# Serving Jewish Children With Disabilities and Their Families

Jennifer Laszlo Mizrahi and Meagan Buren

After centuries of persecution, we Jews have become deeply committed to developing one asset over almost everything else—our minds. This asset is the one thing we can take with us to a new country, and it has contributed to our survival. This devotion to education and achievement has been good for us and for the world as is evidenced by the many Nobel Prizes won by Jews for discovering lifesaving breakthroughs.

But what does that mean for those of us in the community who are not destined for acceptance at the top colleges or to win a Nobel Prize? What about the child who is born with an intellectual, learning, mental health, or physical disability or the individual who acquires a disability? The Jewish community, which values achievement so highly, can be an exceptionally harsh and lonely place for someone with a disability and for those who love them. Time and time again, we in the Jewish community shut our doors to people with disabilities, or we serve them in segregated institutions when separate is never equal. Sometimes this is done intentionally, but far more often it is done because we simply do not know how to truly serve all.

Studies show that 9 out of 10 women overall who take the test to discover if they are carrying a fetus with Down Syndrome choose to abort. What message does this send to people with Down Syndrome and their families, and what are we doing as a community to welcome them in our community as equal? What are we doing to embrace a family with disability issues when members of the Jewish community say to the mother of a child with Down Syndrome, "why didn't you consider abortion?"

The impact of exclusion of people with disabilities (PwDs) goes beyond hurt feelings. It leads to isolation, fewer affiliated Jews, family disruption, and, all too often, even divorce. If we are going to bring everyone under the tent, then we must include people with disabilities.

According to the U.S. Census, 18.6% of Americans (approximately 1 in 5) have a disability. Because Jews carry genetic risks and on average have children later in life than any other demographic group in America, it is likely that the percentage of Jews with disabilities is higher than the national average. That is all the more reason why Jewish communal agencies, their staff, and lay leaders must welcome, accept, and support individuals dealing with disability issues. When people are welcomed, accepted, and treated equally, disability can actually be an asset to the community. We come to learn the true meaning of humanity and understand that, though everyone is

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different, all people were created in the image of G-d, "b'tselem Elokim bara oto."

A nationwide poll fielded by RespectAbility of more than 3,800 Americans in the disability community (half of whom were people with disabilities, and half were family members and providers to PwDs) shows that Jews with disabilities are far less engaged religiously than are Catholics, Protestants, or Evangelicals. Less than half of Jews surveyed answered that religion was "fairly" or "very important in their lives," and nearly 40% reported that they rarely or never attend synagogue. A higher percentage of Jews do not attend services than in any other religious group polled. We can learn a great deal from how other faith groups welcome and serve people with disabilities and their families. For example, the Church of the Latter Day Saints (Mormons) has mandated that every one of its 24,000 congregations or institutions have an inclusion director/coordinator to ensure that PwDs are welcomed.

Even though the Americans with Disabilities Act (ADA) was passed in 1990, it has not ended discrimination in religious institutions, in part because they are exempt from its regulations if they do not accept federal money or services. Therefore they have little legal obligation to serve or hire people with disabilities. Unfortunately, this "pass" has hindered the implementation of simple accommodations such as accessible doors and ramps to enable people with physical disabilities to participate in religious services and programs. While these institutions are legally exempt, the same does not hold true for moral or religious obligations. It is time for real participation in all aspects of Jewish life, including access to the bima, kiddushes, bar and bat mitzvahs, and all activities that say, "I am a welcome member of the community."

In a study conducted by Mizrahi and Buren for the Foundation for Jewish Camp in early 2013, 46% of Jews with disabilities who attended overnight Jewish summer camp reported that they have been denied access to other Jewish institutions due to their disabilities. Given that most children with significant disabilities are not yet served by camp, it is likely that an even higher percentage of Jewish people with disabilities (JPwDs) have been denied access to Jewish life.

A poll of 2,607 Jews conducted in September 2013 by RespectAbilityUSA. org and Jerusalem U shows that Jews, particularly young Jews, feel very strongly that Jews with disabilities need to be included in Jewish life. Fully 89% of the Jews polled strongly agreed that "Jewish events and organizations should be as welcoming and inclusive of people with disabilities as everyone else." An additional 9% somewhat agreed with the same statement. Indeed, they felt more strongly about inclusion of people with disabilities in Jewish life than about being connected to Israel, marrying someone Jewish, or having Jewish children. The gaps in intensity were more pronounced among young Jews.

