

# Michael's Voice



## *A Quarterly Newsletter for the Michael Boussina Inclusion Program*

The Michael Boussina Inclusion Program provides education, programs and resources that encourage inclusion of special needs children and adults. This program is named in honor of Michael and is dedicated to providing a voice for him and others who cannot speak for themselves.

The MBIP is a 501K non-profit organization.

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A recent picture of Michael



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# Keeping Up With Michael



5th Grade Graduation Ceremony



Graduation celebration with proud family



Father-son love of baseball



Jewish Special Needs Family Camp



School Friendships



Bike Riding at School Recess



## Spotlight On:

### Jewish Learning Works & Include Family Camp

#### About Jewish Learning Works:

Jewish Learning Works (JLW) advances Jewish learning that enriches lives, and that enables the learner to flourish as a human being and as a Jew. JLW accomplishes its mission by empowering educators and parents and by operating the Jewish Community Library. For over 100 years, JLW has served as an essential foundation for Jewish education in the Bay Area. Today JLW builds on that rich tradition with a refined focus. JLW also provides professional learning for Jewish Educators. They employ the best thinking from inside and outside of the Jewish world to develop Jewish education that serves the needs of 21st-century students. By supporting parents, families are empowered. Parents are the ultimate Jewish educators. JLW applies the wisdom of our tradition to deepen their impact on families, the community, and the world. JLW is supported by the Jewish Community Federation & Endowment Fund, private foundations, individual donors, and fees for tuitions and service.

The JLW offers resources for the community and parents, including:

**Special Needs Inclusion** - Jewish LearningWorks serves families with children who have special needs. With the goal of fostering an environment of warmth, acceptance, and meaningful inclusion in the Jewish community, JLW provides resources and training to educators to develop programming designed with the needs of different types of learners explicitly in mind. They host Special Needs Family Camp, have produced activity pages for kids, host workshops for educators and have a robust online resource for families with children with special needs.

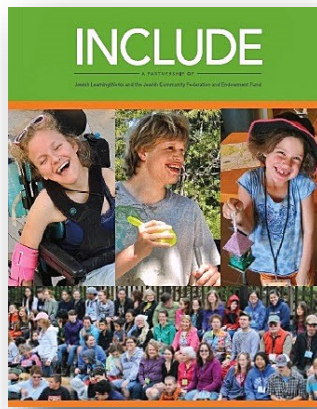
To learn more about the ways we're empowering parents, email Deb Fink - [dfink@jewishlearningworks.org](mailto:dfink@jewishlearningworks.org)

**@Home Parent Guides** - These printable resource guides support parents with young children as they enrich their families' celebration of holidays and their experience of Jewish life. They empower parents with "how to" information crafted with pluralistic, inclusive and nonjudgmental language. Through stories, songs, art, movement, recipes and social action projects, families explore traditions, values, rituals, community engagement and more. The JLW's concierges build relationships, offer consultations, provide skills training, and refer parents to educational programs through local Jewish organizations. Parents report that this one-on-one support is pivotal in helping them build Jewish homes.



*Michael enjoying time with a JLW Camp counselor*

For more information on Jewish Learning Works visit [www.jewishlearningworks.org](http://www.jewishlearningworks.org)



**JLW: INCLUDE Family Camp** - Every spring and summer, The Jewish Learning Works offers programs filled with outdoor games, arts and crafts, hiking, yoga, music & more! Located at the lovely Walker Creek Ranch on 1700 Marshall Petaluma Road in Petaluma, CA, the Family Camp is sure to be nourishing to the mind, body, and soul.

Each year, children with special needs and their siblings, parents, and grandparents enjoy three days of community, creativity, and fun in a Jewish setting at Special Needs Family Camp. Together they participate in Jewish communal and lifecycle events and worship services. They attend workshops, relax, find support, and share experiences.

INCLUDE Family Camp is a magical weekend for all attendees. It gives families the chance to play and recharge while strengthening their ties with Judaism and meeting and bonding with other families who share the same joys and challenges. Siblings and campers challenge themselves and make new friends while engaging in outdoor and indoor activities with the support of trained staff.

