B.I.N.A.

Best practices Information News Awarness
A Newsletter for Special Needs Jewish Education

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Hoping that everyone finds things in this issue that helps us all in knowing about what is available both for <u>H</u>anukkah, Jewish Disabilities Month (February) as well as information about local and national programs that deal with education and services for individuals with disabilities.

Please feel free to send in anything you would like to see included in subsequent issues as well as to comment on the content. Sharon

Thanks – Todah Raba! Thank you to the congregations that have contributed so far to keep BINA going! We welcome contributions to be able to maintain this service. Any agency or individual who is interested in offering support can send their financial support to:

BINA, c/o Adath Israel Congregation – Resource Center Services, att. Hedda Morton, 1958 Lawrenceville Road, Lawrenceville, NJ

INSIE THIS ISSUE- THE HIGHLIGHTS

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Save the Date!

Do you have a child with special needs? Are you looking for a meaningful family activity to share with them over the winter break? Look no further!

Please join Temple Emanu-El and the JCC of Central NJ for their upcoming Ma'ayan Program: A Family Hannukah Celebration! This unique event is designed for families with children ages 3 through 8 with special needs. Please look for a detailed flyer to follow.

The event will take place on Monday, December 26th, from 10:00-11:30am at the JCC of Central NJ, 1391 Martine Avenue, Scotch Plains.

For more information, please contact Amy Ash, Ma'ayan Program Director, at 908-232-6770, ext. 137 or emailaash@tewnj.org.

March 13, 2011 | 11:19 pm

Purim: The whole megillah of sensory integration

Posted by Michelle K. Wolf

"Hava narishah - rash, rash, rash (Wind your noisemakers - rash rash)"—Chag Purim song lyrics

The chance to scream "boo" at each mention of the arch-enemy Haman during the *Megillah* (scroll) reading of Purim is a pretty fun experience for most Jewish children.

Purim, which this year falls on March 20th, is one of the more festive Jewish holidays that celebrates the deliverance of the Jews from their enemies in the biblical Book of Esther. Purim encourages kids (and adults) to dress up in costume, have a few drinks (for adults) and in general, to cut loose and act a little crazy.

Sounds like a good holiday for Jewish children and teens with special needs, right?

The problem is many children with special needs, especially those on the autism spectrum, also have sensory integration issues. Simply put, this means that their bodies respond to sensory input differently than typically developing children. For someone with severe sensory issues, many everyday sounds, such as an electronic can opener or a squeaky shopping cart, can be perceived like nails dragging on a chalkboard.

Imagine then, what that cacophony of groggers, screams and yells in response to the 54 mentions of "Haman" can feel like to someone with sensory integration issues?

When Danny was younger, he would start screaming and crying at the very first mention of "Haman"; he would become completely inconsolable. We learned to take him out in the hall, or into a nearby room where he could still hear the excitement, but the sound was highly buffered. This was challenging when his big sister was participating in the costume parade for young kids and wanted to stay in the sanctuary for the *megillah* reading.

With the help of different sensory integration interventions, which included deep pressure "brushing" through the use of a special brush followed by gentle compressions to the shoulders and elbows, Danny was eventually able to tolerate louder and louder noises. In fact, now he likes to stand as close to the speakers as possible whenever amplified music is played. At age 16, he is also now able to sit through an entire *megillah* reading and will even ask for "more" when the reading is completed.

But what about all those kids who can't handle a typical synagogue *megillah* reading (one local shul boasts of holding the "world's noisiest *megillah* reading" but asks that families refrain from bringing "cap guns or explosives". If hearing the *megillah* read is considered a important *mitzvah*, how can all our kids participate?

In Los Angeles, Rabbi Jackie Redner & the Nes Gadol (Great Miracle) Program at Vista Del Mar held their first annual sensory-friendly pre-Purim celebration on Sunday that featured a retelling of the Purim story without any noisemakers (just "jazz hands"). This is a low-cost easy-to-implement idea that I hope many other synagogues, community centers and other Jewish organizations will start to offer in the coming years.

One of the lesser known traditions of Purim is to give either food or money to the needy, "matanot la'evyonim," and as part of that tradition, we are supposed to give a small

donation to whoever asks without first asking to check the person's bank statement. (My Dad has fond memories of going door-to-door on the Lower East Side in New York and saying a few Yiddish lines in verse which resulted in a sizable amount of cash by the end of the day).

In the spirit of "matanot la'evyonim" let's make it a communal goal that sensory-friendly Purim celebrations be created in all Jewish communities so that every child will have the opportunity to hear the Purim megillah. It's a small donation that will yield many gifts in the years to come.

A great website with a wealth of quality materials to view and download for special needs classrooms for holidays and Jewish practice.

Gateways: Access to Jewish Education, 333 Nahanton Street

Newton, Massachusetts 02459

Phone: 617-630-9010 | Fax: 617-517-9160

INFO@JGATEWAYS.ORG | WWW.JGATEWAYS.ORG

Special Camps for Special Kids

by David Ogul | November 2011, Popular Stories from SDJJ | Post your comment »



By David Ogul

For the family of Brandon Levine, a New Yorker who was diagnosed with a brain tumor when he was 3, who suffered from seizure disorders in the years that followed and who dealt with learning disabilities all his life, the Yachad Program at Camp Morasha was a godsend.

It was here, in Pennsylvania's peaceful Pocono Mountains that Brandon, now 20, polished his davening skills, honed his love of Jewish life and took part in a variety of sports through a program designed for special-needs children. "For us, as parents, to have a program over the summer where our son is being properly watched and taken care of 24 hours a day was a great thing," says Brandon's father, Danny Levine, who owns a Judaica store in Manhattan. "For Brandon, to be in a camp where he is having fun, having a great time and being with a larger Jewish community was just wonderful."

When a child is a healthy, well-adjusted, rambunctious tyke, finding a summer camp that suits his or her needs can be no more difficult than embarking on a Google search. But when a child is fighting cancer, struggling with autism or living with Down syndrome, options can be more limited and the search more daunting.

That, however, is changing.

Responding to the growing demand of parents raising special-needs children, an increasing number of agencies have created or refined programs that enable handicapped youth to forget about their challenges while enjoying the Jewish camping experience.

"It's a great way to help make these kids grow and for them to get the most they can out of life," Levine says. Virtually every branch of Judaism now has a camp that offers programs for special needs children. In many cases, these kids spend part of the day within their own group while enjoying sports, synagogue services and sandwiches with children who are not living with physical or emotional challenges. Other camps of are created specifically for children with special needs.

The Union for Reform Judaism's Camp Newman near Santa Rosa, Calif., embarked on a Neshama Program two years ago that is tailored toward Jewish youth with autism spectrum disorders.

The program's mission, according to a statement, "is to honor the unique characteristics of every camper and provide access to Reform Jewish camping by creating individualized accommodations and modifications that allow each camper to succeed."

"The first summer was very much a pilot year, and we learned a lot about how best to implement the program and support our campers and their families while they are at camp," says Rabbi Erin Mason, Camp Newman's associate director. "This year, we integrated the Neshama campers much more into the greater community, involved their families in opening day programming and had constant communication throughout their week at camp. We created materials to send to them ahead of time to prepare them and help the campers understand camp even before they arrived. Staff was hired that had experience in Jewish camping that served the needs of this community."

The Shemesh Program at Camp JRF in Pennsylvania is affiliated with Reconstructionist Judaism. There, "campers will swim, play sports, sing, dance, explore nature, take an off-camp trip and be part of the vibrant Jewish experience," its Web site says. "Designed as a parallel inclusion program, Shemesh campers will not only have time as a unit — as

much as possible, they will participate alongside their peers in a variety of programs, including our moving Shabbat celebration."

