

WayMark Survey – Respondents' Comments March 2015

What is your vision of success for Illinois libraries providing community information on ASD? What would success look like (in 1-3 sentences):

Libraries as an information resource:

- Success would be a comprehensive dissemination of information on ASD.
- The library should serve as a place where accurate information and referrals to medical experts can be accessed.
- I think libraries could be a clearing-house of information and a place where those with autism or families with a family member with autism find a welcoming space and community.
- 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.
- There is an abundance of information about ASD, but much is fad and crack-pots. People need help to sort it out. Look at the damage over the idea that vaccinations cause autism.
- 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 environment.
- My vision for success would include increased accessibility to resources that increase knowledge, awareness, and availability of services for families of individuals with ASD, particularly families of color, who face disparities in the diagnosis of ASD.

Enabling community integration:

- Acclimating people with ASD into the community.
- With growing numbers of individuals having ASDs, it is becoming more vital to provide the community with information regarding these disorders. With increased access to information will come the understanding that is needed to ensure these individuals are included (and not excluded) from our society.

Utilizing library resources

- To provide a more welcoming and informed environment for families, caregivers and patrons.
- That patrons with ASD would feel comfortable using the Library and get the services they need.
- A place of all people on the spectrum to find a comfortable way to utilize the library services.
- That all libraries provide volunteer opportunities for those with ASD. That we are educated to meet the needs of those patrons with ASD.
- My vision of success would be a 'Community Resource Area' in all Libraries state-wide to help people not only suffering with ASD, but other disabilities, diseases or circumstances. Connecting people to resources and programs for whatever their needs [are] and truly making a difference in their lives. Helping them to be the best that they can be and to live life to their greatest potential!

State-wide structure:

- State wide agency. Current information provided to libraries. Local not for profit ASD support groups leading their community.
- A network of information providers led at the state level and connected by a common network of information.
- Communities sharing resources and information among themselves without a sense of competition.

Bottom line:

- A unified gateway to local resources for families who are affected directly and also information to educate the community so those family's can be understood and supported.

- The library will provide programs and spaces where individuals on the spectrum can be comfortable and have an opportunity to expand their social skills. Once spectrum families become comfortable using the library, the librarian can help direct them to additional services.
- 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.
- Success would mean children with ASD, their families and community members could come to the library and get gain the resource information they are seeking or be given the available local resources they could use.
- Space easily accessed with sensory issues addressed.

What other comments do you have about ASD, the role of libraries in providing information about ASD, or other related matters?

Libraries and librarians are important:

- As librarians we are more important to ASD than I realized
- The library would be another resource for families needing another source to find information on ASD. Calm, friendly atmosphere in which to research their needs and questions.
- Libraries need to provide the materials for people of all ages to learn about ASD
- Public libraries are popular places for adults with ASD since many are unemployed and need a place and activities.
- The overall role of libraries is to provide information and space to communities whether that be through books, resources, or articles. All libraries, rural and urban, should have available or should have access to solid information on ASD for whomever needs the information.
- I believe that libraries have the potential to shape the future of awareness of ASD. I believe that public libraries, particularly those in disadvantaged neighborhoods have the challenging task of serving as a first source of information for many families who may otherwise, not be able to access it.

Challenges for families:

- ASD is often misdiagnosed and children are 'labeled' without parents having the information on the disability or where to turn for assistance. They need a resource for dealing with IEPs, doctors, social services, and the role of the school. Schools here provide few alternative classes for ASD students: they are either kept in special education classrooms with no instruction or put into 'regular' classrooms with no hope to master the material due to their disability. This seems a school issue -- not a library one. Our role should be to provide information and resources to guide parents.

Limited resources:

- Our library is quite small and it would be difficult to hold programs on dealing with ASD that would garner public interest.
- Libraries, especially small ones, will need some funding to purchase a few book resources.
- 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.
- Librarians are not social workers, and I wouldn't ask them to be. 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.

