# AUTISM RESOURCES FOR PUBLIC LIBRARIES: ISSUES, CHALLENGES, AND RECOMMENDED RESOURCES

by Shannon Bloomquist

## INTRODUCTION

One of a public library's true callings is to meet the needs of the community in which it exists. For public libraries, "community need is the dominant factor in selection" of library materials for the collection (Evans, 2000, p. 99). People often think of factors like age, ethnicity, or socio-economic factors when they attempt to describe the makeup of a community. Often overlooked, however, are a community's disabled and special needs clientele. People with disabilities exist in every age group, ethnic, and socio-economic categories in Indiana communities. According to the United States Census Bureau (2000a), roughly 8% of the 5 to 20-yearolds in Indiana are affected with some disability. Roughly 17% of Hoosiers aged 20 to 65 have a disability; and 44% of Hoosiers over the age of 65 have a disability (United States Census Bureau, 2000b, 2000c). Public libraries have a responsibility to respond to their communities with library collections that include resources which support, encourage, and educate people with disabilities and their advocates.

One of the most common disabilities to which a public library collection must respond is autism. Autism is more common than childhood cancer, cystic fibrosis, and multiple sclerosis combined. In fact, the Autism Society of American (ASA) (2003) estimates that one out of every 250 babies born in the United States will develop some type of autism. ASA (2003) reports that 1.5 million Americans have autism, and that 15 million Americans are impacted by autism as the loved ones, health care professionals, care givers, and educators of those with autism. Ivey (2004) articulates the necessity that parents, educators, and clinicians "fully understand the nature of autism" so that they can work together collaboratively to help those who have it (p. 31). To effectively respond to the information needs of this population, librarians must also understand what autism is and how it impacts on those affected and their families and friends.

#### WHAT IS AUTISM?

Autism is a relatively new phenomenon in medical history. In 1943, Dr. Leo Kanner of John Hopkins

University was the first to use the term 'autism' to describe a group of children who "appeared selfabsorbed and had severe communication, social, and behavioral problems" (Edelson, 1999, para. 1). Around the same time, a German researcher named Dr. Hans Asperger observed a milder version of the same set of behaviors, which became known as Asperger's syndrome (Strock, 2004, para. 1). Today, medical professionals understand more about autism, but much about the condition remains a mystery.

An ASA (2003) publication titled What is Autism? defines autism as "a brain disorder that affects a person's ability to communicate, to reason, and to interact with others. It is a spectrum disorder that affects individuals differently and to varying degrees of severity" (para. 1). Both Asperger's syndrome and Pervasive Development Disorder (PDD) are a part of this spectrum, with Asperger's syndrome representing the higher functioning end of the autism spectrum (Tager-Flusberg, Joseph, & Folstein, 2001, p. 21). An Asperger's diagnosis is usually made in later childhood because children with this condition tend to exhibit some autistic behaviors but also develop language skills normally, often having few or no delays in intellectual development (Landau, 2001, p. 32). PDD is a diagnosis given to children who display some autistic behaviors but do not exhibit enough of the symptoms to be given the "classic" or "Kanner's" diagnosis of autism (Landau, 2001, p.32).

Even among medical professionals, there exists many unanswered variables and debate regarding the diagnosis of autism and its related disorders (Tager-Flusberg et al., 2001, p. 22). For example, some individuals with "classic" autism are completely nonverbal, even into adulthood; others develop language skills at a delayed rate as young children, but as teens or adults, go on to possess normal language skills (Lawson, 2002, p. 55). In her book *Understanding and Working with the Spectrum of Autism*, Wendy Lawson (2002) explains that she did not develop language skills until she was 4years-old (p. 55). This is certainly delayed when compared with typical language skills development that occurs around the ages of 2 to 3. Yet, Lawson (2002) was diagnosed with Asperger's syndrome, not classic autism, at age four. Lawson's experience evinces the broad range of symptoms and the subtle differences that exist within the various points on the autistic spectrum.