It's important to note that the family camp truly does mean **FAMILY!** The JLW recognizes the problem of siblings of those with disabilities feeling neglected. Siblings are at a greater risk than average of developing emotional issues, anxiety, and stress. They may also become overly responsible or protective of their brother/sister at the expense of their own well-being. By acknowledging siblings' unique situations and roles in their families, the family camp practices inclusion even for those who don't have disabilities.

"Normal" school and after-school programs can seem like an out of control merry go round to children with special needs. Confusing instructions, activities at a breathless pace, vague expectations—all of these can lead to an overwhelming sense of panic and isolation for children dealing with everything from autism to sensory processing issues. "A tone of voice that sounds normal to typical students may come across as urgent or frustrated to those with special needs," David Neufeld, director of special needs activities at JLW explains. Jewish institutions try to include all Jewish children, but a lack of specialists still leads to misunderstandings and feelings of exclusion. One mom, whose son was diagnosed with ADHD and anxiety, commented:

"We were shushed by other congregants, kind of shamed and shushed [and ejected from child care during High Holy Day services]. We were kind of feeling like we were being kicked when we needed support."



## **JLW: INCLUDE Family Camp ... Continued**

Here's where Jewish Learning Works' INCLUDE program comes in! The INCLUDE program (which is currently under expansion) helps Peninsula-area synagogues, preschools, and day schools serve children of different abilities (the program soon will expand to the East Bay and Marin). Neufield explains that "simple steps, like creating a quiet room where children can retreat during services or community events if they feel overwhelmed, can make a huge difference in making families feel supported and welcomed." He further recommends that institutions "raise awareness about disabilities, so if a child is being noisy, for example, others in the community will not interpret it as misbehavior."

**Sadly, there will be no Include Family Camp in 2019  
Please support JLW: INCLUDE Family Camp for a possible return in 2020**



**Color and texture stimulation experience**



**Camper Comradery (Michael in front row)  
During School Field Trip**



**Michael experiencing the joy of riding a horse**



# Diane Miller Assistive Technology Story Books Program

Part of the Michael Boussina Inclusion Program



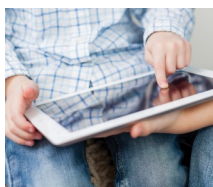
The Story Books Program will provide accessible books to communicate with, educate, empower and inspire individuals with special needs. This program is named in honor of Michael and is dedicated to providing a voice for him and others who cannot speak for themselves.

Communication is the sharing of thoughts, experiences, feelings, and information. Effective communication is primary in the life and dignity of each individual. Literacy - the reading and sharing of books, is important to develop and support communication skills. Books are not always easily accessible for individuals with physical and learning challenges.

A vast majority of the books chosen to be recorded and provided to the community through the Story Books Program are PJ Library books. **PJ Library [run locally through the Jewish Federation of the Sacramento Region (<https://pjlibrary.org/About-PJ-Library>)]** sends traditional format children's books to Jewish families every month. PJ Library shares Jewish stories that can help families talk together about values and traditions and relate them to personal experiences. People learn about the world around them through stories. Books encourage us to dream. Stories give us smiles. The program goal is to assist individuals by recording books and capturing the illustrations in a format that can make the stories accessible to individuals who cannot independently enjoy reading. For example: on a computer, a child with physical challenges can use a switch to turn the pages of a book, to listen to the words and to see the pictures. The books are prepared by young volunteers. Books and flash drives will be available to identified individuals.

The literacy experiences of reading and sharing books develop and support relationships, communication skills, shared experiences, traditions, values and personal connections.

**A shared voice!**



***This program is an ideal opportunity for community service and/or B'nai Mitzvah projects!***

Please contact Dee Miller at [diane4ac@gmail.com](mailto:diane4ac@gmail.com) or Taliah Berger at [taliah@mbiprogram.org](mailto:taliah@mbiprogram.org) for more information.

