New Hampshire

RAP Sheet

The Latest in Disability Research, Advocacy, Policy, and Practice

Summer Issue 2006

ALL YOU NEED IS LOVE

Included – With Friends

Zach Rossetti is a Doctoral candidate in Special Education at Syracuse University. He grew up in Concord, NH and is an avid Red Sox fan.

I recently asked my mother why she insisted that my brother Todd be included in school. Her answer surprised me because it was so short and simple. Thinking about it since then, I am surprised that it struck me as short and simple because it is, well, perfect. She answered, "I just wanted him to go to school like everybody else did."

The "everybody else" in her answer refers to the rest of our family. Erik, Megan, Shane, Mariah, and I all went to school, tried our best, and made friends. While I could probably recall the quadratic formula, manifest destiny, and how to conjugate the French verb "etre," if pressed, what I remember most vividly from school are my friends and the things we did together. Late night study sessions, first romances, winning the state soccer championship, and just hanging out laughing with people who I still am close with today made school memorable and important.

STEVEN BOYER

Brothers Todd and Zach Rossetti

But Todd didn't go to school like everybody else did. He did not attend his high school prom or have food fights at lunch or goof around in between classes. He rode the small bus to school and worked on functional skills and was fed his lunch by an adult wearing rubber gloves. I feel that too many of his classmates and teachers missed out on the *privilege* of knowing Todd as we (his family members) do. Most classmates and teachers would say hi to him, shake his hand, and try to make him laugh, but most relationships remained on that surface level. No one called him at home after school or on the weekends.

Welcome to the Summer Issue of the Rap Sheet contemplating the importance of love and friendship. For all of us, the quality of our lives is influenced most significantly by the presence of people who love and care about us. For people who experience disability the search for meaningful personal relationships can be challenging. We hope the stories in this issue will touch your heart.

Susan Covert, Editor

A collaborative effort by the

Disabilities Rights Center, Institute on Disability, and NH Developmental Disabilities Council

(Cover story continued)

It seems to me that his teachers and classmates knew Todd as the young man with cerebral palsy who got around in a wheelchair, had a huge smile, and did not talk. They did not know Todd as the young man who wants to be a poet, loves the Red Sox, and is very smart even though he drools sometimes. They did not know that he communicates by looking at the desired choice, or how to ask him questions with choices. His classmates did not know how to be friends with him…or that they could.

Inclusion, like mainstreaming and integration before it, is rooted in the social goals and benefits of students with and without disabilities learning together. If we believe that friendship is an essential element of a fulfilling life, and we know that the only way students will be able to develop friends is to be educated along side each other, then we must ask the question: *If everyone agrees this is so important, then why do so few kids with disabilities have real friends?*

I often think that how teachers treated Todd affected how classmates perceived him. It's not that Todd couldn't be a good friend, it's that he didn't have the opportunity to interact with and get to know his classmates. And, over time his classmates learned that he was not a potential friend.

While attitudinal and educational barriers may have limited his development of friendships, he *was* included, but for Todd, friendships did not "just happen." So, what contexts and what supports lead to the development of friendships between students with and without disabilities?

I recently conducted a qualitative research project focused on friendship, specifically three case studies of friendships between high school students with and without disabilities. Several themes emerged from my research. First, the context of these successful friendships was one of purposeful and unconditional inclusion that included several key strategies:

1) Academic supports were geared towards participation (because students want to be friends with classmates they see as smart and who are valued by the teacher).
2) An adult acted as a *Bridge Builder* between students who may not naturally connect on their own.
3) Adults faded back whenever possible and encouraged classmates to take their places. When adults were not next to students with disabilities, their classmates filled those spaces.
4) Intentional facilitation of friendships started with one student and others followed.

Second, friends possessed insider knowledge related to specific support needs. For example, Shaffer did not always reply immediately when his friend Grace said hello. She learned to wait for his reply where other students tended to keep walking down the hallway. While friends develop this knowledge over time, it may be helpful to provide potential friends with this type of information first so the opportunity to develop a friendship is not missed from the start.

Third, the nondisabled friends in my study stressed that they were not special in any way. Their friendships with students with disabilities were similar to their other friendships; they were based on similarities, having fun together, and shared histories. They also explained that these friendships were especially meaningful, because they had worked hard to figure out communication differences or to accommodate their friend's need for supports.