The assortment of diagnoses of autism overlap, so thinking of autism in terms of a spectrum of observable behaviors helps those who know little about the disability understand that there are few hard and fast rules regarding the condition's manifestation (Tager-Flusberg et al., 2001, p. 22). While some behaviors or symptoms are typical in each type of autism, many individuals with autism have symptoms that fit into several categories on the spectrum. Tager-Flusberg et. al. (2001) suggest that Asperger's syndrome may be distinguished from autism and PDD on the basis of higher verbal IQ's, greater social deficits, higher rates of the disorder in first-degree relatives, and different rates of co-morbidity<sup>1</sup>, especially higher rates of depression (p. 22). Vermeulen (2001) points out that in addition to these identifiers, many individuals without autism exhibit some of the typical behaviors associated with the condition and are diagnosed with an "autismrelated" disorder or autism syndrome disorder (ASD) (p. 13).

While autism is known to be a developmental disorder, the genetic issues relating to autism remain largely unknown. Medical professionals have yet to pinpoint the genes that cause the disorder (Vermeulen, 2001, p. 11). Because autism cannot be diagnosed based on genetic information, diagnosis usually hinges on an evaluation of an individual's behavior over time (p. 11). In addition, the need to seek out a medical opinion may not be apparent to families of infants and toddlers with autism until the children are aged 2 to 4 (Landau, 2001, p. 10-11).

Dr. Temple Grandin, who was diagnosed with autism at age two but went on to earn a Ph.D. in animal science, describes one of her earliest memories as a 3year-old in an interview with the Center for the Study of Autism's Dr. Stephen Edelson (1996): "I can remember the frustration of not being able to talk. I knew what I wanted to say, but I could not get the words out, so I would just scream" (para. 3). Grandin's speech therapist in nursery school aimed a pointer at students when she wanted them to speak, eliciting shrieks from Grandin each time she aimed the pointer at her (para. 4). As Grandin explains, "I screamed because I was taught that you never point an object at a person because it could poke out your eye. I could not tell the teacher that I was taught at home not to point things" (para. 4).

Severe language deficits like those described by Grandin are one of the many signs of autism (ASA, 2003; Strock, 2004). Other symptoms that parents may notice in young children include little or no eye contact, difficulty interacting socially, avoidance of cuddling, showing emotions for no apparent reason, oversensitivity or under-sensitivity to pain, little or no response to verbal cues despite testing in normal hearing ranges, insistence on sameness and strict adherence to routines, delayed verbal and language skills, uneven fine and gross motor skills, sustained odd play, and echolalia (repeating words or phrases in place of normal responsive language) (ASA, 2003; Strock, 2004).

Bill Stillman (2003), an adult with Asperger's syndrome who is very active in the field of disability awareness, reports that doctors know for certain that autism is not a "disease" one can catch, nor is it "an illness or sickness" (p. 8). Stillman explains that autism is something people are born with — "part of who [they] are" (p. 8). Stillman likens attempts to "cure" autism to attempts to "permanently alter what one experiences as naturally as his or her eye color, skin color, or heritage" (p. 9). Autism is a lifelong disorder that cannot be cured; however, individuals with autism can be accepted for who they are and lovingly supported and guided to exert control over their own experiences (2003).

#### COLLECTION DEVELOPMENT CHALLENGES

Corey Seeman, the parent of an autistic child and the Assistant Dean of the University Libraries at the University of Toledo, is Library Journal's regular reviewer of autism resources. Seeman makes recommendations on the most appropriate selections and selection strategies for various types of libraries. He points out that in recent years there has been a "boom" in the diagnosis of autism syndrome disorder (ASD) (Seeman, 2003, p. 45). In the 1970's, the ASA estimated that 3,500 Americans had some form of autism (2003). Today, one to two individuals per 1,000 are diagnosed with ASD, which translates into a 700% increase in the last 30 years (Ivey, 2004; Seeman, 2003). In response to the drastic increase in the number of diagnosed cases of ASD in America, the number of books published about ASD has also dramatically increased. Since 2000, publishers have released 650 titles on the subject, which accounts for 20% of the total number of books published on the subject since it was recognized as a medical health issue in 1943 (Seeman, 2003). Individuals with ASD and their loved ones, friends, and health care professionals require access to resources and information that can help them navigate their way as a team (Stillman, 2003, p. 10). Public libraries have a responsibility to select the very best resources from the overwhelming amount of recently published materials.