The Tikvah Program, available at Camp Ramahs across the United States, is affiliated with the Conservative movement and is designed for Jewish adolescents with learning, emotional and developmental disabilities. "All of the campers come to camp for the same reasons: to have fun, make friends and learn about Jewish things," according to the Ramah Web site. "They are included with their non-disabled peers throughout the day. During the academic hour, a teacher with special education training is able to provide self contained education to those campers for whom it is more appropriate."

At Camp Simcha in Glen Spey, N.Y., a Chai Lifeline-sponsored endeavor, youth 6 through 20 battling cancer are provided with "the chance to forget about illness and concentrate on being normal," the organization's Web site says. The program allows campers the ability to "share their hopes, fears and triumphs with friends, or just forget about illness for a while. Campers are lavished with love in a positive environment that imbues them with the confidence and fortitude they need to navigate the forthcoming year's trials." Simcha, which is free, provides everything from traditional camping activities to medical care and counseling. "It is truly a remarkable program that gives such joy and provides so many smiles to kids who are going through such great challenges," says Jeremy Fingerman, CEO of the Foundation for Jewish Camp, an umbrella organization based in New York that works and coordinates with Jewish camps across North America. Fingerman's organization does not keep statistics that track the increase of special-needs campers over the years, but says unequivocally, "It clearly is a growing trend." Available programs run the gamut and cater to children "with physical disabilities, cognitive developmental delays, and there's even a trend in catering to children with food allergies. "Camps are much more sensitive to the range and needs of campers today," Fingerman says. "The joy of being in a Jewish camp should be accessible to everybody."

Despite what those in the industry say is a growing number of opportunities, others contend more needs to be done. Elana Naftalin-Kelman runs the Tikvah Program at Ojai's Camp Ramah. "The Jewish community is far behind where we should be on supporting kids with special needs," she says.

Synagogues and education programs are a good place to start.

"Day schools on the West Coast are not focusing as much on kids with special needs," Naftalin-Kelman says. "More kids and more families are seeing the doors closed because of the special needs of their child." She says the solution begins with rabbis and education directors thinking more broadly about the populations they are serving. "It starts with education and awareness," she adds.

She praises the program at Camp Ramah, along with Camp HASC, an award-winning summer program of the Hebrew Academy for Special Children. The latter, located in the Catskill Mountains of upstate New York, offers more than 300 mentally and physically handicapped children and adults a seven-week excursion each year.

Naftalin-Kelman says Camp Ramah offers the only camp for special needs children west of the Mississippi that runs longer than a week. The focus is on children with behavioral and developmental disabilities, such as autism and Down syndrome.

"The program has been incredibly successful. We've been able to accommodate kids with a variety of backgrounds," says Zach Lasker, Ramah's camp director. "The stories and the experiences that come out of this program are incredible and life changing."

Judy Rosenthal spent nine weeks each summer for 14 years teaching art at Camp Ramah in Ojai. Tikvah, she says, "is a fabulous program. Every child is treated individually." The kids, she says, contribute more than they take. "They are a blessing for everyone at the camp," Rosenthal says. "These special-needs kids seem to have a real love for Judaism. You see them leading the services, calling the pages (of the *siddurim*) out, whatever it might be." Depending on the needs, some kids may sleep in the same areas as other special needs children, but they do virtually every other activity with children who do not have special needs. They may go to synagogue services and take part in sporting events with other children. And through a "buddy" system, a child from the general population is paired up with a special needs child, forming a friendship that can last a lifetime. The most notable difference at Ramah between the Tikvah Program and the standard camp is that the counselors working with the Tikvah kids are more experienced — and there are more of them. "The counselors in that program are the cream of the crop," says Tom Fields-Meyer, a writer from Los Angeles who also serves on the board of directors at Ramah in Ojai.

Fields-Meyer and his wife, a Conservative rabbi, have three children. The middle one, 15-year-old Ezra, lives with autism and has been taking part in the Tikvah Program for the past five years.

"We want all of our kids to have the Jewish camping experience, and this is a great way for him to be with other Jewish kids and learn about Judaism in a fun and enjoyable atmosphere. He goes for four weeks, and it's the best month of his year."

He elaborated on the experiences his family had in a recent opinion piece published in The Jewish Daily Forward. "Camp Ramah places children like Ezra among its top priorities. In the process, it teaches him and his peers — and many adults — a Jewish lesson as old as the Talmud: *Kol Yisrael arevim zeh l'zeh*. 'All Israel is responsible for one another.' We are all a part of the same community."

It is a sentiment expressed by most parents, Danny Levine included.

A camp with programs including special needs children teaches kids to be sensitive, he says. "It teaches kids that not everyone is like them. And it gives them the ability to help other kids."

Camps Nationwide with Programs for Special-Needs Kids

Responding to a growing need in the Jewish community for summer camps that can cater to children with special needs, many sites have created specialized programs — either parallel or inclusive — for kids with different types of challenges. Among the camps that are solely for children with special needs:

- Camp Simcha (www.chailifeline.org), in Glen Spey, N.Y.
- Camp HASC (www.hasc.net/camp), in the Catskills
- Round Lake Camp (www.roundlakecamp.org), a NJY Camp in Lakewood, Penn.
- Camp Yaldei (www.yaldei.org/summerCamp.asp), in Wentworth-Nord, Quebec, Canada.

In the western United States, the following camps offer programs for children with special needs:

- Camp Akiba (www.templeakiba.net/fellowship.asp?pid=48), in Santa Barbara
- B'nai B'rith Camp (www.bbcamp.org), in Oregon
- Camp Charles Pearlstein (www.campcharlespearlstein.com), in Prescott, Ariz.
- Camp Ramah (www.ramah.org), in Ojai
- Camp Tawonga (www.tawonga.org) in Groveland, near Yosemite
- Camp Kalsman (kalsman.urjcamps.org), in Arlington, Wash.
- Camp Newman (newman.urjcamps.org) in Santa Rosa

Other camps in North America with special needs programs include:

- Camp Kaylie (www.campkaylie.org), in Wurtsboro, N.Y.
- Camp Kingswood (www.kingswood.org), in Bridgton, Maine
- Capital Camps (www.capitalcamps.org), in Waynesboro, Penn.
- Camp Livingston (www.camplivingston.com), in Bennington, Ind.
- JCC Camp Chi (www.campchi.com), in Lake Delton, Wisc.
- Camp Morasha (www.campmorasha.com), in Lake Como, Penn.
- Camp B'nai Brith (www.cbbmtl.org), in Lantier, Quebec, Canada.

Parents can visit www.jewishcamp.org/camps and click "Special Needs" in the search tool.

Source: Foundation for Jewish Camp

Summer/Autumn 2011 (Vol. 39, Nos. 3 & 4)

The How-To's of Accessibility

Congregations benefit when people with disabilities participate.

Mark I. Pinsky



FOR WITTY, FAST-TALKING JEWS there are several marquee occupations: stand-up comic, radio talk show host, trial lawyer, and, arguably, rabbi. Lynne Landsberg (MTS '76) was already a witty, fast-talking Reform rabbi and budding political activist—another genetically programmed profession—on January 10, 1999. That day, her car crashed on an icy, Washington, D.C., street leaving her with traumatic brain injury, her life in the balance, and on the long road to becoming one of the nation's leading religious disability advocates.

Landsberg made a vivid impression on her fellow students at Harvard Divinity School, as well as on her faculty adviser, Harvey Cox. Although she was the first of his students headed for the rabbinate, she was avid in her study of New Testament. "Of the hundreds, maybe thousands, of students I have taught over more than four decades at Harvard, she stands out and is in a

class of her own," he recalls. "She was a superb student and a real class act," he says, "dazzling everyone with her looks and her charm and her brains."

