

LIBRARIES PARTNERING TO SERVE THE AUTISM COMMUNITY: NATIONAL FORUMS OFFER DIRECTION

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Executive Summary

Autism Spectrum Disorder (ASD) is the fastest growing developmental disorder in the United States. According to the Center for Disease Control (CDC), between 1-2% of the world's population¹ have been identified as having autism. The resource and support needs of those on the spectrum are complex and require holistic community engagement.

Throughout their history, libraries have strived to enhance the quality of life among community residents. Libraries provide learning and recreational outlets for residents, offering welcoming, comfortable communal spaces and free access to all types of information resources. However, much anecdotal evidence suggests that those affected by autism are underserved by libraries. Further, librarians and public services staff need to learn more about the characteristics of ASD to enable them to accommodate this special needs population and to ensure inclusive library services.

Libraries Partnering to Serve the Autism Community: National Forums Offer Direction is the result of two national forums that were convened at the Illinois State Library in 2015 and 2016. The forums were funded through the National Leadership Grant (NLG) Program of the Institute of Museum and Library Services (IMLS). The forums exposed the need for libraries throughout Illinois and across the nation to better serve patrons and families affected by autism. The need for autism education and training, as well as, partnerships with non-library stakeholders is essential for providing comprehensive library service to this special needs population.

The Issues

Large and growing population affected by autism

The incidence of ASD is reported to be 1 in 68 births (CDC). Many more people are impacted when family members and those with autism with no formal diagnoses are considered. All need access to reliable information, resources and access to support services. Yet, due to a lack of knowledge of and outreach to this community, libraries have been underutilized. Parents of children with autism often keep them away from libraries, either due to negative experiences or a fear that their child will have a meltdown and not be welcomed.

Libraries have a responsibility to serve the whole community

The overarching mission of libraries includes a responsiveness to the diversity of the communities that they serve. Explicit within the ALA Policy Manual, "...Libraries can and should play a crucial role in empowering diverse populations for full participation in a democratic society..." (Diversity, section B.3).

More needs to be done in Illinois

The results of a 2013 survey of Illinois libraries conducted by the Illinois State Library showed that only 27.1% of respondents provided any special services or programming to patrons with ASD.

¹"Data & Statistics." *Centers for Disease Control and Prevention*. Centers for Disease Control and Prevention, 11 July 2016. Web. 18 Jan. 2017.

National forums convene to educate, address the issues and advocate for more inclusive libraries

Stakeholder alignment survey identifies challenges and opportunities for collaboration

Waymark Systems, a stakeholder alignment organization based in Champaign, IL, conducted a statewide survey of all autism stakeholders, including but not limited to, librarians and library staff members. Overall, stakeholders were aligned about the important role of libraries to provide resources and access to reliable information for the ASD population. There was also agreement on the need for libraries to form sustainable partnerships with community stakeholders. There was some resistance concerning training issues and the kinds of programming that would be workable in individual libraries. All saw the need for libraries to be welcoming and knowledgeable about ASD, and to provide inclusive environments.

Participants gain a deeper understanding of autism

Forum presenters shared a wide range of knowledge and experience about autism as well as the vital role libraries can play in the ASD community. Participants heard from autism services providers, disabilities experts, self-advocates on the spectrum, autism parents, librarians and educators. They learned about the history of autism from John Donovan and Caren Zucker, who discussed their book, *In a Different Key: The Story of Autism*. Finally, Ariadne Blayde engaged the audience with the topic of autism as expressed through the art of storytelling, via the theater. Blayde showed the Kennedy Center's production of her play, *The Other Room*, which won the VSA Playwright Discovery Award in 2008. The viewing was followed by a discussion on the power of the arts to educate and create social change.

Some key points from the forums:

- The characteristics can be individualized and hidden; therefore, those with ASD are often misunderstood. Often, people on the spectrum and their families don't feel accepted.
- It's important that the entire community, including libraries, work together to support individuals on the spectrum.
- Libraries have an opportunity to impact children's lives for the better.
- There is no substitute for knowing each of your library patrons on the spectrum, including what their reading preferences are and what tools work best for them.
- Most programs offered in a library can be adapted to accommodate the needs of individuals with ASD.
- Some individuals with ASD do not communicate by speaking. Librarians should be aware of the various ways they may try to communicate, including hand signals, American Sign Language (ASL), iPads and the use of an alternative communication device, such as electronic pictures or picture cards, e.g., Picture Exchange Communication System (PECS).
- Many people with ASD prefer tight quarters and may find reading nooks a safe and secure place to settle.

- Some behaviors may seem unusual, including: hand flapping, flicking, chewing—including on clothing, hitting themselves, taking odd positions on the floor, covering their faces and making various noises.
- Librarians, public services staff and library school students need disabilities training to enable them to work with a diverse patron base, including those with autism.
- Librarians need to be aware of the potential for meltdowns to occur. They need to learn ways to prevent crises and intervene when necessary.
- Librarians can help to educate the community in many ways, such as holding forums, parent talks and providing information resources that would be helpful to parents, teachers, student teachers and those with ASD.
- The Americans with Disabilities Act (ADA) was always meant to be inclusive of developmental disabilities.
- Principles of universal design should inform library decisions about the optimal choices for learning/reading spaces as well as format in which books and online information should be presented.

The importance of conducting community needs assessments

A community needs assessment is an essential first step to considering new services or programs. Libraries need to identify key stakeholders within their communities and assess current programs and service gaps. Existing services should not be duplicated or replaced. They also need to identify and include those people who are passionate in order to garner and sustain the engagement of stakeholders. Examples of successful needs assessments and community collaborations were shared at the forum, providing many models of best practices.

Outcomes

- Librarians reported how the knowledge gained at the forum resulted in changes made back in their libraries. These changes ranged from environmental accommodations, programming adaptations and volunteer placements for individuals on the spectrum.
- A small grant program *Autism Welcome Here* was developed to help libraries start or expand an existing service targeted to residents with ASD.
- *Targeting Autism* social sites (blog, Facebook page, Twitter and discussion list) have been very active statewide, nationally and globally.
- Finally, IMLS has awarded a second phase of grant funding to the Targeting Autism initiative. As a two-year, Laura Bush 21st Century Librarian grant project, *Targeting Autism: A Comprehensive Training and Education Program for Librarians*, partners the Illinois State Library with Dominican University and Syracuse University to deliver a multi-faceted ASD training program that combines face-to-face and online components. Annual forums and social sites will be ongoing. Based on a train-the-trainer model, this project is highly replicable and intended to impact the ASD community throughout Illinois and the country.

I. INTRODUCTION

Why a National Forum on Serving Library Patrons on the Autism Spectrum?

Libraries are a valuable asset to society, offering their patrons access to a wealth of resources in a wide range of formats, as well as, via the Internet. These resources are designed to nurture personal interests, growth and learning. In addition, libraries provide environments for individual work and for group meetings. As a hub of activity, they are thus uniquely positioned to offer rich informational opportunities and to support the quality of life for all community residents. This paper describes how Illinois, acting under an IMLS National Leadership Forum Grant, began work to explore how the library experience could be improved and expanded for individuals on the autism spectrum and their families.

Large population affected

The population of people affected by ASD is large, transcending geographic boundaries and racial, ethnic, and socioeconomic divisions. Since 2012, the CDC has estimated the incidence of ASD at 1 in 68 births. A more recent government study, however, revealed that the number is more likely closer to 1 in 45² when counting people who are receiving services, yet have no formal diagnoses. ASD is the fastest growing developmental disability. Autism's impact extends to loved ones and community; all are in need of information, resources, and access to support services.

Libraries have a responsibility to all citizens

The future of libraries will be determined by the services and programming that conforms to the needs of our diverse and changing communities. The American Library Association's (ALA) Libraries Transforming Communities (LTC) initiative, in partnership with the Harwood Institute and the Bill & Melinda Gates Foundation are fostering a nationwide movement to strengthen the role of libraries as community leaders and change agents. This new direction places a greater emphasis on working with local organizations to develop innovative library programs that meet individual community needs. In "turning outward,"³ librarians place a priority on responding to local issues and aspirations as a key objective to fulfilling the library mission. This approach aligns with ALA's overarching goal of promoting "equal access to information for all persons and [recognizing] the ongoing need to increase awareness of and responsiveness to the diversity of the communities we serve...Libraries can and should play a crucial role in empowering diverse populations for full participation in a democratic society" (ALA Policy Manual Diversity section B.3).