#### SELECTING THE BEST RESOURCES AVAILABLE

Seeman (2003) reminds librarians to choose works that represent the varying interests of four main divi-

sions of people: parents, educators, children, and interested patrons (p. 46). Selecting materials that are produced by professional associations and organizations that will provide accurate, balanced, and useful information is a first step libraries must take toward truly meeting the information needs of those affected by autism (Seeman, 2004). At the same time, however, Seeman (2003) also advises that librarians set aside their fears about selecting materials written by "apparent nonexperts," such as parents or family members who have personal experience with autism (p. 46). While these authors may lack traditional professional credentials, their authority lies in their real-life experience and a desire to help those affected with and impacted by autism. Finally, Seeman (2003) asserts that publication year is a very important factor in selecting autism resources. He states that "ASD is practically a different condition than it was 20 years ago." Books written before the mid 1990's tend to suggest that autism is grounded in cold and unloving households, which, as today's research proves, is false (p. 46). Thus, materials published before the mid 1990's may be dated and should be weeded from current collections. Personal narratives, however, are an exception to this rule. Regardless of their publication dates, personal narratives provide first-hand, valuable insight into life with autism (p. 46).

Seeman (2003) also recommends three publishers who routinely produce excellent resources about autism. Jessica Kingsley Publishers is a London-based firm that publishes the greatest number of autism titles each year, and Future Horizons is "an excellent source for videos and workbooks" (p. 46). The 'Topics in Autism' series from Woodbine House Publishers, a publisher that focuses on disability information and awareness resources, is also highly recommended by Seeman.

## **CRITERIA FOR EVALUATING AUTISM RESOURCES**

In order to provide balanced and accurate resources for persons interested in learning more about autism, several factors have been considered in the selection of resources for the recommended titles list below. All resources included in this list exhibit the following characteristics:

- The resources discuss ASD in language that laypeople will comprehend.
- Resources (other than children's fiction) were published in 1997 or later.
- The resources promote the use of person-first language.
- The resources show respect for persons with autism.

- The resources focus primarily on ASD, with secondary focus on Asperger's syndrome and PDD.
  - As a whole, the resources provide a variety of format choices for patrons wishing to access information about autism.
  - Each resource focuses on one or more of the following audiences:
    - ° Parents
    - ° Children
    - Educators
    - Other interested patrons (i.e. advocates, school administrators, physicians, etc.)
    - One positive professional review of each resource exists.
      - <sup>o</sup> Exception: Resources in vertical files

The most limiting aspect of these criteria is the fact that only those sources that have been positively reviewed by professionals are included. This restriction severely limits what may be included in the recommended titles list, especially in the area of young adult nonfiction and audiovisual materials, as many intriguing titles exist which have not been professionally reviewed. Even so, this list is a good starting point for public libraries attempting to wade through and select from the vast quantity of resources published about autism in recent years. As time goes on and more resources are reviewed, librarians would do well to supplement and expand this list. All these materials, including pamphlets kept in a vertical file, should be cataloged in the OPAC.

## RECOMMENDED AUTISM RESOURCES FOR PUBLIC LIBRARIES

## Brochures, Pamphlets, Newsletters, and Information Sheets

Autism Society of America. (2003). *What is Autism?* [Brochure]. Bethesda, MD: Author. Retrieved July 24, 2004, from http://www.autism-society.org/site/ DocServer/What\_Is\_Brochure\_8.5x11.pdf?docID= 722&AddInterest=1041

This brochure contains very helpful information for parents who have recently discovered that their child has autism. It explains the basics of autism and the background and mission of ASA.

Autism Society of America. (2004). Next steps. [Bro chure]. Bethesda, MD: Author. Retrieved July 24, 2004, from http://www.autism-society.org/site/ PageServer?pagename=ASA\_Brochures\_2004 This brochure provides a nine-page general over view of Autism Spectrum Disorders, including a description of treatment options and information about education and services that are helpful to children and adults with autism.

