

# Inspiring Each Other

by Maryann B. Hunsberger



Jason  
and Jenni  
Newbury



It seems that 21-year-old Jenni Newbury has always been working to help people with disabilities break down barriers.

At first it was with her younger brother Jason, 19, who has Down syndrome. Then came the volunteer work with the school district's extended school year—at age 12.

“That was when I developed a passion. I realized I needed to work in this field.”

She enjoyed the work so much that she also volunteered for the town's preschool program for students with disabilities for the next four years.

Like any good big sister, Jenni has always looked out for her brother.

“He went to the same public school from elementary through high school. My friends were his friends.”

Jenni and Jason's mom Robyn said her children were close right from the beginning.

“She took over when he had been home from the hospital for a week. She came out of his room carrying him in her arms!”

Jenni was two-and-a-half.

“When Jason started Early Intervention, Jenni came along and the therapists taught her to do therapy with him,” said Robyn. “She did his therapy with him every day. When he was in fourth grade, we went to his class to answer any questions Jason's classmates had about disability. Jenni, who was in sixth grade, came along. She's been a real ambassador.”

Jenni's sibling support extended to her friends.

“Whenever Jason had an issue, such as having a crush on a girl, my male friends would talk to him. Even if they didn't have all the answers they could still help Jason figure some things out.”

Robyn said she thought Jason might have more problems after Jenni graduated. But by then the connections had been made.

After her freshman year in high school, Jenni attended the National Down Syndrome Conference in Philadelphia with her family. An exhibit for a program called PALS (Peers Assisting Learning Support) particularly impressed her. The program worked to promote friendships between students with and without disabilities.

“That was when my advocacy really started,” she said.

“In the fall of my sophomore year, I presented the program to my principal, who liked the idea. More than 80 people came to the first meeting. I worked with this program throughout high school, providing inclusive after-school activities. This began to define my leadership as an advocate for individuals with disabilities. This program still provides inclusive social interaction at my old high school.”

When Jenni was 16, the individuals who started PALS enlisted her help in forming a summer camp. Camp PALS pairs students with Down syndrome from ages 14 to 21 with volunteers. They become roommates, are on teams together, and develop friendships. The sleepover camp runs for one week each June in the dorms of Cabrini College.

“We started with 17 campers and 20 counselors,” said Jenni. “We now have 80 campers and 110 volunteer counselors. People return year after year. The counselors come from all over the country. Some are from England. They recruit at their own colleges to bring people back every year.”

Gabe Cohen, the son of broadcast journalist Meredith Vieira, has worked as a camp counselor for the past three years. This led his mother to become a sponsor.

“She has donated thousands of dollars to the camp,” Jenni said. “She is even more beautiful and sweet in person. Her family is fantastic.”

Jenni serves as a director of the camp, recruits and selects campers, speaks with parents, reviews camper forms, chooses which student is paired with which volunteer, and handles any emergencies. She also speaks at various conferences to publicize the organization and the camp. Recently, she received the President's Award from the National Down Syndrome Congress for her work with both PALS and Camp PALS.

Like any good big sister, Jenni has always looked out for her brother.



"Jason is my inspiration for everything I do. . . . Every moment we spend together is inspiring."

**Jason and Jenni Newbury at home in Hillsborough New Jersey. Jason loves books about sharks and Jenni reads with him.**

While still in high school, Jenni also worked with her township's parks and recreation department to create inclusive recreational programs, such as gymnastics and soccer.

"We also encouraged older people to come and volunteer," said Jenni.

The summer after her senior year of high school, Jenni founded Camp HEART (Hillsborough Education and Recreation Together) as an alternative to the recreation component for the township's extended school year program.

"Based on what we had done at camp, I started this for children ages 2 1/2 to 18. We divided the students into ages and provided speech therapy, arts and crafts, music lessons, Applied Behavioral Analysis (ABA) therapy and more. The school district bused all the students to the middle school to do this. I spent eight weeks of my summer running this program."

When she began attending Princeton University as a psychology major, Jenni founded a school club called Princeton Disability Aware-

ness. The group began hosting an annual Down Syndrome Conference on campus. They pair a Princeton student and a child with Down syndrome for the day. They also include the child's siblings.