²"Autism Cases in U.S. Jump to 1 in 45: Who Gets the Diagnosis, in 8 Simple Charts." *The Washington Post*. WP Company, n.d. Web. 18 Jan. 2017.

³"About LTC." *Libraries Transform*. N.p., 15 Mar. 2016. Web. 18 Jan. 2017.

What's being done nationally?

Inclusion of the ASD community is intrinsic to the mission of libraries. Several initiatives that embrace and support the ASD are listed below:

- *Libraries and Autism: We're Connected* is a model New Jersey program that began in 2008 with the support of IMLS grant funds. Developed by the late Meg Kolaya, director the Scotch Plains Public Library, and Dan Weiss, director of the Fanwood Public Library, the program was designed to help patrons with ASD have a more comfortable and positive library experience. In addition to ongoing outreach efforts and onsite training sessions, Kolaya and Weiss developed a customer service video to help library staff understand and better serve the ASD community.



- *Project Enable (Expanding Non-Discriminatory Access by Librarians Everywhere)* is an IMLS-funded project created in 2011, led by Dr. Ruth Small and a team from the Center for Digital Literacy, the School of Information Studies, and the Burton Blatt Institute at Syracuse University. Project Enable began as an initiative to provide in-depth training to school librarians on ways to provide appropriate and effective library and information programs and services to students with disabilities. The need

for wider distribution of this training resulted in the development of freely accessible online, self-paced training modules. Public and academic libraries are also targeted to receive the training.



- *Panhandle Autism Library Services (PALS) aka Project PALS* This IMLS-funded project out of Florida State University is led by Dr. Nancy Everhart, School of Library and Information Studies, working with colleagues at the Autism Institute at the College of Medicine. Beginning in 2013 as an education program to improve information services for rural patrons with ASD, Project

PALS has since expanded their scope nationwide. PALS currently provides an online, self-paced course intended for librarians and library staff wishing to learn how to better serve their users on the autism spectrum. The project [PALS course](#) is freely available on WebJunction.



- *Special Needs and Inclusive Library Services (SNAILS)* As a networking group, formed in 2013 by two suburban Illinois public library youth services librarians, Renee Grassi and Holly Jin, the mission of SNAILS is to expand and improve library services for children and young adults with all types of disabilities, including ASD. More than 40 public libraries in the Chicago area meet



quarterly to exchange ideas and expertise, and to create programming and services in their libraries, fulfilling their shared purpose.

Overall, these ongoing initiatives provide excellent examples of collaborations that prioritize library services for individuals with ASD and other disabilities. As discrete programs, however, their impact on the large and global ASD community is limited. Models like these need to be adopted more extensively. Expansive networks of support and broader geographic reach are crucial to achieving the overarching goal of providing ubiquitous inclusive library services.

Illinois survey – more needs to be done

In 2013, the Illinois State Library conducted a survey to better assess the value of libraries in the ASD community, as well as, the need for training to educate librarians about ASD. Of 202 respondents, representing all types of libraries throughout Illinois, only 55 (27.1%) reported that their libraries provided any special services to patrons with ASD. The survey results also pointed to an interest in a forum for furthering the discussion on the need for better training and ways that the library community could foster additional collaboration and support.

Pursuant to this survey, the Illinois State Library applied for and received an IMLS National Leadership Grant, *Targeting Autism: A National Forum on Serving Library Patrons on the Spectrum*. This grant focused on finding ways that all types of libraries can address the topic of ASD, as well as, form partnerships with and between service organizations, education and medical facilities, and appropriate governmental agencies and representatives. Two informational forums were convened in Springfield, IL, as part of this initiative. The forums were designed to:

- (1) help participants to gain a basic understanding of autism;
- (2) discuss the role of libraries in serving those impacted by autism;
- (3) share expertise and resources; and
- (4) initiate multi-stakeholder collaboration in the design of programming and services to increase the value and use of libraries within the autism community.

II. NATIONAL FORUMS ADDRESS CURRENT CHALLENGES; NEED FOR COLLABORATION AND EDUCATION

The two forums brought librarians from all types of libraries together with autism services providers, various stakeholders and advocates from across Illinois and beyond. The first forum was held on March 4-5, 2015, and the second was held on March 10-11, 2016. More than 80 persons attended each forum.

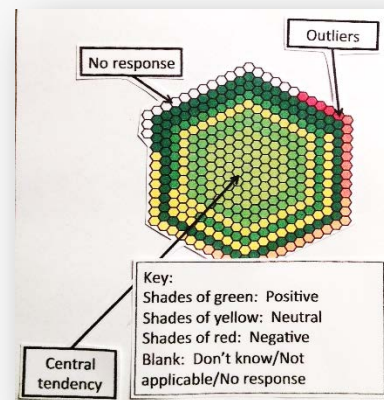
Both forums served to educate and jumpstart discussions on how libraries could work within their communities to play a more targeted role in serving those affected by ASD. Overall, participants gained a greater understanding of autism and an appreciation of the vital responsibility that libraries have to respond to the needs of the ASD community. Many of the forum highlights are shared in the following sections.

First steps: Illinois identifies challenges and opportunities for collaboration and education

Stakeholder Alignment – Survey Results and Discussion

Prior to the first forum, [Waymark Systems](#), a stakeholder alignment organization based in Champaign, IL, conducted an online survey to assess the opportunities and potential challenges faced in forming collaborative relationships among librarians and autism stakeholders in their communities. Results were compiled and distributed at the beginning session of the March 2015 forum. Some 387 people responded to the survey. Approximately **40%** of the respondents were librarians—with the majority of those (82%) being public librarians. Other respondent groups included community residents (**21%** of respondents, with 76% of those identifying as being an ASD individual or family member); educators (**16%**, and some 82% of those were at the k-12 level and 10% were at the university level); community-based organizations (**10%**) and health care workers (**3%**). Responses to the questionnaire showed a range of thoughts on the need for, and ways in which, libraries could serve individuals and family members impacted by ASD.

The Waymark data were presented, in part, as Z-flower™ visuals of stakeholder responses (as shown in the diagram). These are colored hexagonal depictions of the tendency of survey responses to lean towards the positive or negative. Each Z-flower™ is made up of tiny individual hexagons, each representing a single response to a particular survey question. Colors range from dark green (the most positive), through shades of light green, yellow, orange to red (the most negative). White is a “don’t know” response or no response given at all. The Waymark survey data provides a mean (average) or central tendency score, and a standard deviation (SD) from this mean. SDs that are smaller numbers represent less variation in all the responses given. In our sample of library-related questions, the central tendency scores ranged from .88—which were depicted as z-flowers showing a good deal of dark green (positive responses) to .67—which were depicted as z-flowers with a good degree of color variation including reds and oranges (negative responses). The SD values ranged from .16, which shows fairly minimal deviation in the responses from the mean, to .26, a more notable degree of deviation in the responses from the mean. Mark Nolan from Waymark Systems cautioned forum participants to heed the negative responses, however few in number they may be, because even only a relatively few negatives can impact the success of an endeavor. Indeed, some important concerns were raised via open-ended responses to several of the survey questions. These will be specified a bit later.



