



# Libraries and Autism: Why it matters



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TARGETING AUTISM: A NATIONAL ON SERVING LIBRARY PATRONS ON THE SPECTRUM

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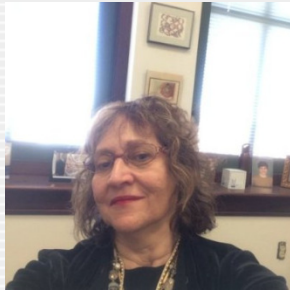
*Supported with grant funds from the Institute of Museum and Library Services*



# Agenda



- Introductions →

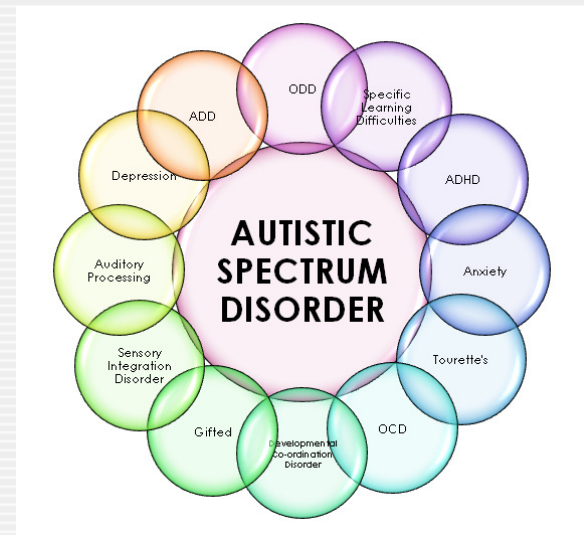


- What is autism spectrum disorder (ASD)?
- Why should libraries care about ASD?
- What is the *Targeting Autism* project?
- What does the future hold?
- Resources
- Q & A

# What is autism spectrum disorder (ASD)?



- ASD is a neurologically based developmental disorder
- ASD has both genetic and environmental components, although specific causes remain unknown
- *Spectrum Disorder* means unique set of symptoms that vary in severity across individuals



# ASD Impacts



- Communication – from nonverbal to highly verbal
- Social functioning – difficulty with nonverbal cues, interpersonal communication, may not know “social rules” or expectations
- Behavior – can be limited (restricted, including restricted interests) or repetitive; may respond in unexpected ways

*“If you know one person with autism, you know one person with autism”*



- Signs of ASD and the need for support or assistance will vary greatly from individual to individual. This means there are wide variations in:
  - Communication ability and skills
  - Intellectual ability
  - Behaviors
  - Physical abilities
  - Levels of independence

# ASD: General Information



- Affects 1 in 68 children (CDC, 2013)
- Rate is likely even higher
- ASD is more common than childhood cancer and diabetes combined
- Diagnosed 4 to 5 times more frequently in males than females

# People with ASD



- May be nonverbal, have limited speech, need assistive device (pictures, tablet, computer)
- If verbal, may have trouble with speech volume or intonation
- May echo words or phrases
- May talk to themselves or to no one in particular
- Use or understanding of gestures might be limited
- May be very literal or concrete (“waive” might be interpreted as “wave”)
- Speak obsessively about an unrelated topic
- Be blunt (seeming rude at times)

# Communication Considerations



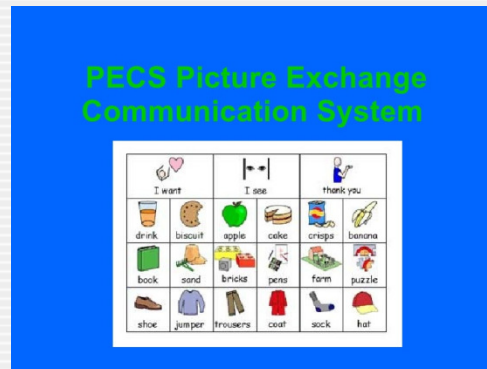
- May not understand slang, jokes, sarcasm, metaphors. Short, direct phrases most effective
- Person may need time to process what you say
- May need things repeated or clarified
- May have difficulty with non-verbal cues; gestures may be seen as threatening
- Might not be able to communicate with language



# Communicating Without Language



- May be used to using symbols/icons to communication (PECS):



- May have been taught sign language (ASL)
- May need assistive device (tablet, phone, etc...)
- Use of picture cards and/or sign language bypasses the need for verbal processing and can result in quicker understanding, improved response especially during times of stress or threat

# Problems with Eye Contact

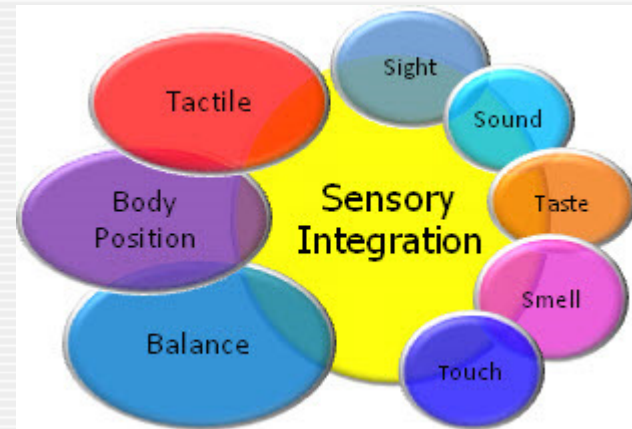


- People with ASD are often taught to make eye contact, but don't understand appropriate eye contact – may stare making some uncomfortable (stalker stare)
- May lead to misunderstandings, complaints

# Sensory Issues



- Sensitive to sounds (may cover ears) – including sounds you might not hear
- Self-stimulatory behavior (may rock back and forth, twirl or spin objects, flick fingers, wrists or arms)