The 2013 Pew study, A Portrait of Jewish Americans, in many ways paints a dismal picture of the Jewish communal future; smart, dedicated leaders are spending a lot of time and treasure to find the best ways to connect with unaffiliated Jews while at the same time many passionate Jews are being turned away based solely on their disabilities. This article provides guidance on how to serve Jewish children with disabilities and their families.

#### **SELF-ASSESSMENT ON INCLUSION**

Self-assessment is the first step in developing a comprehensive approach to serving PwDs. Here are some key questions to ask about your organization, inspired by material developed by the JE & ZB Butler and Ruderman Family Foundations.

- 1. Does your organization have policies and/or programs that support meaningful inclusion of people with disabilities at all levels? Are they prominent on your website and materials?
- 2. Does it have a disability advisory committee/inclusion committee, and if so, are Jews with disabilities themselves and their family members on the committee?
- 3. Will ALL people with any kind of disability be welcomed to participate? If not, why not? If so, how do you plan to identify, reach, and welcome them?
- 4. Do you serve Jews with disabilities in an inclusive way (welcoming them inside the full community), or are they forced into segregated "special needs programs" that are inherently unequal?
- 5. Has someone who uses a wheelchair personally checked the physical accessibility of your offices and programs for people who use wheelchairs?
- 6. Has a person who is blind and who uses adaptive computer technology checked your website and facilities for accessibility?
- 7. Do the videos you use have captions? Do you have a way to communicate with people who are deaf or use other adaptive supports?
- 8. Do you employ individuals who have disabilities? If so, what are their jobs? Do they receive the same compensation and benefits as all other employees in like positions?
- 9. How do you educate your staff, board of directors, trustees, and other key people about serving and partnering with people with disabilities?

If you are like many Jewish organizations, you may answer "no" to many of these questions. But do not be discouraged. Now is the time for action. Follow this road map and you will be on your way to achieving full inclusion.

#### STEPS TO FULL INCLUSION

#### 1. Leadership at the Top Needs to Buy in and Share That Vision

Academic studies show that for inclusion of people with disabilities to be truly successful there must be buy-in from top leadership. The CEO and lay leadership must communicate the message that all people are of equal value and must be respected and heard fairly. They are responsible for the implementation of the vision, mission, and tone of the agency, which must be embedded in its policies, budget, and staffing.

One prominent agency in which top leadership has set a course toward a focus on inclusion is the national umbrella organization, Foundation for Jewish Camp (FJC). It has implemented a smart, holistic strategic planning process that includes budgeting and training to ensure that all its member camps in North America are on board. Jewish overnight camps, such as Ramapo for Children and HASC, have been serving children with disabilities (albeit in segregated institutions) for years. This year, Howard Blas and the Tikvah program at Ramah Camps won well-deserved recognition from the Covenant Foundation for their work in

inclusive camping where children with and without disabilities are welcomed as equals. The FJC is only beginning the journey to full inclusion by serving children of ALL abilities, but because it is being done strategically from the top, this effort is an example of what more Jewish day schools, synagogues, and Federations could and should be doing.

Among the federations, Combined Jewish Philanthropies in Boston, the Jewish Federation of Greater Washington, and the UJA-Federation of New York are making important efforts to build support for inclusion. In addition, The Associated in Baltimore has created a user-friendly website where Jewish parents of children with disabilities can easily find agencies that will welcome and serve their children. Some individual Jewish Community Centers have had successful inclusion programs. The Reform movement, which has long benefited from the able work of Rabbi Lynne Landsberg, now has the added voice of its top leader, Rabbi Rick Jacobs. Yachad, a youth inclusion program through the Orthodox Union, and Friendship Circle, both of which bring together teenage volunteers and children with special needs, have provided quality access and dignity to Jewish children with disabilities for years. Vocal and visible leadership from the top matters tremendously.

#### 2. Nothing About Us Without Us

People with disabilities need a seat at the table and must be involved in decision making: organizations must work WITH people with disabilities, not FOR them. If currently there are no Jews with disabilities participating in your decision-making process, then bring them in. Value their experiences and opinions. Remember that even people who cannot physically speak have opinions that must be shared and heard.

#### 3. Use "People-First" Language

Take the time to learn "people-first language," which respects human beings and their right to be appreciated for the strengths they have and which does not define them by their disabilities. For example, using people-first language, you would call a child with Down syndrome by his or her name, not "the kid with Down Syndrome" or, worse yet, the "Down syndrome kid." A person who uses a wheelchair is a person first, and that wheelchair is a tool of liberation: he or she is not "wheelchair bound." The focus is on "people with disabilities" (PwDs), not the "handicapped" or the "disabled."