The Waymark survey questions of most concern to libraries showed the following:

	<u>Mean value (SD)</u>
It is important for me to have access to ASD information	.84 (SD, .19)

It is easy to get ASD information	.67 (SD, .24)
Education/training on ASD should be included in librarian professional development	.80 (SD, .21)
Library staff should be required to receive ASD education	.68 (SD, .26)
Libraries are good places to learn more about ASD	.73 (SD, .23)
Public libraries should collaborate with teachers and school librarians to help students with ASD achieve academic success	.81 (SD, .19)
Users need help navigating the large amount of ASD information	.79 (SD, .17)
<u>Libraries should:</u>	
Provide ASD information	.88 (SD, .16)
Provide programs welcoming to people with ASD and their families	.88 (SD, .16)
Provide space for ASD support groups to meet	.82 (SD, .20)
Provide spaces that are sensitive to the range of ASD behaviors	.79 (SD, .22)
Integrate children with and without ASD when providing services	.79 (SD, .20)
Form sustainable partnerships with the community relevant to ASD	.79 (SD, .20)
Provide an environment addressing the sensory needs of patrons with ASD	.78 (SD, .22)
Provide space or services targeted for children with ASD	.76 (SD, .23)
Provide space or services targeted for teens with ASD	.76 (SD, .23)
Include services and resources helpful to teens with ASD who are in transition	.76 (SD, .23)
Assist agencies in educating the ASD community on funding and support services	.76 (SD, .21)
Provide employers with resources and information about hiring and working with persons with ASD	.73 (SD, .24)
Provide programs to help ASD patrons build social skills	.69 (SD, .25)
There should be a centralized Illinois ASD website showing regional & local resources	.86 (SD, .17)
There is a need for a state-wide coordinated system of ASD information	.84 (SD, .18)

The complete set of visuals can be accessed [here](#). Overall, the data suggest that there is general agreement that libraries should provide resources and access to information that is pertinent to the ASD population. However, there was some resistance concerning the training issues and programming that would be workable in individual libraries. One key finding that surfaced was that collaboration with ASD support agencies was regarded as essential for smaller libraries whose resources are limited. A sampling of all concerns is expressed in the respondents' comments shared below and was included in a [handout](#) distributed at the first forum.

“There should be some kind of centralized online location that librarians and workers can show people who come in asking for information. This site should be easy to navigate to find answers or have the ability to send queries to experts who can answer them in a timely manner.”

“More and more children are born with ASD. The libraries can become a liaison between the ASD community and the support and resources they so desperately need.”

“I do not think libraries should be responsible for specialized groups beyond basic disability accommodations. It is the responsibility of the individual to adapt to the environment.”

“My vision of success would be a ‘Community Resource Area’ in all libraries state-wide . . . connecting people to resources and programs for whatever their needs . . . Helping them to be the best that they can be and to live life to their greatest potential!”

"Libraries, especially small ones, will need some funding to purchase a few book resources."

"Librarians are not social workers . . . But if they can be that central source of information -- and can get a person to a social worker, or to information or resources, that would be great."

"The library would become a hub of information, gathering and support for individuals and families affected by ASD. It would be a known resource to educators, health care professionals, community members, families, and individuals."

"All libraries, rural and urban, should have available or should have access to solid information on ASD for whomever needs the information."

"Our library is quite small and it would be difficult to hold programs on dealing with ASD that would garner public interest."

"I think the library needs to be welcoming to people with all special needs. They can't devote lots of funding to any one group in particular--but need to do the best they can to the greatest number of people within their budgets."

"I wish that librarians would be as good about hiring people with ASD and other disabilities as they are at helping them as patrons. Librarians are very altruistic and want to help people, but they want their staff to be disability-free."

"We need to step up to this plate and help all members of our community be successful. This means a true commitment to training clerical, security, reference and all staff, re-thinking our spaces and re-designing our programs based on what we learn."

"I'm hopeful that when the community realizes there are resources in the local libraries that would be helpful to those living and learning about ASD, more people will use this as another way of educating themselves."

"The concern is that the information about ASD disseminated to the public by libraries must be relevant, statistically sound and evidence-based."

"There is still the stereotype that libraries are quiet places, so parents who have kids with unpredictable behavior don't feel comfortable bringing them in."

"I don't want to be 'mandated' to provide programming or activities for children. My programming options are open to anyone, regardless of ability. . . I am afraid this initiative will put the job of 'educating' ASD children onto libraries, instead of on schools where it belongs."

"I would need direction as to services that are needed. I would need to be given a source whether individual and/or organization to get in contact with when questions arise."

"I think there needs to be a balance between librarians/library staff having knowledge of what is available, but not being viewed as an 'autism specialist.' It is important for families to identify the individuals with whom they can collaborate to learn more about ASD, versus getting a diagnosis, etc."

The range of Waymark survey results were used to inspire a large group discussion on shared goals, expectations, next steps and a vision that encompasses autism awareness, acceptance and support. The discussion was summarized and distributed as a [handout](#) after the morning session.

Listening to the experts

Growing in our understanding of ASD

ASD services providers, individuals on the spectrum, family members and various other advocates contributed to a deeper, more nuanced understanding of the individualized and often hidden characteristics of autism.

Keynote Speaker (March 4-5, 2015 Forum), Russell Bonanno, Director of The Autism Program of Illinois (TAP) challenged forum participants to use the two-day venue to focus on determining how libraries could "support, inspire, strengthen, improve, inform, and educate" people with autism, their families, and their caregivers. He emphasized the diversity amongst those individuals with ASD, indicating that they come in all ages, shapes and sizes, with varying behaviors, needs, dreams, desires--just like the rest of us. "They want to feel comfortable in their lives and in their communities [but] they often have difficulty communicating. They're frequently misunderstood; they don't often feel welcome or accepted. And much too often, they're right [and] their families don't feel welcome and accepted either."



"What role do libraries play in helping to improve the quality of life for people with autism and their families?" asked **Keynote Speaker, Russell Bonanno, Director, TAP**

In his comments during the second forum, Bonanno noted that major budget issues in Illinois [and this may be true elsewhere throughout the country to some degree] have severely limited and/or completely curtailed the work and services of several ASD support organizations. He noted, “This project and what the libraries are able to do in conjunction with community providers and agencies is especially important.”

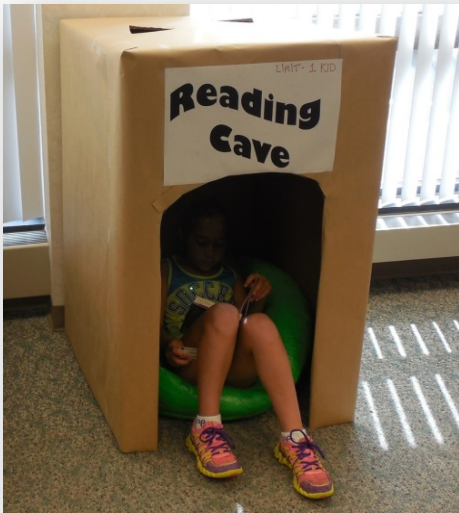
Adria Nassim, Disability Advocate and Speaker, provided the perspective for forum participants of “what it’s like to walk in the shoes of the children and individuals you’re aiming to serve with this grant.” As an individual with autism and several other disabilities, Adria emphasized that we all share the responsibility to work with ASD individuals. She said: “It takes everybody . . . my parents--both of them--and my sibling, and doctors and therapists, and a dog trainer, and a swim coach, and clergy, and summer camp staff--a whole slew of people to give me my best life. But it also takes librarians.”



“I want to impress upon you now the opportunity you have--and maybe also the obligation--that you have to children who may be in some instances overlooked . . . The opportunity that you have to impact these children’s lives and individual’s lives, for the better.” **Disability Speaker, Adria Nassim.**

Keynote Speaker (March 9-10, 2016 Forum), Marty Murphy shared ideas and insights useful for all types of libraries. Marty explained that some individuals with ASD may be non-verbal or have limited speech and may, therefore, seem non-communicative. Librarians should be aware of the various ways ASD individuals may communicate, including: (1) hand signals; (2) American Sign Language (ASL); (3) iPads and/or; (4) the use of an alternative communication device--either electronic or via picture cards, such as those used in the Picture Exchange Communication System (PECS). Knowing about the range of communication options and having some alternatives available (even pictures from magazines or a computer) may help bridge the communication gap so that librarians can better understand the resource needs of their ASD patrons. Murphy also noted that many individuals on the spectrum prefer tight quarters: “... [many] people with autism are the opposite of claustrophobic...” and may find reading nooks a safe and secure place to settle.





Even a large empty cardboard box with cushions can be fashioned into a comfortable reading cave for children, as shown in this picture from [Tiny Tips for Library Fun](#) blog. This reading cave is one example of an inexpensive and effective way for libraries to provide welcoming spaces to accommodate children with ASD.

Murphy described some of the behaviors of individuals with autism that might seem unusual to the general population. Among these behaviors are hand flapping, flicking, rocking, chewing--including on clothing, hitting themselves, taking odd positions on the floor, covering their faces, and making various noises. She went on to explain that librarians should be aware of the potential for emotional meltdowns to occur, sometimes suddenly. When this happens, librarians might ask the patron questions to ascertain the problem. It might be helpful to find a private space in the library to invite a conversation about what is bothering them. In addition, librarians might also offer to call someone the patron knows who can reassure them further. Murphy noted that it is not advisable to touch the person, as touch can be "physically painful" to someone with autism.