"The day begins with brunch. The child and volunteer spend all day at a student-operated carnival. Family members, teachers and educators from the local community spend the day hearing about social, education, medical and legal issues through exhibitors and volunteer speakers.

"A student a cappella group performs after dinner. More than 500 attendees and 400 volunteers took part this past year. It was the largest student-run volunteer event in Princeton's history. Princeton has embraced, supported and encouraged my ideas, donating more than \$10,000 to this event every year."

Jenni wrote her junior paper on siblings of people with disabilities. Her senior thesis will compare and contrast having a sibling with Down syndrome with having a typically developing sibling.

“I will study the emotional aspects, self-esteem, pro-social behavior, and understanding and acceptance of individuals with disabilities. I will research and interview siblings between the ages of 8 to 12. Princeton is paying for me and Jason to travel to the National Down Syndrome Conference, where I hope to find siblings to interview. Jason and I will also travel to Ireland to the World Down Syndrome Conference to study these effects on an international scale.”

In February 2009, they traveled to the Special Olympics World Winter Games in Idaho.

“They had a campaign on ending the ‘R’ word and Jason was very excited about that. He now speaks about it often. He hears people using this word, even when talking to him. He speaks up and tells people they need to ban this word. I never heard him speaking up for himself so eloquently until he got inspired by this rally.”

Jenni and Jason have also traveled nationwide together as speakers for the National Down Syndrome Congress. Their mother said this work is helping Jason to grow as an individual.

“It’s so great to see them traveling together to these conferences. This is giving him many more independent living skills, such as learning how to run Power Point presentations and speaking in front of groups. And it’s helping him learn to advocate for himself.”

Robyn is quick to point out that Jason is also a help to his sister.

“They are opposites in personality. I think that’s why they hit it off so well. She’s a multi-tasker who is off in a million directions. He’s organized and provides stability. Jenni has a very strong personality, and having Jason for a brother has given her a direction and an outlet for her leadership skills. She has always had a nurturing personality, but he has helped her keep the right perspective in life. He has opened up a whole

new world for all of us and taught us what is really important.”

Jenni spent this past summer working for Project UNIFY, a division of Special Olympics International. Project UNIFY is funded by the US Department of Education and works to promote inclusion and implement Special Olympics opportunities within schools throughout the country.

Besides majoring in psychology, Jenni is working on an education certificate.

“I’m not sure exactly what I will do with my degree, but I know I will work in the disability field. I would love to take the Camp PALS model and implement year-round programming with getaway weekends, parent training and workshops, sibling workshops and job skill training.

“I’d like to start a Camp PALS Exchange for an older population who would build a relationship with a counselor and get specific job training at their counselor’s place of employment. That would involve a lot of money.

“I’m a huge proponent of inclusion, so I am passionate about education. I’m passionate about Special Olympics, so working for them is an option as well.

Young people are ready and willing to be engaged with this population, so I would like to take it to different regions of the country.”

Jenni said that having a sibling with Down syndrome has defined who she is.

“Jason is my inspiration for everything I do. My public speaking ability and my passion for people with disabilities both came from having Jason as a brother. His passion, his honesty and his genuine love for the people in his life is so moving. Every moment we spend together is inspiring.”

For more information about Camp PALS, go to [www.camppals.org](http://www.camppals.org). P&F



The  
Newbury  
family

# Thicker than Water

by Kathi Wolfe

BROTHERS  
AND SISTERS  
WRITING ABOUT  
THEIR BROTHERS  
AND SISTERS

Perhaps, no relationship is as significant as our connections with our siblings. We play and fight with, learn from, tease, admire, and get angry at our brothers and sisters all our lives.

Usually, our siblings outlive our mothers and fathers, and because we've grown up with them, we sometimes know more about them than we do about our mates. Sometimes we adore our siblings. Sometimes we don't.

But, whether we do or not, we're linked throughout our lives with an indelible bond.

This is especially true when siblings have brothers and sisters with intellectual disabilities.

Siblings without disabilities are often, from their earliest years, thrust into the role of caregivers for their brothers and sisters with intellectual disabilities. Frequently, they receive less attention. On the incapacitation or death of their parents, they face the issue of what the future will hold.