#### 4. Walk the Walk

It is one thing to announce big goals and a plan. Implementation is another. Last year, NJY Camps, which has nine camps under its umbrella, decided to merge its Round Lake Camp for children with disabilities with three of its other camps to make the entire organization more inclusive. As a result, children with disabilities were no longer in a completely segregated institution, and children without disabilities benefited from being exposed in a Jewish context to the diversity of Jewish people that God put on this earth. Every segregated Jewish institution should look closely at how this change was implemented because it took significant training and preparation, and it worked. It was a true example of walking the walk in a big way!

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#### 5. Budget the Time and Money That It Will Take to Do It Right

Inclusion is a lot less expensive than most people think, but it takes the right team with the right training to do it effectively. To ensure success and to develop an accurate budget, camps/schools/synagogues need to know how much funds are needed to have the right staff in place, give them the training needed to make them effective, and make the needed accommodations to the physical plant.

#### 6. Registration Forms and Intake Process Can Establish Trust

Trust is vital—and it comes BEFORE you even meet face to face with children with a disability or their parents. Every sign-up form for every program must ask what accommodations are needed for people to participate fully in what you are offering. When participants indicate that they need an accommodation, their form must go straight to the inclusion director/coordinator so he or she can ensure that their needs can be met. Parents can be your best assets because they are already experts in meeting the needs of their child and can help you serve them successfully as well.

It is fine to indicate that you need advance notice of any disabilities so that you can offer needed accommodations or special services at your events. For example, tracking down a good sign-language interpreter or making a "behavior plan" takes time. Have a ready list of providers or volunteers you can call to meet key needs.

#### 7. Every Organization Needs an Experienced Inclusion Director/ Coordinator

An expert inclusion director/coordinator can ensure that you are ready to meet the needs of Jews with disabilities. This person does not need to work full time, but does need to be available as needed. Some institutions use highly qualified volunteers. For others this is a paid position. There are many special educators/ therapists/social workers who work in public schools or other institutions who are available on a part-time basis. Below is a sample job description from the URJ camps that can easily be adapted for Jewish schools or synagogues.

#### Qualifications for camp inclusion director:

- Ξ Teaching Certification (Special Needs / Special Education) and/or MSW or other appropriate
- Ξ Ability to effectively assess children on multiple levels (social, educational, academic, physical psychological, medical) to determine their suitability for a camp program
- Ξ Ability to effectively design individualized inclusion models for each child that meet their needs and the needs of the camp community
- Ξ Experience with and knowledge of a variety of special needs/disorders, including (but not limited to) the following: Attention Deficit Disorder, Attention Deficit Hyperactive Disorder, Obsessive / Compulsive Disorder, Tourette's Syndrome, Bipolar Disorder, Asperger's Syndrome, Down's Syndrome, Autism, social difficulties, behavioral challenges, homesickness, cognitive disabilities, and a variety of emotional challenges and physical limitations.
- Ξ Ability to work in a team environment, and to collaborate effectively with a number of different stake holders (parents, counselors, unit supervisors, medical staff, camp administration, etc.)

#### Responsibilities

- Ξ Work directly with and report to the Camp director
- Ξ Establish, in collaboration with the Camp Director, the policy and procedures of an inclusion program at Camp for children and staff with special needs to ensure their safety and success
- Ξ Process applicants who register for camp and have special needs. This includes:
  - Create forms and questionnaires to obtain information
  - Direct liaison with parents, teachers, and outside agencies (i.e., medical professionals and government support agencies)
  - Review questionnaires and determine eligibility
- Ξ Maintain parent contact before, during, and after the camp session regarding preparation for summer session, implementation of program, and follow up evaluation
- Ξ Recruit staff members to support campers with special needs
- Ξ Develop and provide a pre-camp inclusion training module for all staff
- Ξ Design modifications to programs and activities to accommodate children with special needs which could include a learning disability, attention deficit disorder, attention deficit hyperactive disorder, bipolar disorder, Asperger's syndrome, social difficulties, behavioral challenges, homesickness, cognitive disabilities, selected emotional difficulties and minor physical limitations.
- Ξ Provide ongoing training and support to specialists, unit heads, faculty, health center, and kitchen staff
- Ξ Involvement in the camp crisis management plan
- Ξ Document all aspects of the inclusion program and maintain ongoing written accountability regarding information gathered, anecdotal notes, scheduling, programming, outside contacts, responsibilities, and follow up
- Ξ Create and implement behavior contracts for specific campers
- Ξ Provide short- and long-term support of staff members of campers with special needs
- Ξ Design individual work placements for staff with special needs and ongoing task analysis
- Ξ Work collaboratively with the camp director around a number of camp issues including inclusion, health and safety, camper issues and staff morale
- Ξ Model and advocate acceptance and understanding for campers and staff with special needs