According to Murphy, "People with autism are bullied. We are the quintessential victim, because most of us don't fight back." Murphy described autism as "the condition of low self-esteem" especially for children who find that they do not fit-in socially or academically in school. However, "if we have a sense that we're important, that we matter in the scheme of our community, our school, our home, our libraries . . . everything else will kind of come together." Murphy noted that librarians have an important role to play in educating the community through holding forums, parent talks and providing speakers. In addition, all libraries should include access to ASD resources written at all levels that would be helpful to parents, teachers, student teachers, and the ASD individuals themselves.

"You want the autistic child and the community to not be afraid of each other, to not distance themselves. You want them to meet each other and say 'Hi' and be comfortable and proceed on with life, and be a part of your library." **Keynote Speaker, Marty Murphy, autism self-advocate and public speaker.**

Parents of ASD Individuals-- Forum participants heard not only from individuals who are on the autism spectrum, but also from parents.



Debra Vines explained her role in starting up an advocacy organization, *The Answer, Inc.* to help bridge the gap in service provisions and networking opportunities in the African American community. Her organization provides support, resources, education, recreation and advocacy for families impacted by autism and developmental disabilities. *Just For Men*, a support group offered by The Answer, Inc., provides a venue for fathers of children with ASD to share their joys, ideas and concerns about raising their son or daughter. Vines noted that in collaboration with TAP, her organization was the first

to bring much needed autism resources into the Proviso Township area of Chicago, including the establishment of an Autism Resource Center in the Broadview Public Library (pictured).



Mary Pelich, formerly with TAP, shared her story as a mom struggling to find the services and information she needed for her son, who was diagnosed at age eight with Asperger's. "There are ways to get people to the resources they need, but we need to use our mouths and heads and the knowledge we have," said Pelich. She encouraged the forum participants to make connections

and to share "whatever little piece of expertise you have [because] it could make all the difference in the world" to a parent trying to make the best life possible for their child.

Addressing the need for resources in Illinois

Librarians from all types of libraries should be able to direct their patrons to well-vetted information sources, and ideally to local support services and programs as well. Forum



participants heard from agency representatives who provided insights about what services they provide and how their work might be interconnected with what libraries offer. Appropriate information in various formats is available without cost in Illinois, but librarians may not be aware of the options for getting it into the hands of their patrons. For example, [the Illinois Early Intervention \(EI\)](#)

[Clearinghouse](#) lends educational materials such as books, DVDs, audio books, e-books, manuals, and assessment and play kits to anyone in Illinois who requests them. Sarah Isaacs, Librarian at the Clearinghouse, indicated that included among these are some “1500 items that are specifically devoted to autism ... a really unique collection of autism materials that [spans] birth through the lifespan.” Items can be mailed directly to an individual’s home or local library, and can be returned to the local library. Materials can be provided in the native language of the individual, and the EI staff is willing to collaborate with service organizations and libraries of all kinds to help get the materials out to the general public. Staff is also available to offer suggestions about where to find other materials, equipment, or services if a question comes up at a library about who/where to turn to meet additional needs.

[Information Connections](#) is an extensive online resource for delivering health information to physicians, clinicians, patients, caregivers and family members. The site addresses information about autism, cerebral palsy, Down Syndrome, ADHD, and traumatic brain injury. Nalini Mahajan, Library Director at the Marianjoy Rehabilitation Hospital in Wheaton, IL, explained



that the website evolved initially from two National Library of Medicine grants as a way to help organize, update, and expand upon the diverse body of information contained within the personal collection of the Hospital’s Pediatric Program Director, Dr. Mary Keen. The website now provides information on the specific conditions mentioned, as well as on support networks, new research, advocacy, nutrition, rehabilitation, education, legislation, insurance, and more. [Information Connections](#) is kid-friendly, offers assistance via a Spanish-language option, and includes links to various national organizations and reliable medical websites.

Best practices from librarians and librarian educators

Both forums included a wealth of practical information regarding resources and programming aimed at enhancing the library experience for patrons with ASD. Many resources and accommodations were shared, equipping forum participants with best practices and tools to apply in their home libraries and communities.



Dr. Lesley Farmer, Author and Professor, California State University, Long Beach, shared best practices for selecting library materials for children and youth with ASD. She stressed that the principles of universal design should inform library decisions about the optimal choices for learning/reading spaces as well as the way in which books and online information should be presented. Although sensory issues are highly individualized for those on the autism spectrum, some generalities apply. For example, textual content

should not be overly busy; font choice and font size are important. Dual coding⁴, using both images and text to convey meaning, is optimal. Simple English Wikipedia contains over 100,000 pages that have been translated into a more basic English to provide an encyclopedia for people with a variety of reading challenges. In addition, the physicality of library materials should be considered. Many items can be easily adapted to accommodate children on the spectrum. For example, spiral bound text is easier to read because pages can be laid flat. Texture can be added to picture books for those kids who need the extra stimulation; props and kits can supplement print materials.

In closing, Farmer shared that ultimately, there is no substitute for knowing each of your library patrons on the spectrum, including what their reading preferences are and what learning aids and strategies work best for them.

"...The most important thing is to get to know your library users as individuals. What are they like? What works for them? What doesn't?... because 'if you know one person with ASD, you know one person with ASD'..." Lesley Farmer, 2015 Targeting Autism Forum



Barbara Klipper, Autism Advocate, Author and Former Librarian shared her expertise regarding developing and adapting library programming for children and teens on the autism spectrum. According to Klipper, "a program is a great way to get these families and kids into the library, to get them to know the librarian, to feel comfortable in the space and that can translate into a lifetime of library use." She recounted the many times that

she was made aware of how sensory story times have created a love for the library for kids with ASD. Most compelling was Klipper's story of a non-verbal Hispanic child on the spectrum who spoke her

⁴ "Chegg.com." *Definition of Dual-coding Theory* | Chegg.com. N.p., n.d. Web. 18 Jan. 2017.

first word at one of her programs. “Miracles can happen and it’s not about the numbers ... individual lives can be changed by these programs.”

Klipper shared how some of her programming workshops have been particularly useful in helping teens develop some practical life skills. Examples include 1) organizing a backpack; 2) budgeting and money management; and 3) dressing for school success.

Klipper also presented best practices for developing autism friendly library programs. She shared her [checklist](#) and [programming](#) suggestions with forum participants. A key consideration should include whether or not these sessions should be inclusive or segregated to include only individuals on the spectrum. Setting limits on group size and making sure that there is a good ratio between the number of participants and helpers is also an important consideration. Because those on the spectrum need predictability to feel a sense of safety and comfort, preparing participants ahead of time for a program is essential. Social stories or holding a library Open House prior to the program works well. Managing transitions is also important for ensuring successful library programs. Because cognitive processing takes longer for people with autism, abrupt changes can result in meltdowns. Visual supports in advance of transitions can make a big difference.



“... You don’t have to do new programs [in your library]. You can adapt what you already have. Just about any program you already offer can become autism friendly with some modifications...”
Barbara Klipper, 2015 Targeting Autism Forum



Dan Weiss, Director, Fanwood Public Library, NJ, and Co-creator, *Libraries and Autism: We’re Connected*, stressed the value of good customer service as the foundation of inclusive libraries. According to Weiss, the best customer service begins with communication and empowering yourself, your library staff and volunteers with some knowledge and training. Toward that end, many great resources, including a [training video](#), are available on the [Libraries and Autism: We’re Connected](#)

website. Weiss cautions us that although we strive for inclusion, there can be many barriers. Parents of children on the spectrum often cope with challenges that make them angry, tired or frustrated. In addition, parents of children with autism often avoid community interaction because of their child’s atypical behaviors or meltdowns. As public service providers, we must do everything we can to ensure our users that their experience in the library can be very positive.

Weiss reminds us that being inclusive is not just the right thing to do, it's the law. The Americans with Disabilities Act is not the Americans with Physical Disabilities Act; it was always meant to be inclusive of developmental disabilities, and not just those disabilities that are visible.