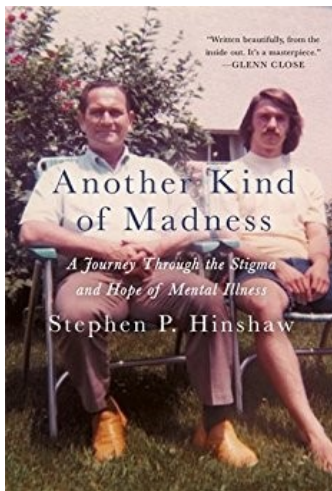
Please consider joining our team

## Book Review

### **“Another Kind of Madness: A Journey Through the Stigma and Hope of Mental Illness” by Stephen Hinshaw**

**By Cynthia Brideson**

*What if Dad never came back? The fear gripped me like the slow, inexorable tightening of a rope, squeezing the air from my lungs. The worst part was that no one ever talked about it.*



*Cover of the book  
showing Hinshaw and  
his father*

***Those coping with  
physical and  
developmental  
disabilities face the  
same devastating  
stigma as those with  
mental illness.***

***End Stigma today!***

Hinshaw's masterful memoir leaves a trail of such foreboding remarks, and yet, the book is indeed inspiring. Through his account of living with his father's struggles with bipolar disorder, Stephen Hinshaw (who, in 2007, wrote the first book in the US about the stigma surrounding mental illness), tells an intricate story of how the lack of openness about mental illness affected himself and each member of his immediate family. Not since Judith Guest's *Ordinary People* has a book so intimately shown the damaging effects of silence and repressed emotion. Hinshaw tells the story of his own life, too, recounting his youth in the Midwest filled with school, sports, friends, and perplexing disappearances by his dad for weeks to months at a time. Hinshaw's mom stoically held the family together and shielded the children for the reasons why their father was gone (stays in hospitals for treatment of bipolar disorder). Well before Hinshaw's father revealed the real reasons for his absences, the impact of the secrets were influencing Stephen. Once his dad finally confided the truth to his son, over the course of years, Hinshaw shares how the truth—a shock, yet a relief— influenced his own life and career.

This book is both a family story and a psychological study and can be appreciated by those who love a good story as well as academics. Above all, the book allows readers to discover that mental illness does not mean the end of a fulfilling life. It is just a *part of* a fulfilling one that can be ever more fulfilling with the erasure of, in Professor Elyn Saks's words, “the pervasive stigma that still clings to mental illness.”

—**Stephen Hinshaw** is a professor of psychology at UC Berkeley and the Vice-Chair of Psychology at UC San Francisco.



*Stephen Hinshaw*

## Culture

### How Comic Books Help Youth With Autism

Written by Cynthia Brideson



*Portions of this article were taken from an interview posted by Michael Barnes on [learnfasthq.com](http://learnfasthq.com) on January 6, 2015.*

Imagine that you can't discern another's motives, expression, or actions. It's like you're watching a mime, but his expressions and gestures do not align with what you assume he is trying to communicate. If only people had thought bubbles above their heads, you might sigh.

Many children, as well as adults on the autism spectrum, find themselves in this predicament. Perhaps this is why a great many of them find comic books not only enjoyable and easy to understand but also useful learning tools.

Dave Kot, the founder of the non-profit organization "Autism at Face Value," is on the high functioning end of the autism spectrum. He has created a comic book, FaceValue, tailored for those with autism. The comic book serves a dual purpose: to allow those with autism to feel included/represented and to teach empathy to their neurotypical peers. Kot has written the first comic book in the world with a hero who has autism.

Kot says, "At worst, the comics are just family fun and entertainment. At best, autistic kids have a hero like themselves. They can understand what autism is or what it isn't, relate to situations and be open to positive communications about autism". The comic stories are set in the future, in the year 2072, and include an interesting cast of characters. Michael is the main character, and he interacts with an array of bullies, crime fighters, and friends/fellow people with autism.