Important considerations:

- An important factor for library staff to consider when serving patrons with ASD is that no two are alike.
- Many people look to libraries for answers to their questions, and even though library staff cannot be universal experts, nevertheless they should have knowledge about and access to information they can share with patrons.

- I wish that libraries 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.
- When i have visited story times it was evident that my children did not fit in and were not welcomed. But would love a story centered around special needs children and their siblings.
- Right now the only way to find real information and help about ASD is simply word of mouth, from parent to parent or teacher to parent. Finding any support services is difficult if one isn't in that network. It leaves parents of the newly diagnosed completely helpless and vulnerable to misinformation. And finding information about teens transitioning to adulthood is nearly impossible.
- It is hard to feel welcome anywhere, including the library when your child is neuro-atypical (ASD, ADHD, Sensory Issues, etc.) and has behavior issues. The library is an especially unwelcome place since people are expected to be still and quiet.

Leading practices:

- We actually employ two individuals who are on the autism spectrum. We have two young men with Aspergers who shelf books for us.
- The library has had 2 grants to purchase materials on health related topics. We feel most of our health topics are current due to these grants. With ASD materials, we would have another topic to share. We feel our patrons would be better served using our materials than relying on the Internet for their health information. No one can verify all of of the information on the Internet.
- I find that the school system does a great job but that's where the communication and partnerships end. Unless someone has a child with ASD, they would not know about any other resources other than school.
- 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.

Is there any specific fear, worry, or concern that you have with this initiative (for Illinois libraries providing community information on ASD)?

No concerns:

- None
- I think it is a great project.
- Nope, I think it is a wonderful idea!
- I think it's an exciting initiative that needed to happen decades ago. I'm just glad that it is finally happening. 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.
- No - I think this would be great.

Insufficient information or use:

- . . . the information found in libraries is no longer current and timely.
- The concern is that the information about ASD disseminated to the public by libraries must be relevant, statistically sound and evidence-based.
- That the information will get locked up in a clunky website, which most government websites are.
- 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 - but there's often no one else to stay with them, so parents don't get info from us, and kids don't get programs from us.
- Teens with ASD won't want to be seen at the public library going into a program which is obviously for ASD.

It will be too complicated or too broad:

- Please don't make it too complicated - too report driven or too broad.

- Mission creep is implied by many of the questions on this survey. Yes, we need to do more. However, libraries are not the right place for every ASD related service.

It won't be broad enough:

- Most of the current planning in libraries (and even the questions in this survey) are specific to children and sometimes teenagers. However, as these populations age, the number of adults with ASD is growing, and there are much fewer services and programs for adults than there are for children. There is a pressing need for adults with ASD to have places to gather, practice social skills, learn about housing options as their parents age and decline, gain job skills, etc.

Finding the right balance:

- 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.
- I am concerned that specific groups like Autism Speaks might try to push their particular agendas/perspectives. There are many individuals on the autism spectrum who can speak for themselves and their voices and perspectives should be a driving force in this initiative.
- In my personal opinion, I think state agencies like DHS, HFS and Public Health need to do a better job at educating the citizens of this state on the programs and services that are out there (gov't agencies, school district, churches, NFPs, etc. all have programs and resources) that can help people with their daily struggles. DHS should be a clearinghouse for services and programs to help people, whatever their need (disabilities, diseases, medication financial asst, mental health, rent/utility asst, etc.). They should work with United Way's 2-1-1 to get the word out on the various programs and services available to people in need in every county in Illinois! If we can get people in need to these types of services and programs state-side, we can help with the stress in their lives, We can also help alleviate the financial burdens on DHS, Medicaid, Health and Family Services, DCFS, etc.), in helping people to be self-sufficient, happier and healthier!

No mandates:

- I don't want to be 'mandated' to provide programming or activities for children. My programming options are open to anyone, regardless of ability. Being 'required' to provide a service -- potentially without being allotted funding -- is going to put a hardship on our library. I have NO PROBLEM offering information, rooms to meet, notice boards, something with soft-impact on library staff and budget. I am afraid this initiative will put the job of 'educating' ASD children onto libraries, instead of on schools where it belongs.