Landsberg credits her journey from a near-fatal collision and near-total incapacitation to a grueling regimen of therapy, and to an upbeat outlook. "Brain injury recovery comes in small steps," she says, "like the first time I smiled in two years, which made my family ecstatic. If you keep a positive attitude and work as hard as your therapist tells you to, things will get better—but in smidgens."

In sermons and speeches (which still require rehearsals with her speech therapist), she also emphasizes the role of her religious faith and the support of her Jewish community. The three elements of that process, she explains, are: prayer, attentive visits, and practical support from congregations. It is an approach that is applicable to all faith traditions. On the road a good deal these days for the Reform movement's Religious Action Center (RAC), Landsberg maintains an almost precrash schedule: advocating legislation at Capitol Hill briefings for new members and staffers ("Nothing about Us without Us"); publicizing Jewish Disability Awareness Month, an effort that involves all branches of Judaism; appearing on panels; and writing op-ed columns. The speed of her speech—which now comes in bursts, with asides for wisecracks—can test the ability of a telephone interviewer to keep pace.

Landsberg worked with a Jewish disability coalition to help pass the Americans with Disabilities Act Amendments Act, a more specific bill than the original 1990 landmark law, which deals with employment discrimination against people with disabilities. She is now busy—through the Interfaith Disability Advocacy Coalition (IDAC)—highlighting and defending those provisions of the 2010 Obama health care reform act that apply to people with disabilities. She is also campaigning to reform the way teachers can seclude and restrain children with disabilities through the proposed federal Keeping All Students Safe Act.

"I find her a model of courage, spirit, and humor," Cox says. "She laughs about her 'coma diet' in which she lost several pounds."

Like Landsberg, others have returned to ministry after devastating and debilitating injury and illness. If Chris Maxwell had lived in an earlier time, the viral encephalitis that wiped out his brain's capacity for short-term memory in 1996 would have effectively ended his pastorate. But with the assistance of modern medication and technology, the Assemblies of God pastor was able to return to the pulpit and the podium. In addition to traditional therapy, Maxwell can control his symptoms with drugs, and effectively outsource his memory to his Palm Pilot, which he downloads nightly to his computer's hard drive. Sermons and scriptural citations once delivered from memory are now made possible with the help of PowerPoint.

While technology enabled Maxwell to return to his congregation and most members welcomed him back and accepted his pastoral leadership, he acknowledges that he encountered another barrier. Some in his Pentecostal church thought less of him after he did not respond to healing by faith when hands were laid on him. So in 2006, Maxwell left the pulpit at Orlando's Evangel Assembly of God to become campus pastor and director of spiritual life at Emmanuel College in Franklin Springs, Georgia, his alma mater, and a motivational speaker and broadcaster.

As one blessed (thus far) with a reasonably unimpaired mind and body, I thought myself an unlikely choice to be asked to write a book about faith and disability, both physical and intellectual. But Richard Bass, head of the Alban Institute, the publisher, explained to me that funders wanted a book that would reach a general audience of clergy and people who may have no personal experience with disability, but who make the congregational decisions about accessibility and inclusion. And so I embarked on the research that led me to Landsberg, Maxwell, and many others, whose stories will be featured in the book *Amazing Gifts: Stories of Faith, Disability and Inclusion*, to be published later this year.

Although many religious leaders led the fight for the landmark Americans with Disabilities Act of 1990, they also managed—for practical reasons, they said—to exempt houses of worship from most of its provisions. A majority of congregations have fewer than 125 members, making the cost of major architectural changes seem prohibitive. Negative attitudes toward people with disabilities create less visible but equally daunting barriers. If members of a small congregation see no one with an obvious disability, they may think there is no need to take action—not realizing who may have been left at home by the family in the next pew, or in a nearby group home, wanting to come if only they were made welcome. A 2010 survey by the Kessler Foundation and the National Organization on Disability found that people with disabilities are less likely to attend religious services at least once per month (50 percent compared to 57 percent for those without disabilities): the greater the disability, the less likely they are to attend.

"They can attend school, hold down jobs and turn the key in the door of their own apartments," wrote Erin R. DuBois in *The Mennonite* magazine. "They have won the legal battle for inclusion, but by the time they land in the pew at church, they may be too exhausted to fight for something more precious than their rights. Friendship is a gift the law can never guarantee to people with developmental disabilities. Churches across the United States, however, are reaping the rewards of building genuine relationships with those in their midst who are epitomized not by their disabilities but by their rare abilities to deepen the congregation's spiritual life."

Congregations have responded in a variety of ways. Some still wait until renovation or new construction enables them to make their facilities fully accessible. Others are like St. Michael the Archangel Catholic Church in Levittown, which, with the backing of the parish priest and the Archdiocese of Philadelphia, built a coalition of disability activists, seniors, and young families with strollers to raise more than \$200,000 to build a new ramp to the sanctuary and an elevator to the basement social hall. At the other end of the spectrum, at East Goshen Mennonite Church in Indiana, all it took was a gifted woodworker to build a pull-out step for Barb Eiler, who was born with a bone disease that caused her short stature, which meant she couldn't be seen above the podium when she served as lector.

Sometimes no economic investment is necessary, and neither class nor race nor history is an insurmountable barrier. In the past year two accounts have appeared chronicling how young white men with disabilities in the South—one in the Mississippi Delta and another in Southside Virginia—found faith homes in black, working-class congregations.¹ In each case, the young white men benefited from the African American tradition of accepting people in their brokenness, and the ecstatic Pentecostal worship tradition of people shouting, speaking in tongues, and falling to the floor after being "slain in the spirit." Despite their intellectual, emotional, and physical disabilities, they could fully participate without drawing disapproving stares.

In the course of my research, the biggest revelation has been that there are converging streams of demography, war, and science creating a wave of people in need, a wave that is about to break at the doors of our faith communities. Despite our never-ending efforts to beat the clock, my own huge cohort of Boomers is aging into infirmity—with all the attendant issues of hearing, vision, and mobility, not to mention mental acuity. At the same time, military veterans are returning from Iraq and Afghanistan with missing limbs, traumatic brain injury, and post-traumatic stress disorder. And advances in neonatal treatment mean that babies born with severe and multiple birth defects are—or soon will be—living into adulthood.

No faith tradition or denomination will be immune from these challenges. Increasingly, people with physical and intellectual disabilities are advocating for themselves and others, and asserting their rights to be full participants in every aspect of life, including their faith lives, with family, friends, and caregivers in support. Beyond a catalogue of congregational best practices, what is emerging from my interviews is a mosaic of stories that I hope will inform, instruct, and illustrate what can be done. At the same time, I am trying to focus at least as much on people who cope heroically as I do on those who conquer—as inspiring as those like Maxwell and Landsberg may be. One of the themes of these stories is

that accessibility and acceptance have more to do with attitude and effort than with economics. I want people to read these stories and say: "We can do that in *our* congregation! / can do that!"

"Many religious organizations have yet to learn what many American families have learned," says the Reverend Joel Hunter, pastor of Northland Church, a large, nondenominational congregation in suburban Orlando with an extensive disabilities ministry. "That is, that the extra work it takes to accommodate those with obvious disabilities is the price of experiencing the kind of deep love and fulfillment that only comes with self-sacrifice."

There is a growing body of serious, theological considerations of disability. The same issues are also working their way into popular culture, reaching larger and broader audiences in the process. Inspiration is the preferred narrative. In 2000, the Disney Channel aired a made-for-TV movie, *Miracle in Lane 2*, starring Frankie Muniz. The heart-tugging feature, later released on DVD, is based on the true story of Justin Yoder, a thirteen-year-old boy with spina bifida and hydrocephalus, who prays for some way to triumph and, in the process of doing so, has a vision of heaven that includes people in winged wheel chairs.