- Autism Society of America. (2004). Building our future. [Pamphlet]. Bethesda, MD: Author. Retrieved July 24, 2004, from http://www.autism-society.org/site/ PageServer?pagename=ASA\_Brochures\_2004 The goal of this 13-page pamphlet is to help educators and school administrators become familiar with the learning styles of students with autism and with the various educational approaches designed to meet their unique needs.
- Autism Society of America. (2004). Growing up together. [Booklet]. Bethesda, MD: Author. Retrieved July 24, 2004, from http://www.autism-society.org/ site/ PageServer?pagename=ASA\_Brochures\_2004 This four-page large-type booklet discusses autism in child-friendly language. It describes how to become friends with a child that has autism and is a great tool for teachers in inclusive classrooms wishing to promote classroom unity.
- Autism Society of Indiana. (2004). ASI advocacy: Legislation update. [Information sheet].
  Bloomington, IN: Author. Retrieved July 24, 2004, from http://www.autismindiana.org/Legislation.html This website promotes the "respectful" and "intelligent" involvement of Indiana citizens in legislative matters concerning autism and is updated as news about autism-related legislation becomes available.
- Autism Society of Indiana. (2000-2005). ASI newsletter. Bloomington, IN: Author. Retrieved July 24, 2004, from http://www.autismindiana.org/Newsletter.html The newsletters available for free download on the ASI website are informational and contain announcements of events around Indiana, personal narratives, and updates concerning news and legislation about autism.

### Children/Young Adult Fiction

Choldenko, G. (2004). *Al Capone does my shirts*. New York, NY: Penguin.

Recommended for grades 6-8, 12 year old Moose Flanagan moves to Alcatraz Island in 1935 due to his father's job at the prison. His 16 year old sister Natalie bas autism and complicates the family's life considerably as she requires Moose's mother's constant attention and sometimes ends up embarrassing Moose and keeping him from doing what he wants to do. In the end, Moose comes to terms with his situation. Positively reviewed by Booklist, Voice of Youth Advocates, and others.

Duane, D. (2003). *A wizard alone.* San Diego, CA: Harcourt.

This book is part of the Young Wizards Series. Young wizard Kit must rescue a young wizard named Darryl who has vanished on his first assignment. The catch: Darryl is a magical prodigy who has autism. This book is recommended for grades 6-8 and <u>School Library Journal</u> states that "the incorporation of Darryl's autism is seamless and drives the plot forward."

Edwards, B. (1999). *My brother Sammy*. London: Bloomsbury Publishing.

<u>School Library Journal</u> calls this book a great choice for "sharing with children who have 'special' siblings and for discussions on feelings." The narrator of the book has an autistic brother named Sammy and at first, he longs for a brother who will do things Sammy does not, like talk with him, build towers with him, and play with him. Once he tries seeing things Sammy's way, his opinion changes. Good for pre-school through second grade.

Ely, L. (2004). *Looking after Louis*. Morton Grove, IL: Albert Whitman.

<u>Booklist</u> calls this book "a big-bearted example of persistence and compassion." This story begins in an elementary classroom full of busy students. The artwork in the book shows that Louis looks just like any other child in the class, but readers notice after a while that he is not participating like the other children are. A girl who sits next to Louis finds a way to involve him in soccer at recess. The book focuses on inclusiveness and not on autism, but a clinical psychologist's note at the end is addressed to adults and explains autism and mainstreaming.

Haddon, M. (2003). The curious incident of the dog in the night-time. New York, NY: Doubleday.
Fifteen-year-old Christopher Boone, an animal lover, finds his neighbor's dog dead in her yard one evening. After he is arrested for the crime, Christopher decides to solve the mystery of the murdered canine himself. Author Haddon, who worked with individuals with autism as a young man, provides a realistic glimpse into the mind of an individual with autism by allowing Christopher to narrate his story in his own words. <u>School Library Journal</u> reviewers state that the book promotes "compassion and understanding" of the behavior of persons with autism.

Ogaz, N. (2002). Buster and the amazing Daisy. London: Jessica Kingsley Publishers. Daisy bas Asperger's syndrome and this novel is written from her point of view. Daisy has trouble with bullies, goes through some tough times with a friend named Cody who uses a wheelchair, and must face her fears of performing on stage in public. <u>School Library Journal</u> reviewers felt that while the plot is "necessarily contrived," the "writing is good, and the dialogue and character development make the book a pleasure to read."

