

Targeting Autism March Forum – Day 1, March 4, 2015
Joel Cutcher-Gershenfeld: Overview of Strategic Goals and Interpretation of WayMark Survey Mapping Data

Initial Session Goals:

- Build shared appreciation of the challenges and opportunities associated with acquiring information on Autism Spectrum Disorder (ASD)
- Identify leadership roles for community libraries in improving community supports/services for individuals with ASD
- Begin fostering stakeholder alignment around a community library ASD initiative
- Begin developing a shared vision of success for a state library initiative on ASD
- Identify next steps

Additional Expectations (organized into categories)

Empowering and serving people on the spectrum:

- Autism affects everyone directly and indirectly – we are all in this together – a goal to empower people on the spectrum to share their story and be self advocates
- The need for the young adult population to have a place to go – libraries can be a great place to go
- The book on services to teens does talk about volunteer opportunities
- Providing more services for adult patrons on the spectrum
- Ensuring that we are inclusive – not segregated
- Libraries are also a good place for employment of people on parts of the spectrum – so they can contribute to the community (a quiet and predictable place for volunteers and paid employment)
- Take the issue of employment back to high school libraries – to begin to develop skills in this area
- As a mother of an adult son, we also need to know how to work with law enforcement and our family members for increased safety
- Pay attention to the part of the population that is non-verbal
- I am here living on the spectrum – not a lot of resources – it is easy to be overwhelmed, but a library has been a favorite place for me – consider building design – such as a quiet room or a calming room – like a nursing mother’s room with rocking chairs or a therapy chairs

Identifying and sharing resources:

- Learning what resources are already out there and finding the gaps that need to be filled
- A focus on technology that can help libraries – using technology to address the needs of the autism community
- Potential for a state-wide license for board maker
- Take into account what is being learned
- Issues of not living in a library district and library not aware of early intervention resources
- A facilitator for the ASD centers -- specifically for these centers – a live person to talk to would be more impactful
- A state-wide program in Illinois called Star-net – I was not introduced to educational rights and responsibilities until my son what in junior high – key to get copies in libraries so library is a resource on rights

- Here as a resource from a community hospital with medical and other resources – funding from the National Library of Medicine – took four years to develop – there is a brochure here on this – building on a two-year needs assessment

Building coalitions:

- Working cooperatively with several organizations in the region -- small libraries and leverage resources in a region – cooperative opportunities
- There are many community organizations working with people affected by ASD, but not connected to libraries – so relationships can be established with the libraries (which may not have all the connections and relationships needed to work with this population) – making visible resources that are not on the map

Training and professional development:

- Looking at training – to take back to our organizations to be comfortable with the tools for outreach and programming – making it okay to come to the libraries without fear of reproductions
- Would like to end up emphasizing to ALA that this should be part of the track for training librarians and part of professional standards

Action items and next steps:

- A focus on action items – resources, even a clear definition – something simple to take back
- Hoping to have concrete ideas to bring back in September
- Marketing – libraries are seen as a quiet place, but they can be a lively social center for the community
- The three M's – marketing, media, modeling
- Survey the needs of people

Discussion on the Stakeholder Mapping Data (first part of the data):

- With the distribution of librarians and the high proportion of women – a need to get data from others
- An implication for library collections – what is available in schools
- Participation by parents – where they go for information is key
- The IEP process with parents – a need to understand how this works and what it is
- A need to get beyond the acronyms – education for librarians
- There are issues being highlighted by people who have needs
- People need to be willing to share information with the library – including the library commitment to confidentiality
- We did a study with librarians and services to students with disabilities was seen as a great area in need for training

Continued Discussion on the Stakeholder Mapping Data (second part of the data):

- We have to make some clear guidelines – librarians should not be giving medical advice, but can point to information
- In smaller libraries – it is not the old model of pointing people to the shelves – there are web resources
- The most important thing is access to medical, but is difficult to obtain – some hospitals are more community oriented than others – there are examples of coordination and video consultation through libraries

- The issue is not just to refer people out, but the number of specialists in the area who have expertise and awareness – these numbers are very small
- This signals the importance of this type of gathering – identify the “bright spots” where it is working in a given community
- Libraries and librarians also have “friends of libraries” who can be part of the multi-stakeholder efforts – we are all stakeholders

Potential Elements of a Shared Vision of Success:

- Everyone in Illinois to have the resources to understand ASD and associated services
- Illinois libraries seen as a value-add stakeholder partnering with others on ASD
- People with ASD would be visible and welcome in libraries – following universal design principles
- Any library would have a common, central data base, with all the information that I need – locally and beyond
- A set of standards for training and professional development for library staff
- A network of point people in place for librarians to get additional needed information
- Media communications – marketing so that there is inclusivity and awareness of what is possible through libraries
- Consistency between urban and rural libraries – services, information and resources
- Less of a digital divide – so that ASD information is available at the point of care and the point of need
- Access for a broad spectrum of diverse communities – urban/rural, immigrant, etc.
- The library can be the heart of the community and to the inviting of stakeholders to the table – centered on ease of access to information and services – creating coordinated community coalitions – spokes of a wheel – with an ongoing dynamic of standardization and innovation
- Harnessing robotics and new technology
- Awareness, Acceptance, Support – AAS across the board
- Overcoming isolations and separation
- A connection to employment opportunities – in libraries and the community
- Library as a friendly community center – leading by example on inclusion
- Community participation is subjective – it means different things for different people
- Both serving people with ASD and educating the rest of the population – so that people can understand and be respectful
- We should not dehumanize this population – let’s get over ourselves and welcome everyone and figure out how to act and get people into the libraries
- Aim, ultimately helping to enable successful participation in society – libraries provide input to make this possible

Summary statement:

- In collaboration with all the relevant stakeholders all the libraries in Illinois will have high quality, accessible information and services for individuals with ASD and their families, and education for all stakeholders, to achieve the full potential of what is possible for individuals, families, and communities.