Kot uses a number of literary devices to tell the stories and communicate with autistic kids. These include one he calls a "social throat punch commentary" in which the text in thought bubbles and even complete pages are upside down. That is his attempt to have readers look at an individual with autism differently than they may have expected. The faces of some characters have been deliberately drawn to emphasize the facial features of people with various emotions like anger, fear, surprise, and sadness. This is designed to help kids with autism better recognize emotions in others to help their understanding and communication. Kot says: "With my clients, I would look over what their general presenting problems would be - bullying, anxiety, depression and so on. What we did during sessions, on sheets of scrap paper, notebook paper, or whatever was available, was to describe the facial features of individuals or even the clients themselves using mirrors, and role-playing between us. I started to teach the kids self-regulation, recognizing those body triggers for when they were feeling sad or angry themselves. And building that through social learning theory, found it to be a very effective technique. I was able to typically discharge clients a little sooner than most.



I kind of built a reputation of being able to develop a very succinct, almost common sense approach to understanding others' expressions and build empathy. What I was really happy with was something I hadn't predicted would happen. I saw kids begin to build predictive empathy.

They started making those connections. I was really impressed that this simple, intuitive idea is multicultural, does not discriminate against age or gender. A person in Australia who is angry looks like a person in Alaska who is angry.

So we started to take those ideas and made them into a comic book using the "steam punk genre". It's an interesting blend of the Victorian era, England modernity. So it just gave us an opportunity to play with history, to play with new science, and time travel.

So by 2072, we'd cured lots of diseases. We'd cured poverty and hunger, and a lot of the social ills of the world. Mankind had learned from its mistakes and decided to put all efforts together to make a better society.

But the one problem we still have is prejudice and misunderstandings. So that is where the Zephyr comes into play. Zephyr is actually Michael from the future.

During this inter-galactic invasion, he goes back in time to save himself. So when we talk about having the first featured comic book hero with autism, yes, it is a little school-aged boy, but it is also the grown crime-fighting, costumed hero, the Zephyr."

Kot goes on to explain:

"I wanted kids to be able to talk about autism. We understood that looking at a lot of resources, there is very little to provide a young person with autism to explain how autism might be. And in our comic books, we include activity pages, everything from finding the number of spy bots throughout the issue to questions to ponder like: who's the worse bully, Edge or Claudia?"

We're taking this as an opportunity to really focus on sensory perceptions and challenges. The character will overcome some of the sensory overload challenges inherent in his autism to still be a hero and still save the day.

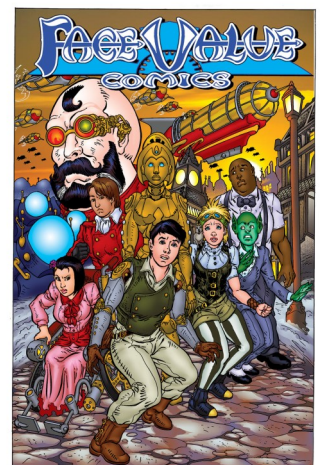
What does it feel like to be me, a person with autism who is writing these comic books?

... I've been fighting insomnia for a while now. And there's a good reason. I can't seem to turn off my brain sometimes. That's some of the challenges inherent in my autism. I was diagnosed as an adult later in life.

For me, that's more of an "Aha!" moment when I began to understand why some social relationships and experiences seem like failures. It wasn't a failure. It was just the wrong way of doing it at that time.

I could have been more successful by applying other strategies, but I just kept putting my head against the wall and thinking that was the only way to get a girlfriend or to get a job or things of that nature.

And the social challenges that I experienced I'm now learning that there's never just one solution to a problem. You can look at it from multiple angles and being a professional helper helping others, I also



*The cover of FaceValue showing various colorful characters.*

helped myself to see some of these opportunities that are available.”

“There is nothing I would change about myself,” he says. “Autism is a part of who I am. How I see things,” he says. Kot didn’t receive his diagnosis until he was an adult.

FaceValue’s first issue was a smash and was picked up by Diamond, The biggest comic distributor in the world. The second issue of Kot’s comic book expanded to feature a non-verbal autistic female character, Myra.

“I wanted to address issues related to girls with autism,” Kot says. “Girls are often diagnosed later or are often undiagnosed. “Myra wears black in public. Most of society doesn’t see her. At home, she wears a bright rainbow-colored kimono.”