Ogaz, N. (2003). Wishing on the midnight star: My Asperger brother. London: Jessica Kingsley Publishers. This story, written for a 5-8th grade audience, describes 13 year old Alex's series of adventures that take him from resenting his "Aspie" brother to appreciating him. The use of non-person-first language is present, but serves a purpose: to show Alex's movement from resentment to understanding. <u>School Library Journal</u> states that "libraries will find this a useful purchase for their special needs collections."

Rees, C. (2000). The truth out there. New York, NY: Dorling Kindersley Publishing.

This is ultimately a mystery centering on 13 year old Joshua's Uncle Patrick, whose death long ago at age 13 mystifies Joshua. Joshua works with Katherine, his neighbor, to uncover the emotional events surrounding Patrick's death. Patrick had Asperger's syndrome and was very misunderstood by his contemporaries. <u>School Library Journal</u> calls the title "original, fresh, and intelligent," and <u>Kirkus Reviews</u> describes it as "detecting with a techie tilt." Recommended for ages 10-14.

Rodowsky, C. (2004). Clay. Minneapolis, MN: Sage brush Education Resources.

This book for grades 5-8 cbronicles the fictional journey of Elsie Clay McPbee and her little brother, Tommy, who has autism. The siblings were kidnapped by their mother, who has a mental illness. Elsie (who later calls herself "Clay," her middle name) must find a way to get Tommy the medical attention he needs despite her mother's warnings not to. The story is dubbed "moving and realistic" for "readers who can recognize the power of Clay's narrative and not be frightened by it" by <u>School</u> <u>Library Journal</u>.

Thompson, M. (1992). My brother, Matthew. Bethesda, MD: Woodbine House.

The watercolor illustrations in this book help its timeless quality though it was published over ten years ago. David tells this story from his perspective, and the reader learns that David understands his little brother Matthew, who has some type of disability that is very much like autism, better than his parents seem to. David also has normal sibling feelings of resentment and frustration. <u>Horn Book</u> recommends the book, calling it "realistic" and "satisfactory in style, content, and illustration."

Werlin, N. (1996). Are you alone on purpose? New York, NY: Ballantine Books.

<u>Horn Book</u> rates this book as "superior." This is a story of a "nerd" named Alison and a school bully named Harry who seem at first to have nothing in common. Readers learn that Alison has a twin brother who has autism, and Harry's father behaves insensitively toward him. An accident after which Harry must use a wheelchair brings him together with Alison, forming an unlikely romance. For ages 10-14.

#### Young Adult Nonfiction

Jackson, L., & Attwood, A. (2002). Freaks, geeks, and Asperger's syndrome: A user guide to adolescence. New York, NY: Routledge. <u>Book News, Inc.</u> states that "Jackson's conversational and humorous text offers helpful insights into the challenges faced by those with Asperger's syndrome." Topics covered include obsessions and fixations, sensory perception, diet, sleep, teen language, school, homework, socializing with friends, dealing with bullies, dating, and moral dilemmas. This book is current, relevant, and may find an audience with parents and educators as well as teens.

Newport, J., & Bass, R. (2001). Your life is not a label: A guide to living fully with autism and Asperger's syndrome. Arlington, TX: Future Horizons. <u>MAPP Quarterly</u> describes Newport's book as "wonderful," stating that bis advice to others with autism will help them "maximize their potential and minimize their grief." One of the few "how-to" books for young adults with autism, this book is a great resource for young adults who have autism and want to know more about dating, money, traveling, and being independent.

Adult Narratives and Informational Books Attwood, T. (1997). Asperger's syndrome: A guide for parents and professionals. London: Jessica Kingsley Publishers.

Seeman writes in a 2003 <u>Library Journal</u> article that this book, despite its age, "still offers tremendous insight into the identification and treatment of children on the higher-functioning end of ASD." Attwood is a leading figure in the ASD lecture circuit and is a respected expert on Asperger's syndrome.