#### 8. Training Seminars and Manuals

When the Foundation for Jewish Camp asked its member camps in 2013 what was the "most significant challenge to serving campers or more campers with disabilities/special needs," the most frequent answer was that they were "only able to accept a certain level of disability and can't have campers with more severe issues." The next most frequent response was "we don't have enough properly trained staff for it." Parents also cited the cost of camp programs and the need for staff trained to assist children in developing peer relationships and building social skills, as well as to help other campers learn to respect and accept campers with disabilities. Professional training sessions

and materials are vital and the following topics must be covered for all Jewish institutions:

- · Participant assessment/intake process
- Accommodation/inclusion plans
- Adaptations
- Inclusion support staff
- Preparing non-disabled peers
- · Facilitating peer interactions/aid and fade
- · On-site technical support
- · Program evaluation

All groups need a staff training manual on inclusion. MATAN (www.matankids.org), which focuses on professional development and mentorship of current of future Jewish leaders, has good materials on its website, and other groups have helpful resources as well (see the resources at the end of the article). A manual of best practices would be a welcome addition to the field. Here are three excellent training manuals:

- 1. "Let's All Play Inclusion Recreational Programs," National Inclusion Project: http://www.pewsocialtrends.org/2010/11/18/the-decline-of-marriage-and-rise-of-new-families/ i-executive-summary
- 2. *Community Recreation and People with Disabilities*, by Stuart J. Schleien: http://www.amazon.com/exec/obidos/ASIN/1557662592/rehabtheraonlinm
- 3. Including People with Disabilities in Camp Programs: A Resource for Camp Directors, by Glenn Roswal et al.: http://www.eric.ed.gov/ERICWebPortal/search/detailmini.jsp?\_nfpb=true&\_&ERIC ExtSearch\_SearchValue\_0=ED422152&ERICExtSearch\_SearchType\_0=no&accno=ED422152

#### 9. Promote "Expected Behaviors" to Reduce Tantrums/Meltdowns

One of the main reasons that Jewish institutions deny access to children with disabilities is that they do not yet understand how to promote "expected behaviors" (the PC way of referring to reducing tantrums and meltdowns by children with disabilities). Thus, they are afraid of classroom disruption.

To expand your capacity to serve participants with more involved disabilities (note they are not called "crippling" or "severe"), staff members need professional training so they can understand the difference between "can't" and "won't," and they need to be given the tools to promote expected behaviors. Simple tools like effective methods for handling transition between activities can eliminate tantrums and keep a group together as a team. Training can make all the difference!

#### 10. Marketing: Getting the Word Out

One of the hardest things for families challenged by disabilities is finding what is available in their communities, and websites can be important tools for letting people know what you offer. Part of the challenge is that in many cases the current state of play is "accidental inclusion" instead of "intentional inclusion." In other words, many Jewish institutions serve who they serve because they were approached by a person with a disability and correctly made accommodations to include them. This effort should be applauded, but it should not stop there. Intentional inclusion should be the goal, and it should be celebrated and shared

widely. If you already have inclusion programs, put your diversity policy on your website stating that you are open to all, regardless of ability. Work to make your website easy to navigate and accessible to people who are blind and deaf.

### 11. What Parents Want for their Children: Social Skills and Peer Relationships

As mentioned earlier in the context of camp, parents of children with disabilities want professionals to be trained in assisting their children to develop peer relationships and build social skills and to help other children learn to respect and accept those with disabilities. In many Jewish institutions the one-to-one CIT/counselor/paraeducators who provide support to children with more involved disabilities mistakenly think their job is to be the child's big brother/big sister/friend. But the best practices role should be to "AID AND FADE."

A key purpose of inclusion is to enable children with disabilities to make friends and have experiences with their "typical" peers. The job of a staff member or counselor is not to fix every problem or to constantly hover over participants; it is to help children discover solutions on their own. There will be times when a counselor will need to assist them, either physically or in a conversation, in meeting their needs. Once the immediate need is met, however, it is then important that children are given the space to be as independent as possible. Their support person needs to step away slowly, allowing more freedom and the space for real friendships to happen.

Doing so is difficult because it requires typical campers and students to make an effort to be friends with a child who may have limited social skills. But that hard work pays off. While many children do not yet understand why these peer relationships are so important, their parents do. Nothing is more important to families than enabling a young person with a disability to be able to self-advocate and to become independent. After all, parents eventually will die. They want their child with a disability to have people who will care about them and vice versa, and who are not PAID to do so.