A new book *Thicker than Water: Essays by Adult Siblings of People with Disabilities*, edited by Don Meyer, director of the Sibling Support Project, addresses the wide-ranging issues involved with growing up and caring for brothers and sisters with conditions ranging from Down syndrome to fragile-X syndrome to autism.

Siblings often play a critical role in the lives of their sibs with intellectual disabilities. At the same time, as the 39 essays in "*Thicker Than Water*" make crystal clear, they don't receive enough attention from their parents or from disability service providers.

Brothers and sisters "will... be in the lives of their siblings who have disabilities longer than anyone—longer than any service provider or even their parents," Meyer writes in the volume's introduction. "They deserve understanding from parents and from service providers who profess to be interested in families, yet manage to overlook their unique concerns."

The contributors to *Thicker than Water* range in age from 20 to 70. Some, like Rachel Simon, author of the bestseller "*Riding the Bus with My Sister*" and Mary McHugh, who was awarded a prize for Special Recognition of a National Project by The Arc of New Jersey for her book "*Special Siblings: Growing Up with Someone with a Disability*," are professional writers. Others, like Libby Gondry whose sister Phoebe has Down syndrome, and Kim Keprios, CEO of Arc Greater Twin Cities, whose brother Michael has physical and intellectual disabilities, are homemakers,

volunteers, advocates and professionals in fields ranging from disability to technology.

As is often the case with these kinds of anthologies, the quality of the writing varies. Many of the pieces are well-written; infused with wit and poignancy.

“If you were to ask me my favorite question of all time, I know exactly what I would tell you: it would be ‘Sis? Can you be a bowl of chili?’” is the captivating opening of “Asked and Answered,” Melissa Garrison’s winsome and touching essay about her brother Brandon, who has autism, attention-deficit/hyperactivity disorder and obsessive-compulsive disorder. Garrison’s essay is one of the best in the collection.

“He heard someone mention a bowl of chili on Sesame Street, and it became an obsession,” writes Garrison, a sophomore at the University of Washington. “It was a lot better than his current obsession: listing every show on every television channel in order by programming block.”

Life can be incredibly hard for siblings of brothers and sisters with intellectual disabilities, says Garrison, speaking for all the contributors to *Thicker than Water*.

“Brandon is screaming. He’s pounding on the walls, because I’ve refused to list the game shows and their hosts for the third time this evening,” Garrison writes. “I’m watching him and I realize: ‘I don’t know how to talk to you any more.’”

Another beautifully written piece is McHugh’s essay “Saying Goodbye to Jack.”

McHugh’s late brother Jack had an intellectual disability. Though there is still stigma surrounding disability today, McHugh grew up at a time when there was more discomfort around people with disabilities. Nevertheless, McHugh’s mix of feelings—love, anger, embarrassment—speak to present-day readers.

“I love him now, but for most of my life I pretended to love him,” McHugh writes. “I think I was an angry little girl who could never show her anger because we didn’t do that. I was mad at my mother because she had to spend so much time with Jackie. I was mad at Jack because he wasn’t like the brothers of my friends. I was mad at my father who played golf and drank Scotch and hardly ever talked to me because he hid his feelings.”

While most siblings with intellectual disabilities will need some type of support, many are capable, with varying degrees of assistance, of living in the community and of engaging in self-advocacy. Though sibs with disabilities often get the most attention in families, “few of us consider whether people with disabilities want things that way,” writes John Kramer in his essay “I Am Not My Brother’s Keeper.”

“If they had their way, most would rather not be the suns in their families’ solar systems.”

Kramer has twin brothers with developmental disabilities. His brother Mike has cerebral palsy, a seizure disorder and an intellectual disability. His brother Matt (whose essay “It All Changes and Stays the Same” also appears in “Thicker than Water”) has spina bifida and a nonverbal learning disability.

Once, Mike decided to visit John in Chicago. As so often happens in families, Mike’s trip to the Windy City brought out differences between how his parents and his brother John felt about his (Mike’s) capabilities. Like many, who came of age before the disability rights movement, when people with disabilities weren’t usually out and about in the community, Mike’s folks worried that Mike wouldn’t be able to fly by himself to Chicago. John, being from a generation that has seen people with disabilities in schools and in the workplace wasn’t nearly as concerned.