Balsamo, T., & Rosenbloom, S. (2003). Souls: Beneath and beyond autism. New York: McGraw Hill. This book is filled with amazing photographs that compliment telling prose, all capturing the challenges, triumphs, and tragedies for the family of a child with ASD. Seeman calls this book "tremendous" in a Library Journal review.

Bruey, C. T. (2004). Demystifying autistic spectrum disorders: A guide to diagnosis for parents and

professionals. Bethesda, MD: Woodbine House. Part of Woodbine House's "Topics in Autism" series, this title interprets and explains the <u>Diag</u>-<u>nostic Statistical Manual IV</u>, clarifying the subtle differences between the various points on the spectrum of autism, such as Rett's disorder, PDD, and Asperger's syndrome. Bruey also discusses several common manifestations of ASD that are not discussed in the <u>Diagnostic Statistical Manual</u> <u>IV. Library Journal</u> "strongly recommends" this book for public libraries.

Collins, P. (2004). Not even wrong: Adventures in autism. New York, NY: Bloomsbury Publishing. According to Library Journal, Collins' bistorical accounts of ASD "without passing judgment or linking them to a single theme" is "exceptionally well-written and a joy to read." Collins discusses bis son, Morgan, who has autism, right along with bistorical accounts of the disability to shed a personal light on the bistory of ASD and to further show that ASD is not a new discovery and that we still do not understand it well. "Highly recommended" for public libraries by Library Journal.

Cohen, S. (2002). Targeting autism: What we know, don't know, and can do to belp young children with autism and related disorders (2nd ed.). Berkeley, CA: University of California. The 2002 edition updates the 1999 volume. <u>Library</u> <u>Journal</u> recommends this book for its "strong overviews" of current trends in autism research and its discussion of the varying life cycles of children with autism through all stages including preschool, elementary school, and adolescence. Cohen uses narratives to further explain her points.

Committee on Educational Interventions for Children with Autism. (2001). Educating children with autism. Washington D.C.: National Academy Press. This book focuses on combining scientific, theoretical, and policy literature written in the past 25 years to create a framework for evaluating the many educational interventions for young children with autism. Interdisciplinary education, inclusion, and characteristics of effective programs are explained. Recommended for parents, administrators, advocates, researchers, and policymakers by <u>Reference & Research Book News</u>.

Harris, S. & Glasburg, B.A. (2003). Siblings of children with autism: A guide for families (2nd ed.).
Bethesda, MD: Woodbine House.
A <u>Library Journal</u> review calls this resource "fantastic" and a must-buy for public libraries. The reviewer explains that because the sibling relationship is likely to be the longest one a child with autism will have during his or her life, this book is

imperative for families who have one or more children with autism, but who also have children that do not have autism. The book discusses perception, needs, compromises, and stresses that siblings may face and includes a chapter on being an adult sibling of a person with autism.

- Karasik, P., & Karasik, J. (2003). The ride together: A brother and sister's memoir of autism in the family. New York, NY: Simon & Schuster. Library Journal states that this book "fills an important gap" as it provides a narrative of life with autism in the family told from siblings' perspectives and compliments the parent-authored narratives that abound. Paul and Judy Karasik chronicle the life of their eldest brother David from their 1950's childhood to today. Plenty of information about the misinformation professionals doled out to families (i.e. poor parents are the cause of autism) is expressed through Paul's comics and Judy's prose. Publishers Weekly calls it "a compassionate account of life with David." It comes highly recommended to public libraries from both sources.
- Koegel, L.K., & LaZebnik, C. (2004). Overcoming autism: Finding the answers, strategies, and hope that can transform a child's life. New York, NY: Penguin. Koegel, cofounder of the Autism Research Center, and LaZebnik, novelist and parent of a child with autism, work together well to create what Library Journal calls a "reference work" that is "more accessible and straightforward than most books detailing treatments" for autism. Koegel describes clinical symptoms while LaZebnik provides a different perspective on them with personal anecdotes. "Strongly recommended for public libraries" by Library Journal and Publishers Weekly.
- Ozonoff, S., Dawson, G., & McPartland, J. (2002). A parent's guide to Asperger syndrome & highfunctioning autism. New York, NY: Guilford Publications. Strongly recommended for public libraries by <u>Library Journal</u>, the first part of this book discusses definitions of Asperger's and higher functioning autism, diagnosis, possible causes, and treatments. The second part of the book covers ways parents and care givers can use a child's strengths to help him or her deal positively with home, school, and the social world into adulthood. This is a rare book that focuses on interventions for older children and adults with autism rather than early interventions.
- Prince-Hughes, D. (Ed.). (2002). Aquamarine blue 5: Personal stories of college students with autism. Athens, OH: Swallow Press. ForeWord Magazine calls this book "essential