Kot concludes that the primary lesson taught in his work is: “Feel safe, feel wanted, and you’ll be successful.”



*Myra playing the flute with tropical birds around her.*

## Graphic Novel Available in MBIP Collection

### “El Deafo”



The MBIP is proud to carry the 2015 Newbery Honor Book *El Deafo*. The book, an autobiography of a deaf girl in comic book form, shows the trials and travails she faced going to school and making new friends. Wearing a bulky hearing aid strapped to her chest certainly made acceptance more difficult to find. This funny, visceral book chronicles author Cece Bell’s hearing loss from meningitis at a young age and her experiences with the Phonic Ear, a powerful, but painfully awkward, hearing aid. The Phonic Ear gives Cece the ability to hear—sometimes things she shouldn’t—but also isolates her from her classmates. She wants to be normal, whatever that is, and find a true friend who doesn’t want to change her. After some mishaps, she triumphs, harnessing the power of the Phonic Ear and becoming “El Deafo, Listener for All.” She finds a place in the world and discovers the kindred spirit she’s been looking for.

Oh, all the characters are anthropomorphized bunnies in Bell’s book. What could be more fun?

Cece’s mom says it best in her review of her daughter’s work:

*I am so very proud of her for baring her soul to write El Deafo. She worked five years to write and illustrate her graphic novel, and it carries so many, many messages to everyone who reads it. I had hoped Cece would write this book ever since she started having her Sock Mobkey books published. I believe she is benefiting from her book-related travels and experiences as much as her readers benefit from her book.*



## Jewish Federation Committee on Inclusion and Disabilities (CID)

*Al tifrosh min hatzibur* (Do not distance yourself from the community)  
Pirkei Avot

The Jewish Federation's Committee on Inclusion and Disabilities (CID), Co-Chaired by Sheila Wolfe and Susan Abrams, meets regularly to improve awareness and develop outreach strategies related to those in the Jewish community with disabilities. CID came together as a grass roots effort to celebrate Jewish Disabilities Awareness Month (JDAM). Since the February 2011 JDAM weekend, this committee has continued to pursue their dedication to work toward disability awareness and inclusion in the Sacramento Jewish community.

The Committee is composed of individuals with a wide range of experience working with disability issues, including parents/family members, professionals who work with the disability community, and advocates. Below are a key list of elements for inclusion approved by Jewish Federations of North America Human Services & Public Policy Disability Committee, April 18, 2013:

**Accessibility**— Ensuring that people with disabilities can access Jewish institutions in our communities and all of the activities held within them.

**Acceptance**— Understanding that each one of us has a role to play so that all people are welcome and can participate in meaningful ways.

**Accommodation**— Adapting and modifying the environment or programming to allow people with disabilities to actively participate.

**Welcoming**— Treating people with disabilities and their families with respect and dignity and celebrating diversity while creating a sense of unity within the Jewish community.

Shelley Christensen, a popular speaker and leader in the field of disability inclusion and spirituality and co-founder of Jewish Disability Awareness and Inclusion Month (JDAIM) provides a compelling insight into the importance of inclusion. Her views mirror those held by the CID:

“Organizations have to ask people, “What’s important to you?” and commit to supporting them in their individual Jewish journeys. People with disabilities can and should make decisions about how they participate in Jewish life.

[We need to] teach our organizations that Inclusion (with a capitol "I") is simply treating people as individuals, not as a group of “those” people whose needs can be met through special programs or occasional visits to synagogues, or community events. Let us change our thinking. Don’t do things for people with disabilities; do them *with* people with disabilities.”



# Interview With Susan Abrams

## “Adapting To A New Normal”

By Cynthia Brideson



Here we go again/How can I stop this maelstrom?/Mirror it, ignore it, joke about it?/Drugs always work eventually/My daughter: the traveler in a world of disability/capability/Riding one to the other and back/Confusion, conflict, and mixed messages in a world of doctors, teachers and drugs: all trying to fix her.../Why me? I love her; she spits in my face, pushes me to a wall, tries to bite me/For what? She doesn't even know she's angry now/She is...an internal war with herself dropping explosives on the very ones she cares about most/ “No,” I said. —Susan Abrams, Jul 7, 1998

This emotive, candid poem was written by Susan Abrams, who for thirty years has worked as an advocate and resource for the elderly and disabled. Susan has a daughter, Julie Henry. Julie was born with Rubinstein-Taybi Syndrome, similar to Prader-Willi Syndrome. It is characterized by short stature, intellectual disability, distinctive facial features, heart and kidney defects, and constant hunger. Learning to treat and cope with Julie's syndrome has given Susan a highly empathetic and unique insider's view into the world of those with disabilities.