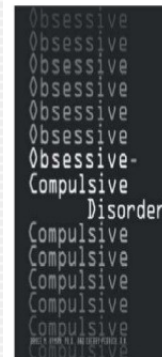
- May be fascinated by lights, reflections and/or shiny objects (like badges)
- May avoid or seek touch (touching or being touched)
- May be insensitive to or have high tolerance for pain

# Obsessions & Compulsions



- Touch or rearrange items
- Stare at displays
- Take an item and not even think of paying (without intent to steal)
- Resist giving up backpack

## OBSESSIVE COMPULSIVE DISORDER



# Victimization



- People with ASD are “perfect victims.” Lack of social understanding makes a great target
- Often targets of bullies at school and in the community. Individuals with high social awareness & low empathy can cause harm without every being caught in the act
- Some bullies may encourage or reward aberrant behavior of those with ASD

# Why Should ASD Matter to Libraries?



- Large population of ASD residents
- Libraries have a responsibility to be inclusive of their entire community
- Accommodations for physical and “invisible” disabilities are part of the American Disabilities Act.

- **ADA Title III: Public Accommodations**

*Public accommodations must make “reasonable modifications in policies, practices, and procedures that deny equal access to individuals with disabilities, unless a fundamental alteration would result in the nature of the goods and services provided.”*



# Challenges for Libraries



- Overcoming the perception that libraries are unwelcoming to residents with autism.
- Helping libraries become more community-focused.
- Overcoming the perception that learning about autism is the job of social workers, not librarians.
- Addressing the need for education and training throughout all levels of the library profession.

# What is *Targeting Autism* and Why Should It Matter?



- (IMLS) National Leadership Forum Grant to help libraries better serve patrons and family members impacted by Autism Spectrum Disorders (ASD)
- Groundbreaking
- Community-wide solutions for achieving inclusive librarianship
- Sustainable outcomes require collaboration
- *Targeting Autism* provides a first step in building a strong foundation to support future initiatives





# Next Steps



From October, 2015 through September, 2016 as part of the *Targeting Autism* grant project, supported with IMLS funding, Russ Bonanno will provide the following services to interested libraries. Limited number of consulting and training opportunities, including:

- conducting site introductory level training sessions in the understanding of autism;
- consulting and providing technical assistance in developing needs assessments related to autism; and
- consulting and providing technical assistance in developing programs or evaluating modifications to better meet the needs of individuals with autism and their families.

Seeking additional grant funds:

Illinois State Library is partnering with Syracuse University and Dominican University to submit a 2016

Laura Bush, 21<sup>st</sup> Century Librarian Program (LB21) grant proposal, entitled ***Targeting Autism:***

***A Comprehensive Training and Education Program for Libraries.***

- A two year comprehensive ASD education and training program, piloted in Illinois and shared nationally
- A collaborative project including: Syracuse University/Project ENABLE, Dominican University Library & Information Science and Russ Bonanno
- Includes a variety of in-person and online learning platforms
- Immediate impact on all levels of library profession and sustainable outcomes

# Targeting Autism Project: Online Resources



Targeting Autism web page:

<https://www.cyberdriveillinois.com/departments/library/libraries/targeting-autism.html>

Targeting Autism blog: <https://targetingautismlibs.wordpress.com/>

Targeting Autism : Helping Libraries Serve Communities Touched by Autism: Facebook Page

The Autism Program of Illinois (TAP): <http://theautismprogram.org/>

Libraries and Autism: We're Connected: <http://www.librariesandautism.org/>

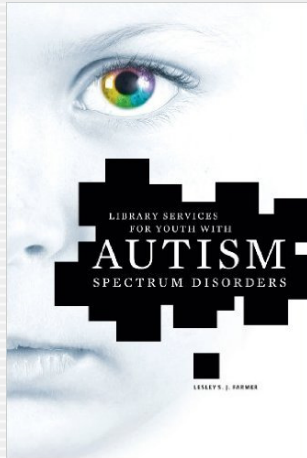
Autism Welcome Here: Library Programs, Services and More Grant:  
<http://librariesandautism.org/grant/>

Project ENABLE (Expanding Nondiscriminatory Access by Librarians Everywhere):  
<http://projectenable.syr.edu/>

Serving Library Users on the Autism Spectrum: Project PALS (four course modules on WebJunction)  
<http://learn.webjunction.org/course/search.php?search=Project+PALS>

SNAILS: Special Needs and Inclusive Library Services: <http://snailsgroup.blogspot.com/>

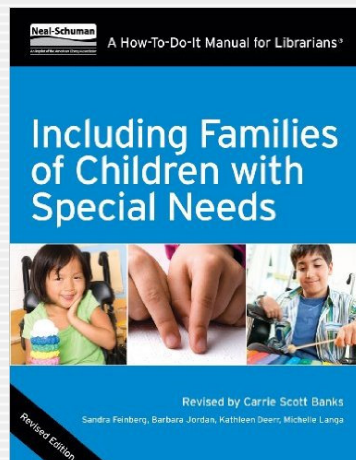
# Targeting Autism Project: Book Recommendations for Librarians



Library Services for Youth on the Autism Spectrum, by Lesley S. J. Farmer, ALA, 2013.



Programming for Children and Teens with Autism Spectrum Disorder, by Barbara Klipper, ALA, 2014



Including Families of Children with Special Needs: A how to do it manual for Librarians, Revised by Carrie Scott Banks, Neal-Schuman, and imprint of the American Library Association, 2014.

## Contact information



For more information about *Targeting Autism: A National Forum on Serving Library Patrons on the Spectrum*, contact:

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To schedule ASD training or a consulting site visit at your library, contact:

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