"...The goal is to strive for universal, inclusive service and to make the library instrumental in allowing all people to be a real part of their library, their community, rather than just in it..."
Dan Weiss, 2015 Targeting Autism Forum

Gaps in library education

The subject of how well Library Science Masters Degree programs prepare students to work with individuals on the spectrum, as well as, other disabilities was explored by a panel of experts at the 2015 forum. Representing the library science graduate schools of Syracuse University, Florida State University, Dominican University, and University of Illinois at Urbana-Champaign (UIUC) were, respectively and from left to right in the photo, panel members, **Dr. Ruth Small, Dr. Nancy Everhart, Dr. Sujin Huggins, and Doctoral Candidate Wei Gao.**



Panel members Huggins and Gao noted that although diversity, including the diverse needs of library users who have disabilities, may be interwoven within the readings and discussions in several courses in their curricula, content specifically addressing patrons with autism is not presently covered. "A disability such as ASD," said Wei Gao of UIUC, "is very low on the radar, overshadowed by race, class, and gender issues." [Universal Design for Learning \(UDL\)](#) is addressed in several library courses, as are accessibility issues and the need for inclusivity. Often times, however, content concerning disability issues is superseded by time constraints and the need to cover other course content.

Other ideas stemming from the panel discussion included:

- The need for pre-service librarians of all kinds -- not just those who specifically work with children -- to get hands-on field training that would better prepare them to work with a diverse patron base, including those with disabilities.
- The concern that library school faculty members themselves need to have the knowledge base to address disability course content as they teach.

- The need for the ALA to make disabilities training a component of the accreditation requirements. Panel member Nancy Everhart noted that the Committee on Accreditation would be a good place to start the process. Panelist Ruth Small indicated that recent ALA leadership had expressed support for generating a greater awareness within the profession of the needs of individuals with disabilities.
- The possibility that elective courses could address specific disability issues, and perhaps even focus on ASD.
- The availability of internships with some of the ASD service providers, e.g., TAP.
- A forum participant noted that librarians need to be aware of the needs of ASD individuals at various phases of their life, and one “niche” in which librarians could support students would be in the transition phase (between ages 13 and 22 years old), as students plan for their futures beyond high school.
- The suggestion that librarians who are beginning to work to improve services to ASD individuals be aware of the importance of measuring the effectiveness and impact of their initiatives.
- The need for academic librarians in particular to be aware of the possible disconnect between the legal requirement that students self-identify their disability at the college level and their possible overarching need for assistance throughout the college setting, including in the library. The college experience is vastly different from a student’s prior education wherein they had an Individualized Education Program (IEP) spelling out their specific needs and education goals.

One forum participant noted during the discussion that the label does not matter as much as the general awareness that someone in the library requires assistance and how that assistance should be provided. Dr. Small noted that, *“The ALA is on record as of 1990 for having a policy that libraries should be accessible and inclusive but that doesn’t mean that all libraries are compliant.”*

Community collaboration

Assessing needs



Jim Runyan, Executive Vice President for Strategic Initiatives, Gov’t. Affairs & Grants at Easter Seals, Central Illinois, shared strategies for developing a successful initiative. According to Runyan, fulfilling the vision of helping libraries become more engaged with the autism community demands the involvement of passionate people who can garner and sustain the commitment of stakeholders. A community needs assessment is

essential before any new service or program should be considered. Libraries need to identify key stakeholders within their communities and assess current programs and service gaps. Identifying these gaps is crucial for determining where new initiatives are needed. Jim Runyan explains that if you find out that what you thought you wanted to do is already

being done by several people, then you should not try to replace or duplicate the effort. Rather, reach out to those people providing the service and work with them to add something of value. To duplicate or replace existing services in your community is non-innovative and a waste of time and resources.

“As part of community *engagement and needs assessment*, you need to be identifying who are these people with fire in their guts for this issue, who are going to be able to get past the first six months of work and are willing to be in there for the long haul...” **Jim Runyon**, 2015 Targeting Autism Forum

Illinois model of needs assessment

Librarians who attended the first forum in March 2015 were charged with the task of finding out what services in their communities were being provided for individuals with various disabilities and what service gaps existed. They were expected to look at ways to form and strengthen partnerships that would serve a shared vision of inclusive libraries.



Amanda Marti, Site Manager, The Autism Clinic, Maryville, IL, The Autism Program of Illinois (TAP) provided an excellent example of a collaborative community needs assessment. A group of seven stakeholders, including public and school librarians, local autism advocates and experts in the southern region of Illinois formed the *Southern Illinois Targeting Autism Collaborative*. Together they identified current services and gaps; prioritized needed services; identified ways in

which libraries can connect families to needed resources and services; and strategized ways libraries can become more welcoming.

Training was identified as the greatest need in the region. Parents shared that training was needed to help employers and members of the community better understand and accommodate their child’s special needs. In addition, law enforcement workers need education to develop the skills to respond and interact with individuals in emergency situations. Medical providers, educators, school staff, caregivers, and librarians also require extensive training on autism according to the needs assessment results.

An obvious role for librarians is to assist parents and other family members in accessing information and tools to help their loved ones learn and cope through various life stages. Educating librarians and public services staff, therefore, requires a strong foundation in the following skills:

- Best practices for accommodating and assisting patrons on the spectrum;
- Diverse learning styles of students;
- Locating materials and connecting to reliable resources;
- Implementing services to offer persons with autism; and

- Communicating and building relationships with patrons on the spectrum

Participants also reported that libraries are well-positioned to serve as conduits to local support services. Aligning autism stakeholders with libraries is necessary to empower them to function as a community hub for special needs populations. For example, better and more specific collaborations between schools and libraries would benefit students on the spectrum by providing additional learning support outside the school setting. Also, health services providers could increase the role of libraries by referring recently diagnosed clients and family members to their local libraries to learn more about autism and the range of local services and programs that are available in their community.

All agreed that libraries need to become more welcoming and inclusive. In order for librarians and staff to connect people to the resources they need, patrons must first be comfortable with using their local library. Toward that end, suggestions included: 1) sensory rooms equipped with beanbags, rocking chairs, sensory toys, etc; 2) quiet rooms; and 3) and ample signage to convey that the library is an inclusive place. Supports should also be available, such as, visual aids, social stories, noise cancelling headphones, fidgets, iPads, computers, etc. Libraries could also offer orientations and develop checklists of children’s support needs.

“...We looked at the needs that families and service providers identified that existed in the community and the highest priority was training...” **Amanda Marti**, 2016 Targeting Autism Forum

Opportunities for partnership

A great example of collaboration that developed from the 2015 Targeting Autism Forum came out of DuPage, Kane and Will Counties in Illinois. Librarians from Batavia, Fountaindale, Gail Borden, Glen Ellyn, Helen Plum, and Warrenville Public Libraries, as well as from Marianjoy Rehabilitation Hospital in the counties of DuPage, Kane, and Will near Chicago, combined their efforts to survey stakeholders in their individual communities. They identified and surveyed nearly 50 stakeholders including those that provide educational, recreational, supportive, therapeutic, and general coordination services, and to a lesser extent advocacy and employment services. The result of the group’s environmental scan was shared at the 2016 forum.



Survey findings identified areas of service provision that were lacking in each community, including a lack of focus on transitional services for individuals entering adulthood. Limits on funding and staffing to provide additional services were major obstacles identified by the group. Most notable among the

findings was that the existing policies within libraries might actually be limiting the effectiveness or ability to provide better service to individuals with disabilities, including ASD. In addition, concerns expressed were: (1) a lack of staff awareness and training amongst the various libraries; (2) confusion regarding which department within a library should provide service to individuals with disabilities; (3) a lack of consensus on whether assistance should be provided to patrons who did not self-identify; and (4) how to manage the additional work that might be entailed when working with a special needs population.