Humor can be helpful, although it can also be disquieting. The late John Callahan, who was paralyzed from the neck down in a drunk-driving auto crash at the age of twenty-one, went on to a lengthy and successful career as a magazine cartoonist known for his exceptionally mordant view of life with a disability. He titled one of his collections *What Kind of God Would Allow a Thing Like This to Happen?*

The theological issue of disability was front and center in a two-part *South Park* episode titled "Do the Handicapped Go to Hell?" and "Probably." The show's four main characters are upset after hearing a fiery sermon in their Catholic church about hell "for those who do not accept Christ." Timmy, one of their friends, has severe cerebral palsy and is unable to say more than his first name. After consulting their clueless priest, the main characters fear Timmy will not be able to go to confession or participate in Holy Communion, and thus faces eternal damnation. "We can't let Timmy go to hell," says one of them. "We're going to have to do something," which in this case means baptizing their friend in a wintry front yard with a garden hose.

It is unlikely that when the prophet Isaiah wrote (11:6), "A little child will lead them," he had in mind one of *South Park's* pint-sized, potty-mouthed fourth graders. And yet, congregations may take the lesson about what caring friends can do to include people like Timmy in their faith communities.

Notes

- 1. Mark Richard's memoir, *House of Prayer No. 2* (Random House, 2011), and *The Year of Our Lord: Faith, Hope, and Harmony in the Mississippi Delta*(Mockingbird Publishing, 2010) by novelist T. R. Pearson and photographer Langdon Clay.
- 2. See Nancy Eiesland's *The Disabled God: Toward a Liberatory Theology of Disability* (Abingdon Press, 1994) and Stanley Hauerwas's *Suffering Presence: Theological Reflections on Medicine, the Mentally Handicapped, and the Church* (University of Notre Dame Press, 1986).

Mark I. Pinsky, longtime religion writer for *The Orlando Sentinel* and the *Los Angeles Times*, is author of *The Gospel According to The Simpsons* and *A Jew among the Evangelicals*. His work appears in *USA Today* and *The Wall Street Journal*, and he reports for BBC Radio 4.

Jewish Disability Awareness Month



February 2012

Jewish Disability Awareness Month

February is Jewish Disability Awareness Month (JDAM). UJA-Federation of New York recognizes the importance of increasing opportunities for all people to feel included in our community. You'll find numerous resources here related to inclusion programming that you can use throughout February and all year-round.

• There's a <u>Facebook</u> page celebrating Jewish Disability Awareness Month. Over 1,000 fans are sharing ideas and resources to celebrate diversity within the Jewish community.

UJA-Federation Beneficiary Agencies and Area Synagogues Celebrate JDAM

- Suggestions for <u>inclusion programming</u> (PDF). While the list was compiled from a planning workshop held at UJA-Federation in October 2007, these programs are timeless!
- UJA-Federation is hosting the fifth annual Hilibrand Autism Symposium on Wednesday, April 25, 2012. <u>Contact us</u> to be put
 on the information list when registration opens.
- Read how UJA-Federation's network and other Jewish agencies are providing services for thousands of New Yorkers in our Resource Directory for People With Disabilities.
- With UJA-Federation's support, the third annual <u>Reelabilities New York Disabilities Film Festival</u> will take place from February 9 14, 2012.

These are just a few examples of inclusion programming happening throughout our area.

National Organizations Celebrate Jewish Disability Awareness Month

The <u>Jewish Federations of North America</u> (formerly United Jewish Communities) has published the <u>Jewish Disability</u>
 Awareness Month Resource Guide, which includes many program ideas applicable to synagogues and human-service agencies.

To learn more about our work and synagogue inclusion programming, contact Diane Scherer at 1.212.836.1604 or scherer@ujafedny.org

February is Jewish Disabilities Awareness Month

Jay Ruderman

Thu, February 17, 2011





Hannah's mom never thought her daughter would find a Hebrew school that was right for her, much less have a bat mitzvah. But last June, after two years in an innovative bar/bat mitzvah class, Hannah, an honor student with Asperger's Syndrome, proudly chanted her Torah portion before 100 friends and family members.

Binny flashed a grin as he accepted his siddur at the ceremony with the other second-graders in his day school. But this moment could never have happened a decade ago for a little boy with Down syndrome.

Third-grader Justin was usually exploding in anger during Sunday school. Two years later, he performed an original song in front of the entire school.

These three Boston-area children — and their Gateways: Access to Jewish Education journeys — have much to teach us about Jewish continuity.

What's more, whether our generation engages — or fails to engage — the nearly 20 percent of Jewish children and their families who live with a disability, will determine how inclusive a community we will become.

We know Jewish education holds the key to our people's survival, and always has. Making sure every one of our children receives that birthright is a driving force behind my family foundation's partnership with Gateways, which makes Jewish education a reality for hundreds of children with special needs.

But as we mark Jewish Disabilities Awareness Month across the country, we're still up against a powerful enemy: ourselves. Although our tradition commands us to "teach a child according to his way," we've developed another tradition: Closing our eyes and looking the other way when someone doesn't measure up. The cost, we argue, is simply too high to include them.

For parents, learning to accept our children with special needs is hard enough. But when our Jewish community turns its back on us, when our schools and shuls aren't welcoming, it risks alienating all of us.

Locally, we have services in place for people with special needs — not enough, but it's a beginning. Our community demonstrates what a committed federation, foundations and other funders can do when we partner with direct service agencies to challenge the status quo of Jewish education for children with special needs in a broad range of educational settings.

Gateways, already Boston's central address for special needs Jewish education, is beginning to share its innovative model with other Jewish communities across North America.

Anyone who contributes even small sums is a funder, and the best way we can invest our resources is in high-impact organizations delivering long-lasting, transformative change for our people. When we begin to respect, accept and educate children with special needs, it reminds us of what we stand for, and we become the people our ancient tradition commands us to be.

Jay Ruderman is president of the Boston-and-Israel-based Ruderman Family Foundation.

March 8, 2011 | 7:58 pm

What does "inclusion" mean?

Posted by Michelle K. Wolf

Ben Azzazi taught: "Do not disdain any person. Do not underrate the importance of anything – for there is no person who does not have his hours, and there is no thing without its place in the sun" —Pirkei Avot

The word "inclusion" in a special needs context can mean many different things – for example, it can mean a physically accessible environment with ramps and elevators, which is very important to those with physical disabilities if they want to be able to literally come through the front door. It can mean having large print siddurim for persons with vision-impairments or having access to assistive learning devices for those who are hard of hearing or deaf. For children and adults who have behavioral challenges, it can mean being more tolerant of strange noises or gestures.

However, for most people with special needs and disabilities, the word "inclusion" is far broader. To quote my friend and mentor Shelly Christenson from Minneapolis and the author of <u>The Jewish Community Guide to Inclusion of People with Disabilities</u>

"Inclusion is the opportunity for people of any and all abilities to participate in meaningful ways within their community. The key word is *meaningful*."

Throughout Jewish communities in North America (and in Israel too), there are certainly more programs and services than ever before to include Jews with special needs (and their families), but all too often the efforts are fragmented, underfunded, and kept segregated from the "regular" programming for lack of a better word. Real inclusion goes much deeper than a special program; to be truly successful, inclusion must permeate every aspect of the institution.

For me, it is all about having a warm heart and an open mind.

Our 16-year-old son, Danny has multiple disabilities including cerebral palsy, and loves going to our synagogue, Beth Am, every Saturday morning. Is it because of the lovely special needs service called *Koleinu* ("Our Voices") which takes place every two weeks with a gifted and trained Jewish educator? Is it the chocolate doughnuts served at the kids services? Or is it the security guard I will call Mr. M?

Mr. M is not a special education teacher. He is not a rabbi. He's not even Jewish. But he knows how to light up Danny's face by saying, "Shabbat Shalom Danny Wolf—give me a high five" and then doing a fist bump (or two, or three...). It's a completely natural and welcoming impulse on the part of a synagogue employee whose job description most certainly does not state that his position will be in charge of "providing special needs inclusion".