Insufficient resources:

- My concern is that libraries may be asked to do more than they have the resources to do.
- It will be staff intensive at first but from my experience the parents of the adults are very willing to volunteer and also the various social agencies in our community have been enthusiastic volunteers.
- How much will it take away from services that benefit all of the population?
- Our library is staffed by 3 part timers who work by themselves. Our yearly budget is \$34,000.00 and extra funds and space are NOT available

Insufficient follow-through:

- Only that it will be a big burst of effort followed by a falling off of concern.

Misunderstanding:

- I worry that people will come to judge all of us by the symptoms SOME of us exhibit. It's called a spectrum disorder for a reason. The common complaint amongst my peers is that we need acceptance not awareness. I also worry that more people will be fooled into supporting autism speaks and their campaign to eradicate us and with that some of the unique talents and gifts we have to offer to the rest of our communities.

The library ASD initiative is hoping that the Illinois public libraries increase their information and services to the ASD community. What would you want or need from this initiative for it to be a success for you?

Recommendations:

- Book recommendations, Best web sources.
- 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.

Materials:

- Current materials for public use to catalog and add to our collection
- Books for all ages on Autism especially for young children as understanding can start at a very young age.
- Resources (books, ebooks, dvd's, online databases, etc.) that my library patrons would have access to.
- Reliable factual materials on diet and eating behaviors.
- Is autism inherited? What are the symptoms? Can it be cured? What careers are best for autism students?

Speakers:

- Experts/Speakers for programs (funding for such).. Materials for the collection (funding would be beneficial here as well).
- A list of presenters who are well trained and able to provide programming to the ASD community at a reasonable cost.

Training:

- Training to deal with ASD children and what works for them. Funding to purchase activity-appropriate materials and supplies. Lists of resources to give parents who bring their ASD child.
- Education for myself and staff on ASD. 2. Access to resource people willing to present public programs at local libraries on ASD. 3. Help identifying the most helpful resources to purchase for our collection.

School libraries included:

- Include school libraries in the group. Learn how to better serve autistic patrons

Leading practices:

- Best practices used to meet the needs of this population in our community.
- Ideas for community outreach and involvement. Ideas to service patrons with ASD at all ages.
- One of our library Trustee's is a caregiver for children and adults with ASD. We have weekly visits to our library from persons w/ ASD. Need ways to easily inform other library patrons of ASD so that (perhaps) they too can become a bit more accommodating to the presence of other patrons w/ ASD.
- When our Asperger's child was growing up, we felt very isolated and lost. A center to link us with support groups and information showing us how to help our child would have been very useful. With the behavioral issues we faced, a welcoming public library also would have been appreciated.
- Programs to teach to learn to read to non-verbal kids.
- Increase library staff awareness of resources for families affected by ASD, such as The Autism Program of IL and the IL Early Intervention Clearinghouse, so they may assist families in being connected.
- Our local library has a children's area where kids are allowed to talk and play. The environment is just so perfect for my son since he is unable to sit and read silently. It is perfect for my sensory issues where silence is rather unnerving to me. The beanbag chairs are just more comfy and inviting than the rigid chairs in the adult area. It is brighter and more colorful and in general just more inviting and welcoming. Our library is just an awesome place to hang out in general.

Sensory opportunities/resources:

- More sensory opportunities within the public library Adapted/Interactive books at different grade levels and topics of interest Easily available information for parents about ASD, specific to the local community
- Larger selection of sensory books/items Themed sensory bins with books/objects designed to spark interest and knowledge for borrowing.

Professional development summit:

- Professional Development Summit for key stakeholders/Directors to raise this in importance On-site support in implementing pilot programs Ongoing resources to support families use of libraries Programming support: ideas, performers, tips, etc. Possibly a round-table of librarians offering services to offer peers best practices, etc.?
- Strategies for best serving college aged ASD students.