“Fear just in general is something that is an obstacle for libraries and is an obstacle for librarians. It’s a word that encapsulates a lot with regards to what’s different, what’s unknown, what’s new.” **Renee Grassi, Glen Ellyn Public Library** (pictured with Cate Loveday, Helen Plum Public Library)



The librarians within DuPage, Kane and Will counties worked to build new partnerships and to create strategies for inclusive library services. For example, Warrenville Public Library designated, librarian, Diana Abraham, as representative for the newly formed Wheaton-Warrenville Special Needs PTA for District 200; the Marianjoy Medical Library added a “Transition to Adulthood” section on its Information Connections website; the Helen Plum Public Library implemented three Sensory Storytime programs; the Glen Ellyn Public Library hosted a half-day training on Disability Awareness for its library staff; the

Batavia Public Library hosted inclusive movie and game night programs for young adults with autism and other disabilities; the Fountaindale Public Library partnered with the Lily Cache Special Recreation Association to coordinate group visits to the library; and the Gail Borden Public Library implemented a new play group for children up to age five, with a focus on developmental play. Successes of the various programs are detailed in the [handout](#).

Holly Jin and Dawn Wlezien of the Skokie Public Library (pictured) described their partnership with the school district and community agencies to provide vocational training for students in the transition phase of their education. The library developed an ambitious plan for community engagement and with multiple opportunities for special needs students to develop necessary workplace skills, involving communication, team work, organization, and/or technology.



The library staff has also customized assignments to enhance individual student goals.

“Libraries should be inclusive places that focus on people’s abilities, not disabilities. We can help relieve some of the stress by getting to know the individual and helping to prepare them for work and independence.” **Holly Jin, Community Engagement Supervisor, Skokie Public Library**

Kristin Gharst, former Family Resource Coordinator for TAP at **CTF Illinois**, led a panel discussion with Jan Pearcy, **Eastern IL Area Special Education**; Misty Baker, **Eastern IL University Child Care Resource and Referral**; and Debbie Einhorn, **Family Matters Parent Training & Information Center**. The necessity for inter-organizational collaboration was underscored for rural areas, where limited funding must be spread over large geographic areas. Gharst shared some of the assistance that her local library provides, including: (1) hosting training sessions for parents and teachers; (2) holding sensory-friendly movies; (3) providing space for informational displays about autism; (4) making connections for parents with the Early Intervention Clearinghouse; (5) making available a binder of visuals and referral information; (6) providing volunteer opportunities for high school students to hone job skills; (7) and maintaining a wish-list of books and materials on ASD that the library can order as funds become available.



*“I’ve been in special ed[ucation] my entire [working] life and I really have never thought about using the local library as a collaborator,” said **Jan Pearcy, Eastern IL Area Special Education**. Jan went on to share her excitement about partnering with libraries to improve service for the students with whom she works in rural Illinois.*

Collaboration with libraries makes good economic sense, particularly during times of limited funding. Providing direction, however, can be challenging for librarians without the needed expertise or knowledge to link patrons with resources.



Ann Ford, Executive Director of Illinois Network of Centers for Independent Living (INCIL), offered that libraries could partner with the Centers for Independent Living because the CILs have vast knowledge of all kinds of disabilities. They can refer people with disabilities to the right resources or support needed. Ford shared her long history working as an advocate for individuals with disabilities, and noted that in her experience that the toughest barriers to break down are not the physical ones, but those involving attitudes.

"It's pretty easy to pass a law that says 'There have to be curb cuts everywhere.' It's not so easy to pass a law that says 'Everybody has to accept everybody else, regardless of the differences.'" Ann Ford, Illinois Network of Centers for Independent Living

The national picture



On a broader scale, Doctoral Candidate Patti Foerster, National Louis University, presented her preliminary findings from research she conducted in Washington, DC, during fall, 2015, concerning what policy-makers, including some of disability advocates, were thinking about libraries. She found that libraries were not on the radar of the policy makers with whom she spoke; they were unclear on the role that libraries could play in serving their constituents. However, the DC policy-workers were very willing to invite libraries to work more fully in coalition with them.

"We need to be at the table... we can't do what we want to do alone ... We want to make our spaces accessible and open to people with diverse needs. And that's what we need to project out to the world--so that every disability organization comes to us as a resource and realizes we have the space to help them serve their population." Patti Foerster, National Louis University Doctoral Candidate

Education and engagement through the arts

Education about autism isn't solely achieved through formal training. As we all know, creative and artistic expression can provide a more direct and personal connection to an individual's experience or story. The forum offered opportunities to learn about autism through original and artistically inspired presentations, which were emotionally engaging and indelible.

Autism talk show

Alex and Hayden are two young students who created a talk show about autism, featured on YouTube. When the boys first met in the fifth grade they soon learned that both had autism. They found that talking to each other was helpful because they understood what each was going through. Thinking that these boys could make a difference for other kids, their teacher, Jan Abernethy, asked Alex and Hayden if they would consider sharing what they know with others by starting a talk show about autism. The next day, the first show was launched on YouTube.

Abernethy stated during the 2016 forum that "In our classroom, we do everything as a community...we got the whole class involved....kids wanted to be on the design team and the research and development team and everybody wanted a part in the show."

The boys shared stories about the ways that this experience has helped them. They have learned how to be themselves in front of the camera; communication has improved as well as social skills and behavior. Hayden mentioned how he has been able to use technology, like gaming, to communicate with Alex even when they are not in school. Hayden's mother spoke about how the family had previously suffered from the stigma associated with autism; and how their small town has become more welcoming and inclusive, as a result of their YouTube show.

Through this seemingly simple idea of a class "talk show" about autism, important relationships were created. Alex and Hayden have forged a lasting friendship, their mothers have found an alliance in raising boys on the spectrum, a class worked collaboratively with diverse learners, and a small community became inclusive. Because of its popularity on YouTube and the reach of social media, the short videos have impacted thousands of viewers worldwide, bringing awareness about autism and inclusion.

The Alex and Hayden Show included 28 episodes. Episode fourteen was filmed on location during summer break at the Greenville Area Public Library, Greenville, PA, where they gave a brief biography of a famous person with autism.



Alex and Hayden are pictured at the 2016 Targeting Autism Forum with their teacher Jan Abernethy (r) and Hayden's mother (l).

The Other Room: A play about autism

Playwright, Ariadne Blayde, at the young age of seventeen, won the Kennedy Center's VSA Playwright Discovery Award in 2008 for *The Other Room*. During the Targeting Autism 2016 forum, Blayde discussed and showed the Kennedy Center's production of the play. Published by Playscripts, Inc.,⁵ *The Other Room* has now been performed at hundreds of high schools and colleges throughout the United States.

From Playscripts: "Austin is a brilliant teenage astronomer who happens to have autism. Lily is his popular classmate who happens to have an interest in astronomy. When a chance encounter after school leads to a growing connection between them, Austin's imagination, intelligence, and constant struggles to connect with the world are revealed in the form of four characters representing his inner life. By turns funny and heartbreaking, The Other Room is a compelling and sensitive glimpse into a unique and misunderstood mind."

⁵ "The Other Room}. " *Playscripts.com*. N.p., n.d. Web. 18 Jan. 2017.



Ariadne explained that she wanted her play to break through fear and prejudices that many kids have toward people who are different. “...It’s really astounding being able to watch how this play is able to change kids’ attitudes toward autism...[and] enable children especially to see their peers who have autism spectrum disorders as not being quite so ‘other,’

making them a little more relatable.” She went on to say that theater is all about telling a story and stories connect people and make our understanding of the world a lot more human.

“I truly believe in the power of the arts, in theater in particular, to create social change and to foster understanding and connection between different groups of people...There’s something about seeing characters on stage and relating to other human beings and their stories that really makes it possible for us to understand and empathize in a way that maybe we can’t when we’re just reading about autism in a textbook.”

Ariadne Blayde, Playwright

In A Different Key: The Story of Autism – a book talk

A most compelling discussion took place during the 2016 Targeting Autism forum with authors John Donovan and Caren Zucker who described their experiences writing *In a Different Key: The Story of Autism*. Donovan and Zucker each have a personal connection to someone with ASD, which fueled their interest in proliferating media coverage on this important topic. They began with a series of stories, called Echoes of Autism, on ABC news, but then decided, as Zucker indicated, that they needed “to do something more enduring.” Owing in part to the stories they heard from family members, they began the investigation into the history of autism. Their goal was:



“To write a book that looks at the past and the progress that has been made, as an inspiration for two things: for readers who are on the spectrum or who have family members on the spectrum--to be inspired by the success and the progress made by the past [and thus] to continue working on the parts of the job (and there are many of them) that remain unfinished. And our other goal was to write a book that would really travel outside the autism community . . . to get a much wider audience--outside the autism community--to care, to relate, and to want to have the backs of people with autism.”