Danny will go out of his way with his walker to find Mr. M, whether his station that morning is in the front of the synagogue, under a tree or in the parking lot, and believe me, Danny will do almost anything to get out of extra walking.

Overall the number of people with disabilities is around 20% and with the number of children diagnosed with Autism Spectrum Disorder still on the rise (the most recent CDC report states that 1 in every 110 children has been diagnosed with autism, including 1 in 70 boys), there is no question that the Jewish community has no choice but to be more inclusive of this growing population. The big question is how.

Mr. M. has shown us the way.

Mentschen

MARCH 22, 2011 · 8:14 AM

You Have Probably Never Met Anyone Like Me

by Jacob Artson

You have probably never met anyone like me who can't speak but can communicate by typing on the computer. I am an example of how someone can be impaired in one area but have great strengths in another. That is true of most people, but it is true in the extreme about people with autism.

When I was diagnosed at age 3, I couldn't speak or move my body properly, and 15 years later I am still extremely impaired in both areas. But if success is measured by being a mensch and helping make this world a better place, then I would classify myself as a success. You can be

the judges.

When I turned 6, my family moved to LA in search of opportunities for me. Our journey took us to many purported experts, but they all saw me as merely my extremely impaired verbal and motor abilities and assumed my cognitive abilities must be similarly nonexistent. After several months, me and my parents came to the last place on our list — the "autism doctor." I am not really sure what I was expecting, but Dr. Ricki looked nothing like I expected. She wore a fashionable sweater with a colorful necklace. But mostly I noticed her smile. I had been to so many doctors at that point I couldn't even remember all their names or specialties. But not one had ever smiled at me like Dr. Ricki. She kept smilling, watching and waiting for me. For the first time in my life, I was able to smile back. I stayed for an hour and we played with puppets, but mostly I was just watching Dr. Ricki in complete fascination. I had expected that she would have some medicine or treatment to prescribe and that would be the end of the appointment. But she said nothing about any pills or therapies. She just smiled at me for an hour as though I was a person worthy of respect and dignity. I had always thought of myself as a defective human being.

It had never occurred to me that a doctor would see me as a person with the potential to be a productive member of society.

At that transforming moment, Dr. Ricki taught me that despite my disability, I was as worthy of love and respect as any other child. That smile gave me hope, and hope gave me the motivation to begin the battle to conquer autism before it destroyed me. So I began my journey of millions of small steps. Along the way I found supporters as well as detractors, and the steps sometimes did not appear to be going forward, but I persevered because I had hope and people who believed I could fly. Today those steps brought me to blog for you.

So that is my story. I think it is also the story of many autistic kids I have met and many poor black and Hispanic kids I have known at school. I think most kids who fail do so for the same reason I did — I didn't believe I was capable or worthy of success.

What makes a child believe in himself or herself? These are the factors that have made a difference in my life:

First and foremost, my family has never wavered in their belief that I am a child of God with an equal claim to dignity and respect as any typically developing child. I know that it has taken a heavy toll on them, but it has been a lifesaver for me. My twin sister is my best friend, fashion consultant, role model and cheerleader. My mom has been my tireless advocate and my rock. My Abba, whom I adore more than anyone on earth, has given me a model to strive to emulate.

Second, I have been blessed to have many wonderful mentors throughout my life, including teachers, Dr. Ricki, my horseback riding instructor, the coaches at my basketball programs and, most recently, my new adult case manager. All these people believed I could achieve greatness despite my body's limitations and the naysayers around them. Kids with special needs don't need to be reinforced like dogs with good job and good listening and similar phrases as if we are in puppy obedience training. What we need instead is stimulation, patience, and someone to believe in us and notice our little triumphs.

Third, I have found great support in God and Torah. I think that people vastly underestimate the importance of spirituality for people with special needs. Of course I have some friends who are confirmed atheists, but many more for whom Judaism is a lifeline. My body and emotions are very disorganized, but the one time that my mind, body and emotions feel totally connected and in harmony is when I pray. I have also learned many important lessons from listening to my rabbis' sermons because we all need to live with meaning and know that we are not alone in our struggles.

Finally, Judaism has taught me the importance of gratitude. For much of my life, my existence was controlled by autism. Autism was at the root of every experience I had or didn't have. I lived with constant anger at my disability and fear that it would isolate me forever. Then one day several years ago, my wonderful physician and mentor, Dr. Ricki Robinson, asked me what is the opposite of anger. I realized that it is not the absence of anger, but rather acceptance, laughter and joy. I also realized that fear and anger just produces more fear and anger, while acceptance brings connection to God and humanity. For many years I had been praying for God to cure my autism and wondering why God didn't answer my prayer. I realized at that point that I had been praying for the wrong reason. I started to pray for the strength to accept autism and live with joy, laughter and connection. My prayers

were answered more richly than I ever imagined! Sometimes I still hate autism, but now I love life more than I hate autism.

But there is one part that is still incomplete before I can truly believe in myself and that is a sense of belonging. Everyone needs a sense of belonging and many of you probably are involved in your Jewish community for precisely that reason. In Los Angeles, there are now several wonderful programs for Jewish kids with special needs, and they deserve your support. My peers and I have been fortunate to have had inclusive opportunities in part due to the fact that our typically developing peers had to fulfill their community service requirements. But now my peers are adults too, so there are no more community service requirements and no one to reach out to all of us formerly cute kids who are now trying to make our way in the world as adults. I love my autistic friends, but I do not want to spend the rest of my life in a special needs cocoon.

So here are some "mensch" ideas I would like to propose for your consideration:

- 1. Inclusion isn't just about me, it is about everyone. I have seen the incredible stress my family has endured because of me, and being excluded from our Jewish community, or having to constantly fight to be accepted as part of it, has greatly magnified our stress. After ten years, we finally left our synagogue and joined a new one where people smile at me even if I am sometimes too loud or excited and no one stares at me like I am a piece of trash. The kids engage with me even when they are not getting community service credit for doing so. I often wonder how many non-disabled families have the same experience of feeling ignored in their synagogue. The truth is that a shul that welcomes me is a synagogue where everyone can find a place and people will want to join and be engaged and involved. This is not something a rabbi can do alone because one of the rabbis at our prior synagogue was and continues to be very supportive of me personally. A synagogue is a community and we all have to reach out to support each other.
- 2 The best peers and aides I have had didn't have any special background. It doesn't actually take any training to be a leader who models inclusion. It just takes an attitude that all people are made in God's image and it is our job to find the part of God hidden in each person.
- 3. My favorite Jewish holiday is Passover because it is the story of our people's journey from degradation to liberation. That is the story of my life and the lives of many of my autistic friends. Our lives are not determined by where we start. God lures us to find our gifts and to choose liberation. My journey has taken me through the desert and toward the Promised Land. I look forward to our journey together toward the day when we can all stand together at Mt. Sinai as one people, the day when everyone is included and together we bring God's glory to all of humanity.

Editor's Note: Please be sure to subscribe to Mentschen to receive updates on this post and on other thought provoking essays! It's easy, just go the subscribe link on the right side of this page!

My autistic child: Putting Ezra first

I'm grateful that scientists are focusing on autism. I'm going to focus on my son.

What matters most to a parent of an autistic child? (Illustration by Donna Grethen $\/$ Tribune Media Services)

by Tom Fields-Meyer

September 21, 2011

As the father of a teenage son with <u>autism</u>, I have coped with many challenges: finding the right school for a boy who can't sit still and has trouble connecting with peers; managing medications to help tame his anxiety and other symptoms; learning to negotiate endless one-sided conversations about my son's two obsessions — animated movies and animals.