“What it really came down to was chance,” John Kramer writes. “Mike and I wanted to take the chance that Mike could fly on his own. Mom? Well, in this case, she got overruled.”

A few of the essays in *Thicker than Water* have more of the feel of a screed or a therapy session than of an insightful or provocative reflection on sibling issues. Take the essay “Why I Am an ‘Uninvolved Sibling’” by a writer who chose to remain anonymous. The essay offers an unsparing look at the violent and nightmarish abuse that her brother with disabilities inflicted on her. The author brings to light issues that need attention. Yet, the piece, at times, comes across more as a rant than as a thoughtful piece of writing.

Yet, this is a minor caveat. All of the essays in *Thicker than Water* are well-worth reading. This collection vividly illuminates issues of importance to families, siblings and people with disabilities.

# A CONVERSATION

Don Meyer  
and  
John Kramer

Don Meyer, director of the Sibling Support Project, edited *Thicker than Water: Essays by Adult Siblings of People with Disabilities*. John Kramer is steering committee co-chair of the Sibling Leadership Network. Kramer's essay "I Am Not My Brother's Keeper" is published in *Thicker than Water*.

Meyer and Kramer spoke by phone with *People & Families*.

## **Meyer:**

Siblings of brothers and sisters with disabilities have unique issues. Sisters are more likely to look after the needs of their siblings when their parents can't. Though there are brothers who do the heavy lifting.

Parents would find it lonely if they had to wait to meet their peers. There are groups out there to match parents with other parents.

Now there are support groups on-line (the listserv SibNet has 1,000 members) and in person for siblings. SibShops are our attempt to give young brothers and sisters peer support and information in a recreational context.

They cook, play games, mix in with these recreational opportunities there are chances to meet other siblings and to talk about the good parts and not so good parts about being sibs—with other kids who get it.

Disability service agencies don't include siblings in their planning for the future. Parents get information from doctors, teachers and parents' organizations. Young siblings if they're lucky, get information from their parents. But siblings don't get this information from service providers.

Most service providers don't see in their job description that they should include siblings in future planning. But, I've never met one who wouldn't do it.

There needs to be growing awareness of sibling issues. We can't let these sibs languish in the literal and figurative waiting room of the service delivery system. They richly deserve a seat at the table.

## **Kramer:**

Sibling voices aren't typically thought of in discussions of advocacy. I'm involved to increase the voice of siblings in advocacy and policy-making.

Siblings' voices are different from the voices of parents and from people with disabilities.

They are a little more likely than parents to encourage their brothers and sisters to take chances; to be more out there. Maybe it's a generational thing. Many parents grew up when there wasn't service or support for people with disabilities living in the community. It's a changing environment.

I also think there's a difference between power relationships between parents and children vs. power relationships between siblings. Siblings in general are more hands-off; not so interested in running their sibling's life.

Siblings offer practical and legal support too. But it's not a one-way street. It goes both ways. People with disabilities provide a lot of support for their sibs that doesn't get recognized.

Siblings without disabilities haven't had much to say in policy. What are their legal rights if something happens to Mom and Dad? It's often not clear if siblings have guardianship.

Some siblings want to take on that role. But, it's not always a positive thing—for both sides. People might not like their siblings—they don't always have a voice to say that.

SLN is examining these issues." **P&F**

# Adam

## Love with the Proper Stranger

by Kathi Wolfe



If you're a young woman, and the cute guy, who you have a crush on, asks—"Were you sexually excited when we were walking in the park?"—you'd likely want to bolt.

That's exactly how Beth (Rose Byrne) feels when Adam (Hugh Dancy) poses this question to her in *Adam*, a movie, released last August and expected to be out on DVD within the next few months. Fortunately, for Adam and for movie-goers, Beth resists her impulse to flee when Adam explains, "I have this thing. My brain works differently."

You see, Adam sometimes can't help himself when he says something inappropriate.

"I have Aspergers syndrome," Adam tells Beth.

*Adam*, written and directed by Max Mayer, is a cross between a drama and a romantic comedy. It's not giving too much away to say that the movie is a love story with a twist.