AID AND FADE is especially important with older campers/students. However, in our telephone interviews with camp directors we heard over and over that it is far easier to provide one-to-one support when the camper is young. With older campers, it is more obvious to the other campers in the cabin that the child with disability has that support. Yet, some of that difficulty would be eliminated if the support person had the experience and training to understand that he or she should be a helper to the WHOLE peer group, and should AID AND FADE the one-to-one support as needed.

Many groups hire young people to be counselors or aides who have been to camp or religious school for many years and have an affinity for helping kids with disabilities, but have no educational background or practical experience in working with people with disabilities. Is this a best practice? At a minimum they need intensive training before camp begins. At best, they could benefit from a program similar to CLASSP (Consortia of Learning and Service to Special Populations) and College CLASSP, year-long programs in more than 20 UJA-Federation of New York's Jewish Community Centers and day camps. Both provide hands-on training and academic learning, provided by Ramapo for Children's Training Institute, to high school and college students who work in their afterschool and weekend programs and in their summer day camps. Participants earn a stipend

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and college credits. Many subsequently are hired to help staff agency programs, bringing their rich experience and skill and enabling the agencies to enhance their programming for youngsters with disabilities. Their CLASSP experiences have led many students to choose professions directly related to disabilities. Moreover, as a result of this rich experience, they are more compassionate individuals who often act as strong advocates for people with disabilities in their daily lives.

An added benefit of these peer relationships was pointed out by Rabbi Steven Weil, in *Jewish Action* (see www.ou.org/jewish\_action/11/2013/inclusion), the magazine of the Orthodox Union, about his son's participation in Yad B'Yad, Yachad's inclusive travel program in Israel: by teaching kids and teens about inclusion, we educate the parents as well.

#### 12. Hire PwDs and Encourage Others to Do So as Well

According to congressional testimony, fully 70% of working-aged Americans with disabilities do not participate in the workforce (compared with 28% of people without disabilities). It is therefore important for Jewish communal agencies not only to develop programs for people with disabilities but also to use them. They should be a model for hiring PwDs, and, if they are running job fairs, should only include employers that hire individuals with disabilities. Congregations can encourage their members to offer internships to young Jews with disabilities or serve as "job coaches" so that Jewish teens with disabilities can be put on track to a life of independence and success.

#### 13. Job Bank

Well-trained, skilled, and sensitive staff and volunteers who are experienced in working with Jews with disabilities are in short supply, and a job bank should be created of such talented people. It would be extremely helpful to have a central database/file of good resumes of professionals who could serve as inclusion directors as well as being one-to-one supports. Because mental health problems, learning challenges, and Autism Spectrum Disorders disproportionally affect males (4:1), men are especially needed in the field to serve as role models.

### 14. Provide Scholarships to Jewish Children With Disabilities and Their Families

Disabilities can impoverish people. Paying for treatments, therapies, equipment, and services that help some people with disabilities adapt to daily life places extraordinary financial burdens on families because these services are not fully covered by insurance or public funds (though we may see some improvement with full implementation of the Affordable Care Act). Taking advantage of financial assistance is often the only way PwDs can participate in programs. When developing programming, it is important to consider scholarship options for families wishing to participate in camps, schools, or synagogues. When doing intakes, make it comfortable for people to ask about financial assistance.

### 15. Creating a Home Away From Home: Mental Health Support or Affinity Groups

Support groups for PwDs and their family members provide emotional support to people grappling with issues they face. They can empower parents who can then

become active volunteers, which helps ensure that the programming will be well attended and successful. These support groups do not need to be facilitated by social workers; existing synagogue and day school staff can be trained to lead them.

It is a known fact that families will move to those communities that offer them the most services and are welcoming. We need to reach out to families and help them plan for the future, ensuring that their children will be welcomed and as independent as possible when their parents are gone. We need to provide support to siblings of people with disabilities as well.

The bottom line: Open our doors to Jews with disabilities and we will be enriched by their abilities. Every person with a disability has strengths, purpose, equal value and a place in the Jewish community. Let's open our tent!

#### **RESOURCE LIST:**

 $http://www.amazon.com/Including-People-Disabilities-Faith-Communities/dp/1557667438/ref=sr\_1\_3?ie=UTF8&qid=1390264133&sr=8-3&keywords=inclusion+faith+disability.$ 

http://www.jewishfederations.org/local\_includes/downloads/61299.pdf.

http://www.njcd.org/blog/news/yachad-announces-hineinu-partnership-across-jewish-spectrum-promote-inclusion/.

http://www.boardofrabbis.org/files/Jewish\_Text\_Resources.pdf.

http://rac.org/Articles/index.cfm?id=21379.

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