



2015-2016 Chicago Synagogue Inclusion Project

Inclusion of People with Disabilities in Chicagoland Synagogues

Funded by the JUF Breakthrough Fund
Ed Frim, Inclusion and Outreach Specialist
Dr. Roberta Louis Goodman, Research Consultant
Jodi Newmark, J.D., Director, Encompass
Tracy More, Associate Vice President, Community Outreach and Engagement, JUF

**Twenty percent of people (and Jews) have a disability.
The majority of Jews with disabilities do not participate in synagogue life.**

In July 2015, with the support of the JUF Breakthrough Fund, Encompass in partnership with JUF's Synagogue Federation Commission, launched the Chicago Synagogue Inclusion Project – a comprehensive outreach, research and planning process to answer key questions about barriers to participation in synagogue life for individuals with disabilities and their families.

What did we do?

- Twenty-nine “listening tour” meetings and focus groups were conducted throughout the metropolitan Chicago area with 96 individuals representing 28 organizations, including synagogue leadership, rabbis, educators and community members
- A community conversation was convened with 110 people attending representing 40 synagogues and related organizations
- A facilitated conversation was held with more than 30 educators from the Reform and Conservative movements
- Private meetings were held with synagogue leadership
- Meetings were held with local resources such as Keshet, Jewish Child and Family Services, CJE, CFJE, Libenu and others
- A survey was distributed to more than 82,000 community members with 1,491 responses
- A separate survey was distributed to 117 synagogues yielding 50 responses.

Survey Respondent Highlights

HOUSEHOLDS:

- Almost 1500 household respondents representing all areas of Metropolitan Chicago
- 56% were synagogue members
- 30% of households had a person with a disability, with half of those between age 23-64

SYNAGOGUES:

- Fifty synagogues responded to the survey, eight were Orthodox
- Synagogues identify including children with disabilities and the elderly with physical disabilities as priorities



KEY FINDINGS

#1: Households touched by a disability report feeling invisible, left out or perceived as disruptive

“Our congregation has been wonderful to us. Our daughter has been welcomed, but it’s the work of a [single individual] who really makes things happen. Now that our daughter is over 18, there’s no programming for her. Very sad.” Synagogue member

Sixty-one households responded that they had a young adult 19-22 with an intellectual/developmental disability.

Thirty-two percent of all survey respondents reported that either they or a family member have a disability, 50% of this sub-group identified the disability as intellectual/developmental, more than any other category, and 51% of this same sub-group identified the person with a disability as an adult (23-64 years old). Yet in the focus groups, it was evident that many synagogue leaders conceived of disabilities for adults almost entirely in terms of physical access to space and worship – getting in the door, being able to read books, access to *bimah* – and of developmental disabilities as an issue mainly affecting children in the educational setting.

#2: Congregations don’t always know who has disabilities

“If we know who we know, there is an exponential number that we don’t know.”
“They do a good job with bar mitzvah for disabilities, but everything else, groups, outings, inclusion, peers is completely missing.”

It was clear in the focus group discussions with congregational leaders that they do not always know who among their congregants have disabilities, and they certainly do not know about potential members in their geographical area with disabilities. Many noted this issue, and most congregations expressed a desire for assistance in identifying individuals and families in their area. Some of what was expressed included:

[Challenge is...] “not knowing enough about individuals with special needs, as well as appropriate accommodations/modifications.”

Individual with household member with a disability

“One of the interesting questions that has come up in our discussions is whether we proactively do something even if we don’t know of a congregant who needs it.” Synagogue leader

“We run into children with learning issues. Some parents don’t want to disclose because synagogue is the only place child can feel ‘normal.’” Synagogue professional



#3: Perceptions of Inclusion Impacts Synagogue Membership

“I have a daughter who has learning disabilities. Our temple did not have a program for her....Twenty years later she found what she wanted in a church.” Former Synagogue Member

“I have been looking for a way to attend a progressive synagogue where my autistic son and my typical child can both feel welcome.” Non-Member

A majority of survey respondents and focus group participants indicated that a congregation’s inclusion efforts would greatly impact their membership decision. A keen desire was expressed among households affected by disabilities for a spiritual home, for a place where the whole family, including children and adults with disabilities, can worship and belong. This is true for unaffiliated households, who don’t know where to go, as well as affiliated households, who do not feel entirely welcome. Seventy percent of unaffiliated households with a disability said that a congregation’s inclusion efforts would positively influence their decision about membership, as did 67% of affiliated members with a disability in their household. Even 57% of unaffiliated households with *no disability* said it would positively influence a membership decision and nearly half (49%) of those currently affiliated with no disability said it would. Clearly, a sustained, community effort around inclusion could bring in unaffiliated members with and without disabilities, and would help retain and strengthen the bonds of all affiliated members.

#4: Synagogue leaders rate inclusion efforts higher than household respondents.

Synagogue leaders consistently reported that their synagogues were doing a better job in responding to the needs of members with disabilities than the actual members with disabilities reported the synagogues were doing. Their different responses to questions about whether “my synagogue or the synagogue near me does a good job of...” revealed a stark perceptual divide: “accessibility to bar/bat mitzvah experience” (leaders 88%, members 63%); “supporting children’s learning needs” (leaders 76%, members 45%); “involving children with intellectual, developmental disabilities and their families (leaders 72%; members 50%). Only when it came to the needs of adults in the synagogue – “involving adults with intellectual/developmental disabilities,” (leaders 50%, members 33%); “involving people with social emotional, mental health needs” (leaders 45%, members 34%), did a majority of leaders waiver in giving themselves high marks, although a perceptual gulf remained between the two groups.