reading for school administrators and for people with autism and their families and friends." Prince-Hughes, herself a person with autism, edits twelve stories of perseverance and success students with autism have achieved at the college level and beyond. She provides a "powerfully clear analysis of the problems faced by people with autism" within the book. The book concludes with a list of recommendations for universities attempting to become more inclusive, web links, and bibliographies for people looking for more information.

Prince-Hughes, D. (2004). Songs of the gorilla nation: My journey through autism. New York, NY: Crown Hill Publishing.

<u>Publisher's Weekly</u> calls this an "affecting thoughtful memoir" in which Prince-Hughes explains how working with gorillas in the wild helped her to escape the feeling that she was alone in the world. The reviewer states that the book is at once "delightfully quixotic and terribly sad," but a good read for all people touched by autism and especially for those like Prince-Hughes who have higher functioning autism.

Richman, S. (2001). Raising a child with autism: A guide to applied behavior analysis for parents. London: Jessica Kingsley Publishers. Richman, a behavior consultant, explains the applied behavior analysis (ABA) activities that parents can employ with children with ASD. Activities such as toilet training, daily living, and increasing communication skills are discussed. <u>Library Journal</u> notes that public libraries do well to make this purchase because, for many parents, an ABA consultant is a financial impossibility and because it is a "strong" and "invaluable" resource.

Siegel, B. (2003). Helping children with autism learn: A guide to treatment approaches for parents and professionals. New York, NY: Oxford University Press. <u>Library Journal</u> praises Siegel for "carefully tailoring her book to multiple audiences," which include parents and educators. <u>Library Journal</u> goes on to say that she "excels" at using commentary and introductory information to explain best practices for helping children with autism to learn and grow. She also provides a wealth of information on Individual Education Plans for students with autism.

Stacey, P. (2003). The boy who loved windows: Opening the heart and mind of a child threatened with autism. Cambridge, MA: Da Capo Press. <u>Library Journal</u> reviewer Seeman recommends that all public libraries purchase Stacey's narrative. Stacey successfully documents the successes and failures of her young son Walker, who has been diagnosed with autism. She discusses family stress, issues with siblings, and gives great descriptions of meetings with Stanley Greenspan, a noted child psychiatrist. Stacey provides information on benchmarks and vivid descriptions of Walker's progress.

Waltz, M. (2002). Autistic spectrum disorders: Understanding the diagnosis and getting help. Cambridge, MA: O'Reilly Media.

Library Journal praises Waltz for her "incredibly useful new book" that is easy to read, covers the latest developments in medical and therapeutic interventions, and provides information on insurance, education, and family issues. The book is filled with personal accounts from Waltz's discussions with families, caretakers, and persons with ASD. It is a great combination of medical and scientific information complimented by personal stories and real-life applications. The book is "strongly recommended" for public libraries.

### Audio Visual Materials

Baldi, H., & Detmers, D. (Directors). (2003). Embracing play: Teaching your child with autism [Motion picture]. Bethesda, MD: Woodbine House.
<u>Library Journal</u> calls this DVD an "excellent guide for parents who incorporate applied behavior analysis with their child." The DVD includes "strong production values and informative illustrations," and describes for parents how play can be used to interact with a child with ASD.

Documentary Television Corporation. (Director).
(2003). Autism: Now what do I do? [Motion picture]. New York, NY: SKF Books.
<u>Library Journal</u> recommends this DVD for parents as well as public libraries, calling it "forceful and persuasive." Produced by Dr. Sabrina Freeman, the mother of a child with autism and the founder of Families for Early Autism Treatment, this DVD provides a 35 minute overview of the basic answer to the question many inexperienced parents face upon learning that their child bas autism: what next? Freeman provides the information and resources to get parents started on early intervention strategies for their children.