Friendships between students with disabilities and those without are possible and should be expected. When individuals are valued as they are and perceived as important contributors to the class community, all students remain in the *pool of potential friends*. From there, the specific strategies, tailored to each student's individual personality and the classroom community help spark the connection that can grow into a friendship. It takes some work but it is doable, and it is so important. Students with disabilities should be able to "just go to school like everybody else."

Friends

Julia Freeman- Woolpert, Disabilities Rights Center

> *You meet a friend – your face brightens. You have struck gold.*
> *- Kassia*

Erica Blom and Sarah Cooley on vacation in Chicago.

Sarah Cooley and Erica Blom go way back. Their mothers are friends and were pregnant at the same time. They grew up down the road from each other, were in and out of each other's houses, and went to school together. Sarah and Erica have always been friends. "We were born in different families," Sarah explained, "but we became like sisters."

Sarah and Erica have a deep affection and appreciation for one another. "Sarah's a true friend," Erica said. "She always invites me to her parties. She sends me care packages at college. I think she's the only friend who does that. She's honest with her feelings, good or bad, so she's a true friend in that sense. She's willing to tell you the truth. She's fun. We always have a fun time together, it's usually laid back and happy."

"We're like soul sisters," said Sarah. "Being part of her life makes me happy. She makes me laugh, she's smart, she's gorgeous, and she's a very hard worker and a very safe driver." Sarah said that the friendship has also meant "being strong for each other and helping each other out when we have problems."

A shared history is part of the glue that cements their relationship. "Over the years we've done a lot together," said Erica. I think that's probably why we're still really good friends, we have a lot of memories. When I was younger, my parents were working and didn't drive me to friends' houses. Sarah's was the closest; we'd bike. I saw her more in the summer than anyone else."

Sarah has a favorite memory from when they were 6 or 7. Erica was sleeping over, as she often did. "There was a huge bowl of Cheerios. I poured the whole thing on her," she remembered.

"No, I think I poured it all over you," said Erica.

"Yeah," continued Sarah. "She poured it all over me. We cleaned it up, our mess, and then I poured it all over her. It's so funny, we were laughing the whole night."

"I think it was the latest we both ever stayed up," added Erica.

The girls loved playing dress-up and games like Sorry! and chess. Both had vivid imaginations. "We played 'Ship', which was a pretend game," said Erica.

"I was the captain," said Sarah.

"And I was the mate," added Erica.

As they got older they spent less time together. They weren't in the same classes in high school. Summers were busier, with Sarah going to camp and Erica working. Now when they got together it was to share a meal at a restaurant.

"We used to go out for dinner a lot," remembered Sarah.

Erica recalled, "Sarah would get a clubhouse sandwich and take everything off except for the chicken! I was like, why don't you just get a chicken sandwich?"

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Actually, chicken is one reason that Erica admires Sarah. When Sarah was younger, she only ate certain foods – fried chicken, pretzels, ice cream, and, of course, Cheerios. Then one night at a restaurant several years ago, "She just changed her eating. She just told me that day she wasn't going to eat fat anymore," Erica explained. "It always was fried chicken fingers and then all of a sudden it was, 'I'm only having grilled chicken breast sandwiches'." Sarah's willpower inspired Erica to improve her own eating habits.

Three years ago, Erica graduated from high school and went to Boston University where she is majoring in Sociology. At the same time, Sarah moved to Concord to finish school. Sarah felt a little left out as she watched Erica and her other friends go off to college while she remained in a post-graduation high school program. But they didn't lose touch.

Sarah and Erica think their friendship has lasted because they put effort into it. Erica said, "If one of us wasn't giving effort the other one didn't stop being friends, they just kept giving more effort until the other friend came back. When I went to college, at first I had trouble organizing my life and staying in touch with people. Sarah called me a lot more than I called her, so she was putting in effort when I wasn't. Other times Sarah couldn't drive anywhere, but I wanted to see her for dinner so I'd drive to Concord even though it's an hour from home. I think we both realize it's an important friendship and we try to make it work."