Adam, an electronic engineer, knows everything you've ever wanted to know and more about astrophysics—from telescopes to how the universe expands. Since his father's recent death, he's lived by himself in his apartment in Manhattan.

Adam is cute and has been holding on to a job—until he gets laid off due to downsizing. Yet, he

has few friends or social skills. On Saturday nights when everyone's out on the town, he's alone with his neatly stacked boxes of macaroni and cheese and astronomy charts.

Then Beth, a schoolteacher and children's book writer on the rebound from a bad break-up, moves into his apartment building.

She's sweet, pretty and a talented writer and teacher. Her parents and young students adore her. Yet, as with Adam, there's a core of sadness in her life.

Her ex was nasty to her. Worse, her Dad, who she's always trusted, is in trouble. He's on trial for tax fraud, and in the midst of the proceedings, has to confess that he once had an affair. Her trust shattered, Beth is lonely and vulnerable.

It's not surprising that Beth and Adam are drawn to each other. As so often happen—both in movies and life—proximity and need throw people together.

From the get-go, we know that theirs will not be the typical romantic relationship.

In one of the first scenes, Beth enters their apartment building with her arms full of packages. Anyone seeing her with all of those bags would offer to help Beth carry them. Not Adam.

It's not that he's unkind. He just doesn't get the social cues.

As the movie progresses, we see the ins and outs of Adam's and Beth's romance. Serious scenes (Beth's father's trial) mingle with comic moments. It's sardonically funny when Adam innocently asks Beth's somewhat pretentious friends at a Christmas party if he's "talked too much about telescopes."

In several interviews, Mayer has said that he used Aspergers as a "metaphor for relationships."

"The more I learned about Aspergers, the better metaphor it felt like for the condition of all of us in terms of a desire for connection to other people," Mayer told *The New York Times*.

"Adam," which received the Alfred P. Sloan Prize honoring "an outstanding feature film focusing on science or technology" at this year's Sundance film festival, works on this metaphorical level. Because he has Aspergers syndrome, Adam has a hard time empathizing with what Beth feels, getting that people may not share his intense interest in astronomy, or knowing when he should stop talking.

"When I get excited, I talk too much," he tells Beth.

With or without Aspergers, who hasn't felt, at times, disconnected from one's love interest? Who hasn't, at moments, found a partner's stories to be interminable, or been embarrassed by their goofy behavior at a party?

Mayer aims for us to see Adam and Beth as any couple negotiating their lives and their relationship—rather than as a movie about a man with Aspergers and a woman without the disability falling in love.

And he succeeds fairly well.

New York has never looked lovelier. As in the best of these kinds of stories, the viewer roots for both Adam and Beth because you identify with their strengths and weaknesses, and the problems they face—finding the right job, trying to make the relationship work, dealing with parents—could be mine, you think. The sub-plot with Beth's father, may be over the top but not out of character for this kind of tale—reminiscent of the 1989 John Cusack movie *Say Anything*.

Jonathan J. Kaufman, founder of the Manhattan-based consulting agency Disability-Works, Inc., was a consultant on *Adam*.

"I was intimately involved with every step of the production pertaining to the character's Aspergers," Kaufman wrote in an email. "I tried to show that Aspergers was a part of who he was and influenced his behavior and choices but not all of him."

Though that comes through loud and clear in the movie—that Adam has a multifaceted personality, of which Aspergers is a part—the Aspergers is a major force. This is mostly a good thing. *Adam* is one of the new, if still limited, crop of movies that are treating disabilities realistically.

Dancy, often compared to Hugh Grant and known for his work on BBC TV shows as well as movies such as the "Jane Austen Book Club," does a good job of portraying Adam as a fully rounded human being. He's straight on when Adam tells Beth, "I have mind-blindness. I have to ask people what they think."

After Adam loses his job, he reads books about what people with Aspergers should do when job-hunting. Beth coaches him on how he should behave on job interviews. But this is no Hollywood fairy tale. "I've applied for 75 jobs," he says to Beth at one point.

Yet, at times, the movie's emphasis on the Aspergers becomes cloying: Beth seems like Adam's mom, or babysitter, instead of his girlfriend, the background music gets sappy, and the metaphors morph into clichés.

In one scene, Beth and Adam see some raccoons in Central Park. When Beth says they don't belong here, but here they are, the heavy handed metaphor with Adam's Aspergers is a bit much.