Films for the Humanities and Sciences. (Producer).
(2001). The invisible wall: Autism [Motion picture]. Princeton, NJ: Producer.
Actor Ed Asner narrates this 51 minute DVD, which provides what Library Journal calls a "good overview of autism and related disorders." Interviews with Temple Grandin, an author with high-functioning autism, and Ivar Lovaas, the creator of applied behavior analysis theory, are invaluable, as well as the case studies that illustrate various interventions.

#### Web Sites

Each of the sites below have been professionally reviewed, are frequently updated, and provide a wide range of information and resources about ASD to parents, persons with ASD, educators, siblings, physicians, and interested patrons. These sites contains resource pages with a plethora of links to many types of organizations and information relating to ASD:

National Library of Medicine of the National Institutes of Health. MedlinePlus

http://www.nlm.nih.gov/medlineplus/autism.html MedlinePlus includes extensive information from the National Institutes of Health and other government agencies and professional organizations. Content includes lists of hospitals and physicians, a medical encyclopedia and a medical dictionary, health information in Spanish, extensive information on prescription and nonprescription drugs, and more. MedlinePlus is updated daily. There is no advertising on this site, nor does MedlinePlus endorse any company or product.

National Institute of Mental Health. NIMH health information: *Autism spectrum disorder*. http://www.nimh.nih.gov/healthinformation/ autismmenu.cfm

<u>Library Journal</u> praises this web site for providing a "good introduction" to ASD. One very useful aspect of this site is the section providing links to documents entitled "Autism Spectrum Disorders (Pervasive Development Disorders)" and "Autism Spectrum Disorders Research" that are available for download. These documents might also be printed out and filed in the library's vertical file, though patrons could also access them just as easily online in this cataloged website. In addition, links to current NIMH research studies on autism and PDD are available on the page and are updated as new information becomes available.

Wobus, J. (2004). Autism resources. Retrieved July 24, 2004, from www.autism-resources.com
Wobus, whose son has autism, maintains this site, which organizes many links by category on the subject of ASD. In addition, Wobus compiled a comprehensive bibliography containing over 700 books and resources about autism and a frequently asked questions page. Library Journal recommends the site and especially likes the section entitled "Advice to Parents Who Discover Their Child Is Autistic."

#### CONCLUSIONS

Florica Stone (2004), the mother of a son with autism, wrote a book of her journey through first attempting to cure, then accept, and then understand autism. She describes what she calls the "advice maze," a maze most parents who find out a son or daughter

has autism must find a way through. This maze consists of recommendations and advice from various parties, all of whom have different opinions about autism, and all of whom try to understand and treat the disability in different ways. Stone has encountered care managers who claim that controlling the behaviors of an individual with autism is possible, but whose techniques showed little respect for her son. Stone describes medical professionals who are fascinated and intrigued by autism so much that they focus on the autism itself rather than on the person who has the condition. She knows people who have spent their entire lives trying to figure out what causes autism, as though they want something to "blame" for its existence. Stone has met some who look to science for a cure, and others who believe behavior modification is the ultimate answer. She has viewed numerous documentaries about autism. all of which "promote" various images of "life with autism," almost like a form of propaganda. Of all the perspectives she has encountered, the one Stone has found to be the most valuable is that of the many wise people who have given her the best advice of all: to keep an open mind and continue searching for loving responses to the challenges of autism (pp. 19-20).

The resources included here have been selected because they serve to help parents, educators, children, and interested patrons learn more about the many of aspects of autism from a variety of perspectives. A library housing this recommended collection of autism resources provides access to historical information, clinical research, realistic fiction, and personal narratives written by authors who have earned the praise of professional reviewers, such as Library Journal's autism expert, Corey Seeman. Public libraries have a responsibility to provide a map of sorts for patrons as they travel through the advice maze discussed by Stone. If used properly, these resources will provide a current and balanced picture of how autism is understood medically, what it means for the individuals who have the condition, and how others may respond to those individuals in a healthy and meaningful way.

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