public through mass media representations. The neurodiversity movement is creating an autistic culture which, instead of fragmenting people from society and themselves, enjoins people in "a unique, meaningful culture and way of being."[42] While not neglecting the struggles many people

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[36] See K. Boundy, "'Are You Sure, Sweetheart, That You Want to be Well?': An Exploration of the Neurodiversity Movemen,." *Radical Psychology: A Journal of Psychology, Politics & Radicalism* 7, No. 2 (2008).

[37] C.C. Park, *The Siege: A Family's Journey Into the World of an Autistic Child*, (New York: Back Bay Books, 1967); C.C. Park, *Exiting Nirvana: A Daughter's Life with Autism*, (Boston: Little, Brown, and Company, 2001).

[38] T. Grandin and M.M. Scariano, *Emergence: Labeled Autistic* (Novata, CA: Arena Press, 1986); T. Grandin, *Thinking in Pictures and Other Reports from My Life with Autism*, (New York: Vintage Books, 1995).

[39] See M. Blastland, *The Only Boy in the World: A Father Explores the Mysteries of Autism*, (London: Da Capp Press, 2006; P. Collins, *Not Even Wrong: Adventures in Autism,* (New York: Bloomsbury, 2004); Park, *The Siege.*; Park, *Exiting Nirvana*.

[40] C. Schall, "Family Perspectives on Raising a Child with Autism." *Journal of Child and Family Studies,* 9, No. 4 (2000).

[41] Grandin, *Thinking in Pictures*.

[42] B. Ventura, "Apergian Pride," http://www.aspergianpride.com/, retrieved July 2, 2010.

with autism and their families encounter, the autistic culture rejects the notion that autism fragments a person, destroys families and begs normalization. This portrayal stands in conflict with popular and scientific notions that claim autism is a dangerously fragmenting condition.

## Imprisonment of the normal child

Since the condition of autism was first named and made into a diagnosable condition in 1943 by Leo Kanner,[43] it has been closely connected to interventions and cures meant to rescue or release the person autism has obscured. Early articles aimed at describing autism held the explicit purpose of developing efficient ways to intervene,[44] and almost all articles had a sense of urgency, noting that missed developmental milestones cause irreparable harm.[45] Methodological orientations may disagree on the best intervention, however, they all claim that early, intense and difficult interventions are required.[46] The sentiment of a normal child imprisoned within is captured in a 1960 article by Dr. Herbert Eveloff: "if the disease goes untreated, the autistic child will virtually be impossible to distinguish from a defective child."[47] Without professional intervention, autism may eventually encompass the entire child, erasing any aspects of normality, and he becomes irreparably "defective."

The need for intervention is also captured in a 1966 article in *The New York Times* profiling a school for children with autism.[48] Black-and-white photos illustrate the techniques used to "get through" to the children by attempting to block out extraneous sensory stimuli (Fig. 2). The image here is of a young boy in close contact with his teacher. Despite the proximity of the teacher holding the child's face, the child is characteristically not looking at the viewer or the teacher. The intensity of the interaction feels and looks uncomfortable and anguished for the child and the viewer.

The image, like most early images of autism, is set in a school, highlighting the need for professional intervention away from the home. The title of the article, "Help for deeply disturbed; L.I. staff gets through to autistic," implies that the teachers are having to disrupt autistic unawareness with urgent force in order to communicate with and remediate these children. The therapeutic approach developed at the school follows a theory that children with autism cannot block out irrelevant sensory stimuli, as non-autistic people can do from infancy. In other words, background noise, peripheral vision, changes in temperature, and other environmental sensory input easily ignored by typical people since infancy is all noticed by children with autism—thus, their ability to restrict sensory input is broken. The teachers at the school must, in a sense, control stimulation to break through the body/psyche prison created by autism using interventions designed to force interaction, "until some recognition lights up the blank eyes." The teachers feel compelled to break through the autistic barrier, which confines the child to an infant-like state.

The image and the sentimental and exotic rhetoric force viewers to feel the urgency in rescuing a child from autism. As the teacher's head obscures a clear view of the boy, the image implies that professional help must take over the child to obscure the autism from

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[43] L. Kanner, "Autistic Disturbances of Affective Contact," *Nervous Child* 2 (1943): 248.

[44] See Clancy, *et al*., "The Diagnosis of Infantile Autism."

[45] See Scholper, "The Development of Body Image;" Soddy, "The Autistic Child."

[46] See, Eveloff, "The Autistic Child;" Frommer, "Autistic Children;" Soddy, "The Autistic Child."

[47] Ibid., 92.

[48] N. Jaffe, "Help for the Deeply Disturbed Child," *New York Times*, 22 February 1966.