These days, it is harder for Sarah and Erica to find time to see each other. Sarah works at the Disabilities Rights Center and has a boyfriend. Erica has a full college and summer schedule that keeps her away from New Hampshire most of the year. In spite of their busy lives, they keep in touch, see each other when they can, and know they will be friends forever. Sarah remembered the song they sang when they were in Girl Scouts together, "Make new friends, but keep the old; one is silver and the other is gold."

Sisters

Julia Freeman Woolpert, Disabilities Rights Center

Sisters function as safety nets in a chaotic world simply by being there for each other.
– Carol Saline, author of Sisters

On October 27, 1956, five year old Roberta Gallant and her four year old sister Jocelyn were driven by their parents from their North Country home to Laconia State School and Training Center where they were left. At the institution, Roberta was placed in Floyd Building and Jocelyn went to Keyes. For the next twenty-five years Laconia staff decided whether or not the sisters could live together and how often they could see one another.

JULIA FREEMAN-WOOLPERT

Jocelyn Gallant gets a hug from her sister Roberta.

Today Roberta lives in Concord and Jocelyn in Salem. While lack of public transportation means that they do not get together as often as they wish, the two remain extremely close. Recently Roberta visited Jocelyn at her home in Salem. The sisters sat at the kitchen table catching up, while dinner simmered on the stove. Roberta showed Jocelyn how to use the new scanner for her computer. Jocelyn played her electric organ while Roberta listened appreciatively, sometimes dancing to the music. They discussed plans for Jocelyn's garden. They also took time to talk about their relationship.

"We're so close. We've been close since we were this little," said Jocelyn, holding her hand near the floor. "Roberta is a very smart person. She helps me with my computer. She helps me to do house cleaning which she likes to do, and then I take care of all of the food. I play the organ for Roberta and Roberta and I watch television together. I love Roberta. She's a wonderful sister, best friend I've ever had. I can't ask for better. No one can take her place."

Roberta smiled. "Thank you for your compliment. That makes me feel good, Jocelyn." she added, "Jocelyn is an outstanding cook."

Jocelyn and Roberta talked about their life at the State School. Their memories of the institution are painful.

"It was not a good place there," said Jocelyn.

Roberta echoed her sister, "Laconia State School was horrible. The staff would always beat up on Jocelyn and me. I became very homesick. All I did was constantly cry, sob, and throw severe temper tantrums."

From the time they were placed at Laconia, the sisters rarely saw their parents or their five siblings. Jocelyn remembered, "We went home a couple of Christmases, and then we didn't go home after that." While the sisters at times lived in the same dormitory, they were frequently separated. Jocelyn remembered being told it was for their own good. "They think we were gonna be too friendly. That's what they said."

Roberta added, "I was also driving Jocelyn crazy and then she was also driving me crazy. They said that we never leave each other alone."

Records from the State School document a number of official decisions to separate, or reunite, the girls over the years. When they were 9 and 10 a doctor recommended, "A temporary separation of these children would be advisable and it should be carried out, if possible, immediately." In his notes he stated the reason for separation was that Roberta was a leader and Jocelyn a follower. He advised that when things improved, "the situation should be reviewed and a decision should be made whether a close relationship between these siblings should be re-established or not." Institutional records showed that the separations were devastating for both sisters. Roberta would fall apart when separated from Jocelyn. The words "emotional deprivation" were used repeatedly to describe their childhood.

In the 1970's parents of Laconia State School residents brought a class action lawsuit against the state that resulted in the closing of the institution. "I left the State School on Nov 13, 1979," remembered Jocelyn, "and Roberta left the state school on June 22, 1980." Towards the end of their time at Laconia, staff made efforts to help Jocelyn and Roberta reconnect with their family. Phone calls were scheduled and visits were encouraged, but the family was not enthusiastic about a reunion, especially one that involved the sisters moving back to their hometown.

Jocelyn explained, "Mom didn't want us to live there - Mom and Dad. They didn't think it was good idea. Would have been nice, right Roberta?"

Roberta answered, "Yes. But now I don't want to move back. There's nothing up there anyways."

When the time came to leave Laconia, the sisters hoped to stay together, but even that was not to be. Roberta and Jocelyn were sent to different towns. Despite all of the efforts over the years to keep them apart, they have remained close. They are devoted to one another and each considers the other the most important person in her life.