John Donovan

Donvan shared how librarians were instrumental in helping them with their research throughout the process of gathering material for the book, and he acknowledged the library profession with its “magic touch for finding gold.”

The two forums served to engage and inspire all participants to continue their work in partnership to create a better, more inclusive society. Libraries are charged with the mission of improving the quality of lives within our diverse communities. Toward that end, The Targeting Autism forums provided a strong voice from stakeholders throughout the nation affirming that libraries should and do “have the backs of people with autism.”

III. OUTCOMES

Knowledge gained

Participants benefited from the Targeting Autism forums in numerous and important ways. They gained a deeper understanding of the characteristics and history of ASD. They learned about challenges regarding social skills, sensory issues and anxiety from individuals on the spectrum. Through discussions, presentations and networking, participants learned that it takes a community of stakeholders to meet the diverse needs of the ASD population.

A wide range of best practices for inclusive library programming, materials collections and good customer service was shared. Participants were taught best practices for conducting a community needs assessment and implementing a program or service. Key considerations were summarized as follows:

- Determine the scope and scale of your needs assessment and stick to it (e.g., geographic boundaries, age group);
- Identify key stakeholders;
 - Assess what services and programs your stakeholders provide so that you don’t duplicate something that is already being done;
 - Determine what needed support is still missing;
- Engage your stakeholders and keep them engaged throughout the process;
- Estimate the number of people you expect to reach in your community;
- Identify people who are willing to collaborate with you;
- Create an action plan (this is essential for accountability); and
- Community needs assessments are evolving documents that need to be revisited periodically.

Collaborations formed

Regional stakeholder groups formed to identify available services, conduct community needs assessments and determine how libraries could enhance support to ASD residents and families. Findings shared by all the regional groups were summarized as follows:

- In general, support services were lacking for older teens and adults;

- By far, the greatest priority was the need for autism education and training. This training was seen as essential for public services employees, including library staff, but also businesses, law enforcement, educators, school staff and family members.

Forum participants also agreed that there is a need for more of the following: (1) reliable information resources for parents; (2) support groups; (3) employment services; (4) proliferation of inclusive spaces; (5) more intervention in schools; (6) job fairs and interview skills mentoring; (7) teen social groups; (8) collaboration between schools and libraries; (9) doctors referring families to libraries for information and to guide them to resources; (10) intern programs at libraries that target individuals on the spectrum; (11) learning partners in libraries to teach assistive technology tools to those with ASD; (12) more community meetings; (13) more welcoming, sensory friendly, calming libraries; (14) more quiet spaces and noise cancelling headphone available in libraries; (15) more visual supports in libraries; and (16) more use of social stories.

Attendees also learned about the importance of partnering with disabilities advocates to create policies that ensure that library spaces are accessible and accommodating to residents with diverse and often hidden disabilities.

Demco Library Innovation Award

The Illinois State Library was awarded the Demco Library Innovation Award for the 2016 Targeting Autism forum. The award was presented by the Illinois Library Association (ILA) and Demco at the Annual ILA Conference in October, 2016. This award recognizes a library, library consortium, or library system's achievement in planning and implementing an innovative or creative program or service, which has had measurable impact on its users.



Pictured left to right: Suzanne Schriar, Illinois State Library and Angie Schoeneck, Demco

Personal accounts of Targeting Autism's impact

- Sheryl Siebert, Director of the **Chenoa Public Library** in Illinois reported that after listening to the forum presentations she realized that she had four daily patrons with ASD. She decided to engage one of them as a volunteer worker in the library. In addition, she created a special needs resources section of the library. She also invites parents to allow their kids to walk around the library during storytime, if needed. This library director shared a story about a patron who comes into the library to check out the same book each week. He does not like to let go of the book to check it out; letting go causes him to have a meltdown. To avoid the meltdown, the circulation staff has been instructed to record the information ahead of time so that he can hold onto the book during check-out. In addition, a local women's group has volunteered to make weighted pads that the children can put on their laps to help soothe them during storytime.
- One month after attending the 2016 Targeting Autism Forum, Donna Miner, District Librarian at **Rantoul City Schools**, Rantoul, IL, was informed that she would be getting a whole new library. The principal asked Donna for her input. Because of all the knowledge she gained at the forum, Donna made sure that the library would include a quiet room as well as three "window box" spaces that are small and cozy with individually controlled lighting and cushions that are covered with soft fabric (pictured below).



New grant program established

One highlight of the 2015 Targeting Autism forum was the establishment of the [*Autism Welcome Here*](#)⁶ grant awards. The Grant Program, developed by Barbara Klipper, was conceived during one of the small group discussions, which focused on developing inclusive library programs and services.

⁶"Libraries and Autism: We're Connected - Autism Welcome Here GRANT." *Libraries and Autism: We're Connected - Autism Welcome Here GRANT*. N.p., n.d. Web. 18 Jan. 2017.

Autism Welcome Here honors the ground-breaking work of *Libraries and Autism: We're Connected* Co-founder Meg Kolaya (deceased) and her contributions in promoting inclusion, connecting libraries and the autism community, and bringing awareness of the needs of individuals with autism and their families to the library community.

Autism Welcome Here awards a total of \$5,000 to one or more libraries to start a new initiative or expand an existing service targeted to residents on the autism spectrum. The grant recipients were invited to the 2016 Targeting Autism Forum to present their project plans to the forum participants.

The recipients were:

- 1) **Simsbury Public Library**, Simsbury, Connecticut for “**Everybody Plays**,” a bimonthly inclusive playgroup, open to all families with children aged birth to five, but well-suited and welcoming to families of young children on the autism spectrum. *Everybody Plays* will provide an inviting space using low lighting and provide equipment to meet sensory integration needs. The library will offer developmentally and therapeutically appropriate toys and activities, including gross motor tools, manipulatives, and sensory boxes. They will work with local service providers and advocates to provide knowledgeable and skillful facilitators for the program; and
- 2) **Tarrant County Community College**, Arlington, TX, for “**Autism Spectrum College Information Talks (ASCIT) Project**,” offering a series of presentations and other resources to help caregivers support students with ASD make a successful transition to postsecondary education.

Online social sites

Several online social media sites were established and remain active. These include: (1) [Targeting Autism blog](#); (2) [Targeting Autism Facebook page](#); (3) [Targeting Autism Twitter](#); and (4) [Autism Works in Libraries discussion list](#).

Presently, the Targeting Autism blog has had nearly 11,000 visits, both nationally and globally. Rhona Dempsey, Research Fellow at **Trinity College, Dublin, Ireland**, who reads the [Targeting Autism](#) blog, reached out to our project staff to explore how the college library might better serve their patrons who have ASD. In November, Russ Bonanno, a chief advisor with the Targeting Autism project, was able to include an in-person consultation with Rhona as part of his vacation to the UK. The purpose of the meeting was to evaluate accessibility and to discuss potential adaptations to accommodate students with diverse needs at the **Trinity College Berkeley Library**. Library staff desired perspectives on what might present as challenges for individuals with autism and what options they might utilize to make the library areas more usable. Physical attributes such as noise, lighting, signage and space were discussed.

IV. NEXT STEPS

Targeting Autism: A Comprehensive Training and Education Program for Librarians – Phase Two

The **Illinois State Library (ISL)** is partnering with **Dominican University** and **Syracuse University** on a two-year, IMLS Laura Bush 21st Century Librarian grant project to deliver an innovative, multi-faceted, replicable training program designed to improve library service and programs for the ASD community in Illinois and throughout the country. The training will consist of a variety of face-to-face and online components that complement each other, reinforce learning and stimulate community engagement.

Team Spectra formed as part of the IMLS-funded, 2015 ILEAD USA LB21 Grant. Illinois State Library team members will contribute to Phase Two of Targeting Autism with a series of technology webinars. In addition, assistive technology kits will be available on loan to Illinois libraries.

Team Spectra, provided a “technology petting zoo” for participants at the 2016 Targeting Autism Forum (pictured below):



The complete narrative of *Targeting Autism: A comprehensive training and education program for librarians* is available [here](#).

References

ADA.gov Homepage. N.p., n.d. Web. 18 Jan. 2017. <<https://www.ada.gov/>>.