**Fig. 2** The intensity of the interaction shown in this photograph suggests an urgent need to reach the child through the autistic barrier

him and the viewers. Only then can the teacher step back to allow the child the space and independence as a whole, rehabilitated person. The physicality of this approach opposes the common perception of psychiatric intervention that usually involves talk therapy. Autism, a much more desperate state than other psychiatric conditions, requires the intensity represented in the image. Viewers witness the strong need for the child to be saved from autism in the postures of the subjects, the setting of a professional school, and the uniqueness of the intervention.

It is rare to read either a scientific or popular article about autism that does not discuss treatment and intervention methods. Currently, Applied Behavioral Analysis (ABA) is the most frequently used and recommended intervention, most often suggested as early, intense individual behavior therapy in the home and classroom.[49] In America, children with autism are often immediately placed on psychopharmacological drugs to reduce autism-related behaviors and traits. Additionally, a host of alternative and, sometimes unsafe, interventions are promoted, including special diets, chelation, equine and dolphin therapy, hyperbaric oxygen chambers, and vitamin supplements.[50] The quantity and popularity of these interventions paint autism as a tragic, dangerous condition that needs to be changed, fixed, or cured with intense and sometimes dangerous interventions. Film actress and supporter of the autism-vaccine hypothesis,[51] Jenny McCarthy, typifies the idea of an urgent need to

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[49] For example see, Frith, *Autism: A Very Short* National Research Council, *Educating Children with Autism,* Committee on Education Interventions for Children with Autism, eds. C. Lord and J. P. McGee, (Washington DC: National Academy Press, 2001); B. Reichow and M. Wolery, "Comprehensive Synthesis of Early Intensive Behavioral Interventions for Young Children with Autism Based on the UCLA Young Autism Project Mode," *Journal of Autism and Developmental Disorders* 39, No. 1 (2009).

[50] P. Offit, *Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure, (*New York: Columbia University Press, 2008).

[51] This is the theory that childhood vaccinations cause autism because of the preservatives they contain. Although several epidemiological studies have failed to find a link, popular support for this notion remains strong.

release children from autism through her organization's name: Generation Rescue. McCarthy and her organization state that autism is curable and preventable.[52]

Such urgency is repeated in popular media articles which describe autism, as a 2007 article in *Time Magazine* does.[53] The image accompanying the article shows a young child sitting in front of a man, presumably his father, who is intensely peering at the boy (Fig. 3). The man's posture is close and penetrating, similar to that of the teacher in the previous image, and his facial proximity suggests some confusion in interpreting the child. The boy, who is in front of a table of puzzle pieces, the nationally recognizable symbol of autism,[54] is looking away from the viewer and the father with somewhat desperate facial and body posturing. With his mouth agape and his eyes opened widely, he seems to be making ocular and sonic 'calls' for help. As verbal communication is often difficult for children with autism, this image implies he must enhance his eyes as a site of communication. His distant look is framed by his hands, making attempts to see through the "windows of the soul" more salient and amplified—similar to how one would try to magnify the voice by cupping the mouth when yelling. The viewer witnesses that the real child within is actually calling out to be rescued, yet his father and the viewer are unsure of how to respond. While the article only briefly mentions available therapeutic options, the image convinces viewers that both child and father desire and deserve immediate release from autism. The article also uses biomedical phrasing, noting autism's social "inept[ness]" as a "lack of basic communication gestures like pointing or returning a smile;" thus, the person is, again, fragmented and broken. This lack is clearly preventing the boy in the image from communicating what he needs in order to be saved.

To witness the autism in this image, the viewer interprets the oddity of the boy's posture along with the man's confusion. Aided by the ubiquitous puzzle piece, autism is ingrained into the image's context. The two are in the home, which is the optimal living and intervention site in the post-psychoanalytic environment of contemporary society.[55] Struck by the fascinating posture and context of the image, clearly an exotic and sentimental visual rhetoric, the viewer is allowed to gaze upon the strangeness of this boy's condition, compelling the viewer to feel sympathy for the confusion and helplessness of the situation. The lost yet urgent look on the boy's face persuades viewers to advocate for his rescue, to help put the pieces of his autistic life back together.

While many families and children struggle with the condition of autism, the neurodiversity movement is working towards tolerance and acceptance of autism and its accompanying traits. People with autism, the movement argues, do not need rehabilitation or normalization to interact with the world or be successful people.[56] This relatively new concept is being promoted by an increasing number of people diagnosed or associated with autism, yet it is still quite controversial. While many maintain that research should focus on accommodations and awareness instead of cures and rehabilitations, others claim this

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[52] Generation Rescue, "Generation Rescue: Autism is Reversible," Generation Rescue, http://www.generationrescue.org/ (accessed May 2, 2010).

[53] C. Wallis, "Autism," *Time Magazine*, August 1, 2007.