Not surprisingly, their years at Laconia permanently damaged ties with other family members. When their father died in 1980, Roberta and Jocelyn didn't learn about his death until after the funeral. They occasionally are in contact with two of their sisters. Roberta uses instant messaging to chat with one sister, and there are occasional phone calls and letters.

They each have a few friends, but not as many as they would like. They attribute that in part to growing up in the institution and away from a community where they would have made lasting friendships in childhood.

"It's not easy," observed Roberta. "Making friends is not that easy for adults with disabilities, but it is very easy for children, little kids, to make friends in the community."

"People today, they just don't want to be bothered, they just want to keep to themselves," said Jocelyn.

Roberta explained, "They are afraid of people who are different. They just do not understand what having disabilities is like."

Jocelyn added, "We had friends and they broke up with us too. You're more likely to lose a friendship than those without disabilities."

Roberta agreed, "Some people with disabilities have no friends at all."

JULIA FREEMAN-WOOLPERT

Roberta Gallant watches her sister Jocelyn play the organ.

Nearly forty years ago Jocelyn and Roberta Gallant were placed at the Laconia State School and Training Center. Jocelyn Gallant, who was four when she went to Laconia, explained why her parents sent her and her sister Roberta to the institution, "They figured we would learn something. We didn't."

Roberta agreed, "We did not learn much of anything. New Hampshire deprived us of an opportunity to receive elementary and secondary grade school education."

"That was a scam," said Jocelyn.

"Yeah that was a scam. You said a mouthful, Jocelyn."

Jocelyn summed up the extent of her education, "All they did in Laconia State School was have us color pictures and cut out pictures and put them in scrapbooks. What kind of a place is a Training Center? To me it's nothing."

Roberta and Jocelyn are keenly aware of the injustices that they suffered as a result of their years in Laconia. Today both sisters are advocates for the rights of people with disabilities. For years Roberta has fought tirelessly for the right to community services and to education for uneducated and undereducated adults. She testifies at the State House regularly, and is well known by legislators and agency directors for her persistence and determination. The Arc presented her with their citizenship award and she has received formal commendations from Department of Health and Human Services and People First for her work. In 1992 the Martin Luther King, Jr. Coalition recognized Roberta for her advocacy on behalf of individuals with disabilities. Jocelyn has worked to improve access to public transportation and is a member of the Greater Derry and Salem Mass Transit Advisory Committee. She also is a long-standing member of the Advisory Council for the Institute on Disability, where she advocates for increased job opportunities for people with disabilities.

A Tribute to Harry Elliot

Gordon DuBois, Coordinator of Training at the NH Bureau of Developmental Services

I first met Harry Elliot in 1993 when I interviewed him for the Laconia State School Oral Histories Project funded by the New Hampshire Humanities Council. Harry had volunteered to talk to me about his life at the New Hampshire School for the Feeble-minded, later known as the Laconia State School. For more than 40 years, from 1936 to 1977, Harry lived in an institution. I felt privileged that he was willing to share his story with me.

Harry told me that when he was just a young boy a "state lady" took him away from his family because "my father didn't work." This was the first of Harry's many separations and losses. He was first sent to the Golden Rule Farm, later the Franklin Orphanage Farm, and in 1937, when he was 11 years old, he went to the Laconia State School and Training Center. Harry told me about his work on the institution's farm and in the laundry. He said that he was moved around a lot, from building to building and staff to staff. He talked about how much he wanted to be a "free man." Harry said of Laconia, "It was an easy place to get into, but a hard place to get out of." With great modesty, he explained that the only way he could leave the State School was to "have a sterilized operation," something that he continually refused to do.

For me, the most poignant story that Harry shared was about the woman he loved. For most of the years he was at the State School, the institution thoroughly discouraged any contact between male and female residents. Men and women lived in separate dormitories, ate at different times, worked in separate locations, and were not allowed to socialize. At the time the country was in the grips of the Eugenics Movement and the State School strictly enforced policies to ensure the separation of men and women residents.