"American Sign Language." *National Institutes of Health*. U.S. Department of Health and Human Services, 27 Sept. 2016. Web. 18 Jan. 2017. <<https://www.nidcd.nih.gov/health/american-sign-language>>.

The Answer Inc. N.p., n.d. Web. 18 Jan. 2017. <<http://theanswerinc.org/>>.

Autism | Information Connections. N.p., n.d. Web. 18 Jan. 2017. <<http://www.informationconnections.org/Autism/Default.aspx>>.

"The Autism Clinic at the Hope Institute for Children and Families." *The Autism Clinic*. N.p., n.d. Web. 18 Jan. 2017. <<https://theautismclinic.org/>>.

"The Autism Program of Illinois - TAP | A Network of Resources for Autism Spectrum Disorders in the State of Illinois." *The Autism Program of Illinois TAP RSS2*. N.p., n.d. Web. 18 Jan. 2017. <<http://theautismprogram.org/>>.

"B.3 Diversity (Old Number 60)." *About ALA*. N.p., 16 May 2013. Web. 18 Jan. 2017. <<http://www.ala.org/aboutala/governance/policymanual/updatedpolicymanual/section2/diversi>>.

Blayde, Ariadne. *The Other Room: A Short Play*. New York, NY: Playscripts, 2010. Print.

Consultants, Inc. Pyramid Educational. "Welcome to PECS-USA.com!" *Welcome to PECS-USA.com!* N.p., n.d. Web. 18 Jan. 2017. <<http://www.pecsusa.com/>>.

Discovery Education. N.p., n.d. Web. 18 Jan. 2017. <<https://blog.discoveryeducation.com/blog/tag/alex-and-hayden/>>.

Donvan, John, and Caren Zucker. *In a Different Key: The Story of Autism*. New York: Crown, 2016. Print.

Easterseals Central Illinois. N.p., n.d. Web. 18 Jan. 2017. <<http://www.easterseals.com/ci/>>.

Farmer, Lesley S. J. *Library Services for Youth with Autism Spectrum Disorders*. Chicago: ALA Editions, an Imprint of the American Library Association, 2013. Print.

Holly, Miss, Gin, and Miss Renee. "SNAILS: Special Needs and Inclusive Library Services." *SNAILS: Special Needs and Inclusive Library Services*. N.p., n.d. Web. 18 Jan. 2017. <<http://snailsgroup.blogspot.com/>>.

- Illinois Early Intervention Clearinghouse*. N.p., n.d. Web. 18 Jan. 2017. <<http://eiclearinghouse.org/resources/library/>>.
- Illinois Network of Centers for Independent Living*. N.p., n.d. Web. 18 Jan. 2017. <<http://www.incil.org/>>.
- Klipper, Barbara. *Programming for Children and Teens with Autism Spectrum Disorder*. Chicago: ALA Editions, an Imprint of the American Library Association, 2014. Print.
- "Libraries and Autism: We're Connected." *Libraries and Autism: We're Connected*. N.p., n.d. Web. 18 Jan. 2017. <<http://www.librariesandautism.org/index.htm>>.
- "Libraries and Autism: We're Connected - Autism Welcome Here GRANT." *Libraries and Autism: We're Connected - Autism Welcome Here GRANT*. N.p., n.d. Web. 18 Jan. 2017. <<http://librariesandautism.org/grant/>>.
- "Libraries and Autism: We're Connected - Watch This Video." *Libraries and Autism: We're Connected - Watch This Video*. N.p., n.d. Web. 18 Jan. 2017. <<http://www.librariesandautism.org/video.htm>>.
- National Center On Universal Design for Learning." *Home | National Center On Universal Design for Learning*. N.p., n.d. Web. 18 Jan. 2017. <<http://www.udlcenter.org/>>.
- "Project ENABLE (Expanding Nondiscriminatory Access by Librarians Everywhere)." *Project ENABLE- Professional Online Development for Teachers, Librarians*. N.p., n.d. Web. 18 Jan. 2017. <<http://projectenable.syr.edu/>>.
- PROJECT PALS*. N.p., n.d. Web. 18 Jan. 2017. <<https://pals.cci.fsu.edu/>>.
- "Stakeholder Alignment." *WayMark Systems*. N.p., n.d. Web. 18 Jan. 2017. <<http://www.waymarksystems.org/>>.
- "Targeting Autism." *Targeting Autism*. N.p., n.d. Web. 18 Jan. 2017. <<https://targetingautismlibs.com/>>.

Selected Targeting Autism Forum Sessions on YouTube

[Targeting Autism: group shares goals and expectations at 2015 forum](#)

[Mark Nolen, WayMark Systems](#), leads the 2015 forum in discussion about what the survey comments reveal about challenges and opportunities for collaboration.

Russell Bonanno, Director, The Autism Program of Illinois (TAP), delivers [keynote address at the 2015 forum](#)

[Adria Nassim](#), disabilities advocate and speaker, addresses the 2015 forum on her experience of life with ASD and mild cerebral palsy, and how living with these challenges has informed her life's purpose of helping children with disabilities.

[Serving Library Patrons on the Autism Spectrum: 2015 forum panel](#), including Dr. Lesley Farmer, Author and Professor, California State University, Long Beach; Barbara Klipper, Autism Advocate, Author and Former Librarian; and Dan Weiss, Director, Fanwood Public Library, NJ, and Co-creator, *Libraries and Autism: We're Connected*

[Library School Education and ASD: Training Librarians](#) – What are the needs and how have they been addressed. Panel discussion at the 2015 forum, including Dr. Ruth Small, Syracuse University, Dr. Nancy Everhart, Florida State University, Dr. Sujin Huggins, Dominican University, and Doctoral Candidate Wei Gao, University of Illinois at Urbana-Champaign.

Jim Runyon, Executive Vice President for Strategic Initiatives, Gov't. Affairs & Grants at Easter Seals, Central Illinois: How to do a community needs assessment, [Part 1](#), [Part 2](#), and [Part 3](#).

[2015 forum panel on needs-based partnerships to support individuals with ASD](#). Panel members include: Kristin Gharst, former Family Resource Coordinator for TAP at CTF Illinois, led a panel discussion with Jan Percy, Eastern IL Area Special Education; Misty Baker, Eastern IL University Child Care Resource and Referral; and Debbie Einhorn, Family Matters Parent Training & Information Center

Marty Murphy, self-advocate and national public speaker on autism, special education and learning disabilities, delivers keynote address at the 2016 forum. [Part 1](#) and [Part 2](#)

Ann Ford, Executive Director, Illinois Network of Centers for Independent Living. [2016 forum presentation on the importance of building relationships with service providers and advocacy groups](#).

Patti Foerster, Ed.D., National Louis University. 2016 forum presentation on libraries, disabilities and Washington, D.C. [Part 1](#) and [Part 2](#)

“The Other Room,” a viewing of the Kennedy Center’s performance and talk by the VSA 2008 award winning playwright, [Ariadne Blayde at the 2016 forum.](#)

[The Alex and Show](#) comes to the Targeting Autism 2016 forum.

In a Different Key: The Story of Autism. [Book talk with authors, John Donovan and Caren Zucker, at the 2016 forum.](#)

Community Reports

Amanda Marti, Site Manager, The Autism Clinic, Maryville, IL, presents a [community report of the Southern Illinois Targeting Autism Collaborative at the 2016 forum](#)

[Community Report, DuPage, Kane and Will Counties. Presentation at the 2016 forum,](#) by Cate Loveday, Youth Services Librarian, Helen Plum Memorial Library (Lombard), member of Special Needs and Inclusive Library Services (SNAILS); and Renee Grassi, Youth Department Director, Glen Ellyn Public Library, member of Special Needs and Inclusive Library Services (SNAILS)

Sheryl Siebert, Director, Chenoa Public Library. [Community Report at 2016 forum.](#)

Supporting Transition Aged at Skokie Public Library. Presentation at the 2016 forum, by Dawn Wlezien, Volunteer Specialist, Skokie Public Library, member of Special Needs and Inclusive Library Services (SNAILS); and Holly Jin, Community Engagement Librarian, Skokie Public Library. [Part 1](#) and [Part 2](#).

[Report from Debra Vines, Founder/Executive Director, The Answer Inc. at 2016 forum.](#)