[54] As David Smukler explains, the puzzle piece has been the logo for the Autism Society of America, and thus an international symbol of autism, for many years. However, the symbol is contested by many advocates due to its association with incompleteness and mystery (Smukler, "Unauthorized Minds").

[55] J.W. Trent, *Inventing the Feeblemind: A History of Mental Retardation in the United States*, *(*Berkeley: The University of California Press, 1994).

[56] Boundy, "'Are You Sure, Sweetheart, That You Want to be Well?; see also K. Seidel, "Neurodiversity Weblog: News, Opinions, Letters, Readings, Announcements," neurodiversity.com. http://www.neurodiversity.com/main.html. (accessed May 1, 2010).

**Fig. 3** Here, viewers intuit the child's confusion and calls for help while his father looks on. Note the scattered puzzle pieces in the foreground, the universal symbol for autism

perspective is not appropriate for people with more significant forms of autism. This population, many argue, can and do vastly benefit from more intense interventions to improve their and their families' qualities of life. Yet the debate on how much and what type of intervention a person with autism receives has failed to enter many popular media articles and autistic representations.

## Conclusion

Two divergent paths of autistic representation—one which is reliant on scientifically based, non-changing definitions and one that relies on narratives of people with or living with autism challenging these definitions—have emerged suggesting that representations of disability and difference can reflect particular realities. The overarching, salient themes of fragmentation and imprisoned children in most portrayals are inseparable and collaborative. People with autism have continually been seen as having a condition characterized by a broken self, psychically and biologically, that is so non-normative and damaging that intense and urgent salvation is necessary. These tropes are repeated both in mass media and many scientific writings, most created by people without autism themselves. Meanwhile, personal accounts from people with autism and their families repeatedly negate the consistency of these purportedly realistic portrayals. And yet, the persistent question in autistic autobiographies remain: do these narratives only represent a specific faction within the autistic population, specifically those with less significant forms of autism? If so then can these narratives be generalized to include and capture people with autism whose communication differences prevent them advocating and speaking for themselves? These questions are of yet unanswered, but are starting to be explored.

A recent issue of *Disability Studies Quarterly* focused on autism-related issues and included an article by Paula Durbin-Westby who discussed the absence of autistic "voices" in research and representations.[57] Along with the tropes discussed here, other representations, including a total unawareness of self and others, are often repeated yet inaccurate. For example, autistic autobiography was, for many, a surprising emergence because of its

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[57] Durbin-Westby, "'Public Law 109–416 Is Not Just about Scientific Research.'"

departure from the long-standing notion that people with autism do not have the ability to be introspective or consider themselves and their lives.[58] Yet there remains a population of people with autism who are not writing, speaking and reading, making the representations advanced by these narratives subject to questions about generalizability.

Regardless, many, myself included, argue that autistic voices can promote a much needed faithfulness and tolerance to future representations of autism and those diagnosed with autism. Images such as the one on the cover of Temple Grandin's second memoir, *Thinking In Pictures*...., provide a model to follow. Here, Grandin is pictured sitting amongst the cattle she loves and protects, looking directly at the viewer with a calm, pleasant facial expression. Seeing her in the context in which she finds success, it becomes less a photo of autism and more simply a photo of a person. Another model is that of Amanda Baggs who produced a YouTube video that explains her repetitious and seemingly odd behaviors. As a non-verbal person, she explains that "far from being purposeless, the way that I move is an ongoing response to what is around me. Ironically, the way that I move when responding to everything around me is described as 'being in a world of my own' whereas if I interact with a much more limited set of responses and only react to a much more limited part of my surroundings people claim that I am 'opening up to true interaction with the world.'"[59] Baggs explains that her method of communication is multi-sensory and, hence, much less limited than traditional verbal communication.

Autistic voices such as Grandin's and Baggs' are necessary but seem to have little impact on popular media. As the general public gathers information on autism as a condition and as an experience, the media has a responsibility to work towards representations that people with autism can respect and endorse. Jackie Leach Scully writes that "accurate experiential accounts like these [disability narratives] contribute to the cultural database of identity narratives about the lives of people with impairment. The end ethical goal is that they should displace more damaging portrayals and insert ones that are missing."[60] Providing representations that show success because of, not in spite of, disabilities are a powerful tool to change misrepresentations.[61] Inclusion and attention to the stated experiences of people with autism and their families should define, not simply supplement, the ways the world understands and represents this state of being.

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[58] O. Sacks, *An Anthropologist on Mars: Seven Paradoxical Tales,* New York: Vintage Books (1995).

[59] A.M. Baggs, "In My Language," http://www.youtube.com/watch?v=JnylM1hI2jc (accessed May 2, 2010).

[60] Scully, 129.

[61] F. Campbell, *Contours of Ableism: The Production of Disability and Abledness*, New York: Palgrave Macmillian. (2009).