Finding #4 Synagogue leaders rate inclusion efforts higher than household respondents

10

My synagogue does a good job of...	% difference between synagogue members who mentioned a disability and synagogue leadership
involving people with social, emotional, mental health needs	-11
involving adults with intellectual/developmental disabilities	-17
supporting children's learning needs	-21
accessibility bar/bat mitzvah experience	-22
involving children with intellectual, developmental disabilities and their families	-22

#5: Synagogues are inconsistent and ad-hoc in their approach and ability to be inclusive of individuals with disabilities and their families

“The first reaction I sometimes get is: ‘Let’s have a disabilities Shabbat’ or the like. We don’t want that; we want every Shabbat (or program, class, etc.) to be accessible to all.”

Synagogue leader’s rationale on why creating a culture of inclusion is the desired approach

[At our congregation], “we believe in full inclusion and universal design. Everything we do with an inclusive lens. Rather than plan programs specifically for people with disabilities (sometimes that is appropriate) that may separate them from the community, we try to make everything we do inclusive. For example: fidget toys are available at all times, and our sign language interpreter is with us once a month, regardless of whether or not our deaf congregants will be in attendance.”

Synagogue leader

Approaches to inclusion and capacity varies greatly from synagogue to synagogue. Frequent barriers to efforts include physical facilities (not all congregations are ADA compliant), resources (human and financial) and synagogue culture. Less than 25% of congregations have an inclusion committee or work with other congregations.

Religious/Hebrew schools vary in the resources they have to support inclusion; overall they have more resources than congregationally based early childhood schools. And while at least 15 schools report having an inclusion specialist on staff, these professionals have never met together or formed a network regionally or city-wide. Fifty-four percent of Religious/Hebrew Schools reporting already have “an inclusion specialist or staff member,” as opposed to only 15% in



Early Childhood; 72% provide “teachers, tutors or support in an alternative environment” (46% in Early Childhood) and 73% provide “aides or shadows for children” (58% in Early Childhood).

Reform/Conservative/Unaffiliated synagogues reported that few of them “work with other congregations,” (37% said they did), “have a committee/group focusing on inclusion,” (26%), or even “offer programming targeted to adults with intellectual/developmental disabilities,” (15%). Even in the limited cases of inclusion efforts, news of it was not reaching the unaffiliated community. In 6 out of the 7 statements regarding the provision of disabilities resources in the synagogue space, unaffiliated members most common response was that they simply didn’t know what was available in their communities.

Congregations also differ in their knowledge and use of local and national resources. It was not just community members that did not know what is going on in the synagogue. Most synagogues were similarly not aware of what resources were out in the community or how to make use of them. Among the Reform/Conservative/Unaffiliated congregations, only around half reported accessing community resources such as JCFS (52%), JVS Chicago (60%), Keshet (50%) and other Movement Resources (40%); or promoted day camps (43%) and overnight camps with inclusion support (52%). The Orthodox/Chabad Synagogues reported even less use of community resources such as JCFS (29%), JVS (14%), day camps (43%) and overnight camps (43%) with inclusion support. Only Keshet was used by a majority of the eight Orthodox/Chabad institutions.

#6: All synagogues state that they share inclusion as a value, and momentum exists to move these efforts forward, yet many do not know where and how to begin.

“It is our moral obligation and ethical responsibility to make everyone feel welcome and safe when they enter their own synagogues and another Jewish facility.”

“This is a high priority for us. It’s important to us to have an expert help us assess what we are doing well, what we’re doing poorly, and how we can improve.”

“Our physical plant is prohibitive in this way [being accessible] and we are short staffed to attend to everyone’s growing needs.”

Synagogue leaders are interested in strengthening inclusion efforts, moving forward on a congregational level and in some cases, regionally or city-wide. But even though a majority of synagogues view inclusion of individuals with disabilities as a shared value, how inclusion is approached – whether through the creation of separate or integrated programs,– varies greatly, along with the importance and urgency on it placed by leadership and the community

There are some isolated examples of networks of synagogues doing inclusion work and programming, crossing denominational boundaries. One example is HUGS (Health Understanding in a Growing Space), a coalition of 8 Conservative and Reform synagogues in the Far North and Northwest suburbs that holds separate worship opportunities that rotate among synagogues, and focuses on holiday celebrations. There are opportunities to learn from these models.



RECOMMENDATIONS

The findings from the community survey and focus groups demonstrate that synagogues across Chicagoland are all in different stages of readiness. A majority of them are just beginning to grapple with the issue of engaging individuals and families with disabilities, and those that are trying to respond to these needs have ad hoc approaches. There is a need for education and training, the development of strong networks and use of outside resources, planning expertise as well as the identification of “champions” of inclusion that are ready to take the next steps.

FOSTER A CULTURE OF INCLUSION

- #1) Provide education/training for synagogue members, staff and lay leadership
 - e.g. Matching individuals with disabilities with existing synagogue programs, and providing training and support to the synagogue to help them integrate the individuals into those programs
- #2) Identify inclusion “champions” (in addition to parents of children with disabilities) and involve more self advocates – people with disabilities
 - e.g. Guiding the development of Inclusion Committees among a cohort of congregations

NURTURE COLLABORATION

- #3) Create/Support regional collaboration among synagogues
 - e.g. Create joint position to provide support in Religious Schools; Joint marketing efforts
- #4) Coordinate efforts to bring together professionals with similar inclusion roles, particularly congregational schools
 - e.g. Create a Network of Resource Teachers that meets regularly

RESOURCES

- #5) Increase awareness and use of outside resources, local and national
 - e.g. Create and disseminate an online directory
- #6) Help individual schools develop new staff positions in Religious/Hebrew school and Early Childhood Education
- #7) Provide expertise to help synagogues plan for and secure resources to increase physical accessibility
 - e.g. Identify and disseminate information on available experts and funding sources; Conduct a seminar for congregational leadership