Fortunately though, through good acting and writing, *Adam* mostly transcends such moments.

For instance, when Beth brings him a box of chocolates to cheer him up, Adam jokes, "I'm not Forrest Gump!"

Fox Searchlight Pictures, which distributed *Adam*, also released last year's Oscar winning picture "*Slumdog Millionaire*." Though it's risky to make predictions, it would be nice if a movie depicting us as human beings got an Oscar nod. **P&F**

# FAMILY SUPPORT

## STATEWIDE REGIONAL FAMILY SUPPORT PLANNING COUNCILS

### WANTED

#### NEW JERSEY'S REGIONAL FAMILY SUPPORT PLANNING COUNCILS ARE LOOKING FOR NEW MEMBERS!

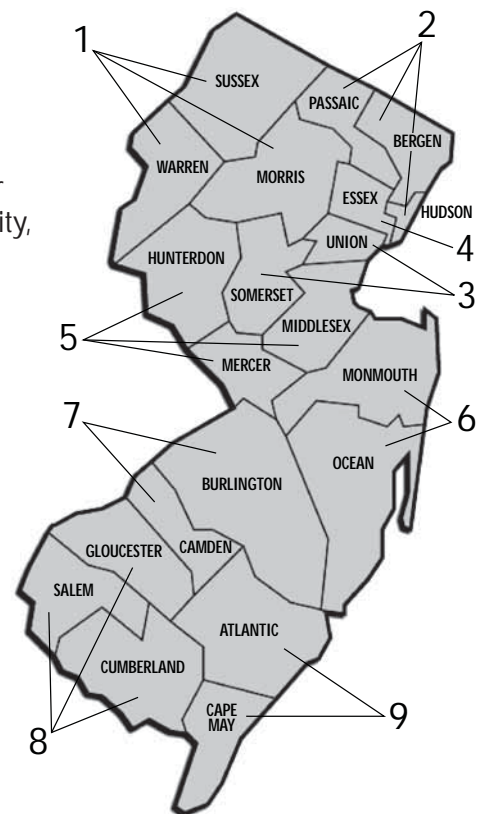
Nine regional councils were established in New Jersey by the Family Support Act of 1993(see map). Their general purpose is to assure that people with developmental disabilities and their families participate in the design of, and have access to, the needed community services, individual supports, and other forms of assistance that promote self determination, independence, productivity, and integration and inclusion in all aspects of community life.

The councils work in partnership with the state's Division of Developmental Disabilities to advise on budget and policy decisions that affect people with developmental disabilities living at home with their families. Councils sponsor events where individuals and their families can learn about the services available in the area, as well as host public forums to solicit feedback from the community. In addition, councils regularly distribute literature with important information for people with developmental disabilities and their families.

Family members of people with developmental disabilities or individuals with developmental disabilities can volunteer to serve on their regional planning council. Council members assist and advise the Division of Developmental Disabilities as to how resources can best meet the needs of families and individuals living in their region.

Councils meet regularly—usually once a month; each Council may have up to 11 members. Council members are volunteers but will be reimbursed for reasonable transportation, child care and other costs related to serving on the council.

**For more information call the New Jersey Council on Developmental Disabilities at 1-800-216-1199 or visit our Web site at [www.njcd.org](http://www.njcd.org) and follow the link to Family Support.**



#### THE FAMILY SUPPORT ACT OF 1993

Establishes in the Division of Developmental Disabilities a system of Family Support designed to strengthen and promote families who provide care within the family home for a family member with a developmental disability.

The system of Family Support shall include, but not be limited to:

- after school care
- cash subsidies
- communication and interpreter services
- counseling services
- crisis intervention
- day care
- equipment and supplies
- estate and transition planning
- home and vehicle modification
- home health services
- homemaker assistance
- housing assistance
- medical and dental care not otherwise covered
- parent education and training
- personal assistance services
- recreation services
- respite care for families
- self-advocacy training
- service coordination
- specialized diagnosis and evaluation
- specialized nutrition and clothing
- therapeutic or nursing services
- transportation
- vouchers



**Jason and Jenni Newbury** - Photo by Rebecca Shavulsky