But those demands have never annoyed me in the way The Question does. Rarely does a week pass without someone asking me: "So what do you think? What causes autism?"

This summer has seen a plethora of headlines on the topic. July brought news of a study showing an unexpectedly high occurrence of autism among fraternal twins, a finding that could implicate both genetic and environmental factors. Then new research revealed that younger siblings of children with the disorder have a 20 times greater chance of developing autism than the general population. Last month's story was British researcher Simon Baron Cohen's "assortative mating" theory. It speculates that parents who share certain tendencies — such as expertise in math and science — may produce children with a higher risk for autism.

So what's the parent of a living, breathing autism specimen to do with the constant barrage of speculation? My standard reply: I'm grateful that scientists are focusing on autism. I'm going to concentrate on my kid.

That's the simple answer. But it's actually more complex. When you read about studies on, say, <u>breast cancer</u> or juvenile diabetes, the objective is clear: to eradicate these awful diseases and save lives.

Autism, on the other hand, occurs on a spectrum. At one end are individuals who can barely communicate, can't care for themselves and seem lost in a constant blur of involuntary movements. At the other end are people with quirky dispositions, rigid personal habits and a tendency to speak and think obsessively about one or two subjects such as train schedules or insects.

My son falls somewhere in the middle: Ezra is verbal, but, at 15, he still tends to talk about the same things over and over: otters, <u>Pixar</u> movies, dog breeds. He doesn't rock or flap his hands much anymore, but his sensory challenges make it difficult to stay in one place, so he paces in math class and during recess while other kids are chatting with friends.

Like many people with autism, he also possesses a remarkable memory. He knows the running times of hundreds of animated films, has mastered the details of several animal encyclopedias and can recall the exact date in 2003 he first heard a woodpecker. Learning a new acquaintance's birthday, Ezra will charm the person by instantaneously announcing which Disney movie premiered on that exact date.

More important, he has remarkable enthusiasm for life, greeting days that are significant to him — the first of the month, for example, or the day of the $\underline{\text{"Cars 2"}}$ premiere — by running around the house before dawn shouting with infectious delight.

When I hear that, I wonder: Would we really want a world without such people? Or without biologists with underdeveloped social skills who can focus obsessively on a particular breed of newt? Or without certain brilliant software engineers who might not make great dinner party guests? (The ultimate irony is that the kind of person who has the obsessive focus to isolate the combination of factors that cause autism might just have a touch of it himself.)

I'm pleased that so much money and brainpower is going toward investigating autism. Thirteen years ago, when Ezra was 2 and first displaying signs of the disorder, research on it was rare and parents like us weren't typically

advised to be alert to its symptoms.

Now, thanks to advocacy groups like Autism Speaks (which merged in 2007 with the Los Angeles-based Cure Autism Now), the science is impressive. Fifty academic and research institutions are collaborating on the Autism Genome Project, the largest-ever study to find genes associated with inherited risk for autism.

Another program is tracking more than 2,000 infant siblings of children with autism to help discern environmental factors that might play a part. Few scientifically proven treatments are available to treat autism's symptoms, but now millions of private and government dollars are helping researchers to focus on finding them.

The increased understanding and public awareness this research brings can only be good.

As for our family, we often deal with our circumstances with black humor. Sometimes when Ezra has the flu or is knocked out by a fever, his behavior is radically transformed. Normally in constant motion, he slows down, cuddling quietly under the covers like any other sick kid. My wife looks at him, then at me, and smiles. "Maybe when he wakes up, he'll be cured," she says, as if some sci-fi movie magic could remove our son's autism.

It's our joke because we can't separate Ezra from his disorder. Nor would we want to. Ezra without the Pixar fixation, without the mental catalog of animal kingdom trivia, would not be Ezra. What would life in our house be like without a 15-year-old who wakes up once a month elated just because he gets to turn a new page on the calendar?

I'll be happy to know when they figure out the science. But I'll still be focused on my kid.

Tom Fields-Meyer, a Los Angeles writer and journalist, is author of the new memoir, "Following Ezra: What One Father Learned About Gumby, Otters, Autism, and Love from His Extraordinary Son."

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Travelers with Disabilities to Visit Israel

By Debra Kerper, Easy Access Travel



- <u>Easy Access Travel</u> is dedicated to meeting the special needs of travelers with disabilities and the mature.
- Have you always dreamed of visiting Israel but a disability or medical condition has led you
 to believe that this will never happen? Now you can visit one of the world's most culturally
 rich locales and have a totally accessible trip with experienced guides who understand your
 special needs!
- On our popular Israel Heritage Tour on February 27 to March 7, 2012, you will travel in air-conditioned lift-equipped vehicles and stay in accessible four star hotels. You can also rent scooters or other medical equipment when you arrive in Israel. Israel 4 All, our partner accessible tour company and, in particular, Tour Guide Eli Meiri, will ensure your experience is both fun and unforgettable.

- In the words on one client when he returned from this same tour in May, "I loved our trip to Israel, and would recommend Eli, Israel 4 All and Easy Access Travel without reservation. Eli knows Israel, and visiting the sites was enriched by his commentary on what we were seeing. But it was more than his knowledge that made the trip so enjoyable. His love for the country and its history is evident and infectious. This added to our appreciation of the places we visited. He also is very skilled and caring in working with people with disabilities. He knows what is accessible and what isn't, and works hard to see that we in his group got the most out of our experience. Finally, and certainly not least, he has a big heart. He gave us more than we expected, and I think we will stay in touch for years to come."
- I think that says it all....won't you please join us?
- We are currently offering space on our Israel Heritage Tour, February 27 March 7, 2012. For full itinerary and prices, please call (800) 920-8989 or email Debra@easyaccesstravel.com. Other tours which are geared to Christian and Muslim faiths are also available, as well as Bar and Bat Mitzvah Tours for families touring with a person with a disability.
- For more information, visit <u>www.easyaccesstravel.com</u>. We look forward to traveling with you!

Dear Son

A Letter of Support to My Special-Needs Child

By Hinda Schryber

Dear Son.

You got sent home from school today.

For being fifteen minutes late.

You got sent home because that was the only way the school knew how to deal with you.

Believe me, I wish it did not have to happen.

I know you packed your bag and brought all your belongings home.

I know.

I know that is a sign of how "wronged" you felt.

Son, I know what this school means to you. I know that even getting there for six whole weeks has in itself been an enormous achievement.

I know how afraid you were to go.

I know that you have not been in school for six years, not been able to keep a job, not really done anything.

I know how you felt about yourself.

I know you felt you could not do anything; I know you feel you are mentally disabled.

I know they didn't have a reply for youl also know that you struggled as a young child to keep up.

I know you were diagnosed with severe learning difficulties.

I know that the tests showed you have a seizure every three minutes for three seconds.

I know and you know.

I know how you felt when your father was diagnosed with cancer.

I know how afraid you were.

I know. I know.

I know you finally felt accepted.

I know you finally felt the teacher found something in you.

I know how proud you were of yourself when you said you had done something good.

I know you felt good because you got up and you went, and no matter how hard it was, you persisted.

I know you asked the school before you left today "if they knew what they were doing to a kid who had really been trying so hard."

I knew you were asking them if they knew how hard it has been and how well you have done.

And I know they didn't have a reply for you.

I know you kept your mouth shut and could have said a lot more.

I know what you could have done.

I'm your mother, I know.

There are very few people who understand what it is to be different

I also know, son, that there are really very few people who understand what it is to be different.

What is means to be in a world where it is a struggle.

What it means to change a lifestyle.

I know, you know, but they don't know.

And because I know all of this, I also know that you can survive this.

That you can take that filled bag right back in there.

And you can know, in full confidence, that you can do it.

I know you—you are not a quitter.

You are not "tardy"—as they called you—by nature.

You are a real survivor.