Susan granted me an interview in May of 2018, discussing her work for and with people with disabilities. “We all have stories,” Susan commented. “Sometimes we just need a new audience.”



Julie

Susan: Julie was my first child I had an expectation for what Julie's life would be like; clearly it was going to be something different. I resisted the urge to think of what could have been, this way I had nothing to prejudge.

Susan commented that she often likened parents' emotions when facing the reality that their child has a disability to the emotions faced by those in mourning. She classifies the stages as: shock -guilt-anger-sadness-objectivity-maintenance/resolution.

Susan: You have to cope with this sense of loss and change; I faced that I may never see my child walk, marry, or even talk. You just have to adjust expectations and accept the child you do have rather than the one you imagined you'd have. Lots of people live in denial but will outgrow it if you can decide what your reality is and move forward, learn a new skill set and vocabulary.

I didn't care if Julie ever learned to count or tie her shoes. I just wanted her to be as comfortable socially in the world as possible. It took time for her to be able to tell time or use a fork at restaurants but she got there...Julie wanted to go to American River College. What did I do? I went to the admissions office, told them my dilemma, and asked is there a way to make this happen? They said if you can answer "yes" to a few questions, then she can apply for admittance. Julie was accepted. Her reaction was "this is the best day of my life, mom! She was just exuberant.

There were times when Susan faced concerned judgment about allowing Julie to pursue her dreams. Naysayers stated that she was exposing Julie to something she couldn't do. Susan considered it "a calculated risk". Julie enjoyed taking non-academic classes and thrived at her school. "There was created a more confident person out of the risk," Susan said. She is proud to share that Julie learned to take public transit herself; Susan prefers the term "self-sufficient to independent to describe Julie, as independent infers that "you don't need anyone" but we all need support and encouragement.

Susan: *Julie is a concrete person with good social skills, but impulse control is still challenging to this day. We learn to live with her idiosyncrasies. We need to start using the word capability rather than disability, we need to start thinking of people first. Wouldn't that change the conversation?*

\*\*\*\*\*

In 1993, Susan was part of team that created a crucial program called "Bridges, Nets, and Black Holes," which acted as training for parents and families on transition and case management. The program teaches how to enable your child, provides help with life planning skills, resource identification, access and development. The program helps parents identify their many roles including:

- 1) Observer: families spend more time with their children than anyone and get to know the child's unique needs.
- 2) Squeaky wheel: parents can change things for the better, create and modify programs to mold to their child and be consistent with his/her goals.

- 3) Accountability: Families are utmost in following through and implementing a child's life plan. Parents have to wear different hats: parent, advocate, legal guardian, teacher facilitator, and case manager.
- 4) Letting go and going on: the goal of parents is to grow the most self-sufficient and self-directed adult. Parents are the best resource for teachers, aides, agency caseworkers, and other support persons.

The heart of the program is a person-centered plan to transition students into adulthood. Pictured below is the program's pioneering person-centered model.

### **More About Susan Abrams:**

As a longtime community activist and organizer in the area of disability both in and outside the educational system and local community advisory committee office member, Susan continues to volunteer her time addressing issues of inclusion and mental health. She is an experienced presenter/trainer for families in issues of disability, independence, and quality of life. Susan was instrumental in designing and field testing a parent training curriculum in Sacramento County school districts. In addition, she helped create a golf program for persons with disabilities which continues to be a huge success. She has a bachelor's degree in sociology from CSUS and a degree in Gerontology. In the past she had her own consulting agency for Advocacy & Resource for the Elderly & Disabled.