I know that you have gotten yourself this far, against the odds.

And you and I know that you are not going to give up now.

So hang on in there, my son.

Life is tough, and there are rules.

And you have to keep them.

And know one last thing.

And that is that you are not alone.

And He who is guarding you knows your struggles and your efforts and your amazing achievements.

And after you understand that, there is nothing more to know.



March 30, 2011 | 9:35 pm

A long anticipated birth: J-CHAI: Jewish Community Housing for Adult Independence

Posted by Michelle K. Wolf

"Everyone came here tonight for a reason," said Dr. Michael Held, Founder and Executive Director of the Jewish special needs non-profit Etta Israel, "whether you are a parent, a potential resident, or a sibling or other relative of a Jewish adult with developmental disabilities." The 70 participants, some wearing head coverings and many not, looked around the room exchanging knowing glances, a collective sense that we are all on the same quest to find a "home" for our loved ones with special needs when it is time for them to leave the nest.

A new innovative independent housing program called **J-CHAI** was launched by the Etta Israel Center Tuesday night in the boardroom of the Los Angeles Jewish Federation, funded in part by a \$200,000 three-year Cutting Edge grant from the Jewish Community Foundation of Los Angeles.

Dr. Held explained that this new housing model was based on four years of research and discussion (including input from the Federation's Task Force on Housing for Jews with Special Needs), and took into account many current trends.

First of all, more adults with developmental disabilities and their families are seeking a higher level of independence than afforded in traditional group home settings (Etta Israel also operates 3 Jewish group homes in North Hollywood and a fourth is in the works). This desire for greater autonomy is accompanied by the fiscal realities of California — more people are now diagnosed with developmental disabilities- and the average costs of each client is increasing as more of the state caseload reaches adulthood along with the mounting

So what exactly is J-CHAI?

It probably helps to begin with what it is not. It is not a building. It is not a kibbutz-style arrangement. And it will not be the same for every participant.

J-CHAI will help families find regular market-value apartments clustered in the Pico-Robertson area, as well as finding an appropriate roommate, and then with its staff, establish both independent living and Jewish life goals for each resident. As Dr. Held joked, "J-CHAI keeps the 'J" in your child's Chai (life)." For the first time in their lives for many of these Jewish adults, targeted at ages 18-35 (and older, on a case-by-case basis), They will have the ability to exercise control over their lives in such areas as community, communication, empowerment/independence and Jewish values.

Each participant's schedule will be individualized, with most residents either engaging in vocational training, educational opportunities or working, depending on their abilities and skills. Through the state-funded Regional Centers, many will receive ILS (Individual Living Skills) or SLS (Supported Living Skills) in such areas as money management or travel training. Those with more significant behavioral or physical challenges may get IHSS hours (In Home Supportive Services) funded by the state, provided the program is still available.

With this innovation and higher level of independence come costs. Families will have out of pocket costs –the costs of rent (shared by a roommate), a sliding scale J-CHAI fee of \$1,200-\$2000 month, and everyday costs of food, utilities, etc. Government funding such as SSI (Social Security Income) can help defray some of the costs. The estimated range is \$2,300-3,600 a month, with the hope of attracting other funders down the line.

The program is designed to provide ongoing support, year after year, All participants are asked to commit for a minimum of one year to be accepted into the program; this commitment will help create with the central goal of building a strong sense of community among the residents.

One of the parents who spoke during the presentation said that her son, now 30 years old, lives in one of the Etta group homes and lives a "full and wonderful life". Most of all, she said, she is filled with gratitude and peace of mind.

Isn't that what every parent wants for their grown children?

THE WHITE HOUSE

Office of the Press Secretary

For Immediate Release

December 2, 2011

INTERNATIONAL DAY OF PERSONS WITH DISABILITIES, 2011

BY THE PRESIDENT OF THE UNITED STATES OF AMERICA

A PROCLAMATION

On International Day of Persons with Disabilities, we recommit to ensuring people living with disabilities enjoy full equality and unhindered participation in all facets of our national life. We recognize the myriad contributions that persons with disabilities make at home and abroad, and we remember that disability rights are universal rights to be recognized and promoted around the world.

For decades, America has been a global leader in advancing the rights of people with disabilities. From the Americans with Disabilities Act of 1990 to the Twenty-First Century Communications and Video Accessibility Act, which I signed last year, we have striven to bring the American dream and comprehensive opportunities in education, health care, and employment within reach for every individual. These actions -- made possible only through the tireless and ongoing efforts of the disability community -- affirm our commitment to an equitable and just society where every American can play a part in securing a prosperous future for our Nation.

To fulfill this promise not only in America, but around the world, my Administration is putting disability rights at the heart of our Nation's foreign policy. With leadership from the Department of State and the United States Agency for International Development, we are collaborating across governments and in close consultation with the global disabilitycommunity to expand access to education, health care, HIV/AIDS prevention and treatment, and other development programs. In 2009, we signed the Convention on the Rights of Persons with Disabilities, which seeks to ensure persons with disabilities enjoy the same rights and opportunities as all people. If ratified, the Convention would provide a platform to encourage other countries to join and implement the Convention, laying a foundation for enhanced benefits and greater protections for the millions of Americans with disabilities who spend time abroad.

We know from the historic struggle for disability rights in the United States that disability inclusion is an ongoing effort, and many challenges remain in securing fundamental human rights for all persons with disabilities around the world. On International Day of Persons with Disabilities, we press forward, renewing our dedication to embrace diversity, end discrimination, remove barriers, and uphold the rights, dignity, and equal opportunity of all people.

NOW, THEREFORE, I, BARACK OBAMA, President of the United States of America, by virtue of the authority vested in me by the Constitution and the laws of the United States, **do hereby proclaim December 3, 2011, as International Day of Persons with Disabilities**. I call on all Americans to observe this day with appropriate ceremonies, activities, and programs.

IN WITNESS WHEREOF, I have hereunto set my hand this second day of December, in the year of our Lord two thousand eleven, and of the Independence of the United States of America the two hundred and thirty-sixth.

BARACK OBAMA

FRIDAY, DECEMBER 3, 2010

Hanukkah, Autism and One Temple's Run at a Miracle

Just a wonderful story from The New York Times. Sad beginning, but a happy ending.

On these days of Hanukkah, as Jews light the menorah's candles, they recite a blessing for miracles of the past, for enemies vanquished and for lamp oil sustained. What might constitute a Hanukkah miracle today depends, perhaps, on what one needs and what one asks. It could even happen on the Upper West Side of Manhattan.

Early in the summer six or seven years ago, Nancy J. Crown set about looking for a part-time job for her teenage daughter, Sadie. By now, as both a mother and a psychologist, Ms. Crown was all too familiar with the struggle of finding any person, any program, any place suitable for a child with autism.

Doctor, dentist, swimming lessons, vocational therapy, tutoring, ballet, even a pair of shoes without buckles or laces – every part of Sadie's life, it sometimes seemed, plunged Ms. Crown into a lonely quest. At the lowest moments, she told herself, "I am not allowed to die," because then who would take care of Sadie?

POSTED BY LUBERMAN AT 2:03

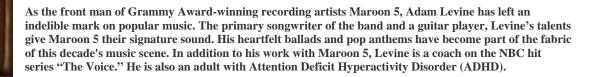
Adam Levine Talks About ADHD

By Keath Low, About.com Guide

Updated October 19, 2011

Adam Levine, lead singer of Maroon 5 and mentor on NBC's The Voice, shares about his own experiences with ADHD in hopes of raising awareness about ADHD especially among young adults and adults.

 $Photo © Jesse \ Dylan$



Q: I understand you were first diagnosed with ADHD as a teenager. What kinds of difficulties were you having that lead you to see a doctor?

Levine: Throughout my life, I struggled with ADHD. I had the symptoms of ADHD – inattention, and hyperactivity/impulsivity. It was hard for me at times to sit down, focus and get school work done. I was frustrated because of the challenges I was having in school. I was really struggling.

Q: What were your thoughts about ADHD when you were first diagnosed?

Levine: My doctor diagnosed me with ADHD in my early teens. What was really helpful to me was learning that this was a real medical condition – I had ADHD. The diagnosis helped explain the challenges I was having in school, including my difficulty focusing, sitting down and getting my school work done.

Q: Is there anything you'd like to share about what it was like growing up with ADHD? What it was like at school? With friends? Whether there were any family members or teachers who made a big difference in your life?

Levine: During high school I was a well-rounded kid and I don't think my peers noticed that I was different in any way but personally I struggled with academics, even though I knew I was fully capable of performing well in school. My parents were so great and supportive while I was growing up. They were really patient with me, especially when helping me devise a plan along with my doctor so I could move forward with a treatment that worked for my life.

Q: How has ADHD impacted your life as an adult?

Levine: As a young adult and adult, I continued having difficulty in the studio as I was trying to write new songs and focus to complete my work. On the first album I remember very distinctly being stuck and not being able to focus. And I had 30 ideas floating through my mind and just couldn't document them. I went back to the doctor to discuss my symptoms and learned that I still had ADHD and that it could affect me as a <u>young adult or adult</u>. Once I knew that I still had ADHD, I was able to work with my doctor to help manage my symptoms. What is surprising to many people is that ADHD is not just a childhood disorder – it also affects an estimated 10 million adults in the US.

Q: What has been most helpful for you in regards to managing symptoms?

Levine: Finding out that I still had ADHD and working with my doctor to come up with a treatment plan that works for me has helped me manage my ADHD.

Q: What is the Own It public service campaign?

Levine: "Own It" is a campaign I'm working on with the Attention Deficit Disorder Association (ADDA), Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD) and Shire to help those who were diagnosed with ADHD as a kid to recognize that their symptoms may still affect them as young adults and adults and to encourage them to get reassessed by their doctor.

Q: Is there any advice you'd like to share with kids or teens with ADHD, their parents, teachers, or other adults with ADHD who may still be trying to find their way?

Levine: If you were diagnosed with ADHD as a kid, you might still have it. If someone thinks they may have ADHD, they should talk with their doctor about it. There is a helpful website, www.OwnYourADHD.com, where they can take a quick ADHD quiz and then discuss the results with their doctor. I would also remind young adults and adults that ADHD isn't a bad thing and that they shouldn't feel any different than kids without ADHD. Always remember there are others going through the same thing.



Surviving the holidays: Dealing with relatives

Special needs families are far from typical. so why do we try to be that perfect "Norman Rockwell" family during holiday get-togethers? Tell yourself right now that you and your family are going to enjoy the holidays in your own way and at your own pace. Stop worrying about what others think and make the holidays meaningful for your child with special needs. Here are holiday issues that might come up and some creative ideas to make it work for your family.

by Dawn Villarreal, One Place for Special Needs



Keep a level head

At family gatherings you may be with relatives who you see only once a year. Relatives who are not familiar with your child's disability may make well meaning but misinformed comments. Some may make comments that appear insensitive and rude. Try not to let it ruin your day. Focus on your child and resist the urge to snap back. Turn the conversation into something positive. Prepare ahead of time by anticipating what certain relatives might say to you.

Deflect the comment

Relative - "When is Johnny going to eat something besides mashed potatoes?"

You - "You make them so tasty he can't stop eating them. How do you make them so creamy?"

Empathize with the relative

Relative - "Your son didn't even look at my present."

You - "I know you feel disappointed but I know he'll enjoy it at home tomorrow when things quiet down. I'll let you know how he likes it."

Focus on the positive

Relative - "When's Johnny going to talk?"

You - "It's hard because there's so much going on but Johnny has really come a long way. He's even reading now!"

Forced politeness

Relative - "Why can't you make your kid sit still at the table? Everyone else is behaving."

You - "On a regular day I might push the issue. But today is a special day and I want Mary to enjoy her time here."

Help others interact with your child

You have been living with your child's disability everyday but your relatives know little about your child and her special needs. Some may be unsure how to communicate with your child. Help them interact so they can see what a great kid she is.

Teach others about your child's equipment

You - "Mary uses a communication device. I know she'd love to talk to you. Let me show you how it works."

Encourage your relatives to ask your child about his special interests

You - "Johnny really loved our trip to Disney World. If you ask him, he'll tell you all about it."

Tell relatives how to phrase their comments to your child

You - "Mary has a hard time answering those kinds of questions. If you give her a choice or make it a yes or no question, she'll be able to answer."

Reserve what someone has said if they talk to you rather than to your child who is sitting within listening distance.

Relative - "So how is Johnny doing in school?"

You - "Johnny, why don't you tell Uncle _____ about your chorus class."

Explain behaviors that might seem odd to others

You - "When Mary makes those sounds, she's really excited but can't put it into words."

Create a cheat sheet for relatives on how to interact with your child

Here are many disability awareness resources to help get you started.

Ask for accommodations

Just as you would ask for accommodations at a restaurant or public place, you are well within your rights to ask for accommodations at a relative's home. Please be tactful when asking for these special considerations as your relative is also stressed from preparing for the holiday get together. Focus on your child rather than simply demanding that a family member make accommodations. A phone call several weeks in advance of the get together is appropriate. Here are some examples:

Physical limitations

You - "I feel bad when Johnny is left in the family room by himself and we all leave to eat in the dining room. I know it's an imposition but could we have an extra table put in the family room closer to dinner time? You can put me in charge of that job. Then family members have a chance to spend some time with Johnny."

You - "Mary has a hard time navigating in your home with her wheelchair. I know it's an imposition but could you move your end table to another room for that day? This would give her the chance to move around better.

Sensory issues

You - "Johnny's sensory issues are so bad that he really can feel sick from strong smells. I know it's an imposition but could you put out unscented candles this time? Then he can enjoy himself at your home."

You - "Mary gets overwhelmed by all the excitement during the opening of presents. Could she watch TV in your bedroom during that time? Then she can open her presents at home where it's more quiet."

Your own accommodations

Don't forget about your own needs during the holidays. It is important to stay both physically and emotionally healthy for your child.

Sharing the responsibility

One parent should not have to handle all of the needs of your child with disabilities. In a two parent household, make arrangements ahead of time on what each of your job responsibilities are at the family event. Taking turns allows each of you to spend some quality time with your family.

Volatile family situations

A few families may experience a particular relative who is verbally abusive to a parent. This relative makes irrational and insensitive comments on your child rearing and may even blame you for the child's disability. While some parents may have a thick skin, you should decide ahead of time if it is worth the stress on yourself and your child to attend this family function. It might be better to create your own dinner with friends who support your family. Find opportunities to visit with other relatives at a later date.

Special needs families learn from each other. Please share your own strategies for family gatherings on our forum or email us at info@oneplaceforspecialneeds.com. We'd love to hear from you!

Other resources

Coping with stress - Over 50 resources on handling stress when you're a special needs parent

Explaining disabilities - Resources explaining various disabilities to family members

Family gatherings - Many helpful tips and articles on helping your child manage his behaviors during family gatherings

Relative issues - Articles and essays on dealing with a variety of relative issues

Surviving the holidays: Family dinners - Our article on handling a variety of special needs issues at the dinner table



Dawn Villarreal runs One Place for Special Needs, a national disability resource that lets you find local and online resources, events and even other families in your neighborhood plus thousands of online disability resources! Stay awhile and check out the site. She is also moderator of Autism Community Connection, a Yahoo group for families in Illinois. Reprint permission granted by including: Reprinted with permission from One Place for Special Needs http://www.oneplaceforspecialneeds.com