In spite of all these restrictions, Harry fell in love. It was a love from a distance. Contact between Harry and his beloved was limited to smiling and waving when they passed each other on the grounds of the institution. Harry said that he was never permitted to speak to the woman he loved, or to touch her, or to hold her. Against great odds, Harry and his love found a way to communicate. They wrote daily to one another, their letters hidden in the laundry that was delivered to their residences. Each day Harry eagerly awaited his small package of laundry with its secret letter.

Amazingly, in spite of all pain and loss that Harry experienced while at Laconia, he was not bitter, nor did he want revenge. Harry was simply thankful to have these years behind him. Harry talked to me about the good times he's had since leaving the State School. He had made new friends and enjoyed being in the community. While I don't know if Harry ever found his "lost love," I do know that his love of life enriched the lives of those around him.

Harry's story is a dramatic reminder of the evils of segregation and oppression, but more importantly his is a story about the resiliency of the human spirit. When Harry left Laconia State School, he chose not look back with regret or anger. His willingness to always seek the goodness in others and the courage with which he lived his life taught me a powerful lesson. Harry Elliot, thank you for your story, but most of all for your loving spirit. It will always be with me. Harry died November 4, 1997. His ashes were spread over a field in the Connecticut River Valley where he once lived with his family.

If you would like more information about the Laconia State School including the Oral History Project or if you are interested in a slide, lecture presentation by Gordon DuBois please call 603-271-5021 or email gdubois@dhhs.state.nh.us

Many documents, pictures, and artifacts from the Laconia State School are stored at the Department of Records and Archives, 71 S. Fruit Street, Concord, NH (603) 271-2236.

COMING SOON:
Including Samuel, a documentary film by Dan Habib

When I became a photojournalist about twenty years ago, I did a story on one of the first schools in New Hampshire to try inclusion. Now my sons go to that school, and I think about inclusion every day.

I'm in the process of turning those daily thoughts into *Including Samuel*, a documentary film currently in production. The film is built on our family's efforts to include Samuel in all facets of school and community. *Including Samuel* also features four other families with varied inclusion experiences, plus interviews with educators, students, parents and disability rights experts. In 2007, *Including Samuel* will be released as a broadcast-quality film and website.


DAN HABIB

Samuel Habib talks with a classmate at Shaker Road School in Concord. Samuel now attends Beaver Meadow Elementary School in Concord and has been fully included throughout his education.

My desire to make this film was inspired by two very different experiences in our lives. My wife Betsy McNamara and I have two sons, Isaiah, 9, and Samuel, 6. Betsy and I both completed the Leadership Series through the UNH Institute on Disability. When I finished that program, I knew I needed to use my abilities as a photojournalist to strengthen our society's understanding of inclusion.

A less predictable catalyst was Samuel's 10-day stay in the Dartmouth intensive care unit following complications from a tonsillectomy. When Samuel was still in a medically-induced coma, his incredible neurologist, Dr. James Filiano, encouraged me to take on

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a documentary project. He said that I had the ability to use photography to tell a story, and I should tell Samuel's story, our story. I was amazed that a doctor in a major American hospital was encouraging me to take photos in the hospital (privacy laws being what they are these days). But that moment in the ICU and the Leadership Series have been constant sources of inspiration for my work.

I think this film will raise as many questions as it answers. My goal is to get people – especially educators - talking about inclusion in a more informed and innovative manner.

Samuel brought the disability rights movement into our home. Creating this film has raised a lot of questions in my own mind. What stereotypes do I have about people with physical and mental disabilities? As Samuel grows up, what can we do to make sure that his cerebral palsy is just one small part of who he is? Can we continue to fully include Samuel as he goes to middle and high school? What about the times when inclusion has to take a back seat, as Samuel misses weeks of school to get through another health crisis?

I don't know the answers to those questions. But I know that Samuel loves life. He loves to laugh and he loves the Red Sox. He wants to keep up with his brother, and be a part of everything that we do. He will teach a lot of people, which is good because the world has a lot to learn.

Dan Habib has been named NH Photographer of the Year six times. Habib was the national Photography Editor of the Year in 2006 for papers under 100,000 circulation. His freelance work has appeared in publications including Time, Newsweek, Yankee, Life, Boston Magazine, Mother Jone,s and the New York Times. He also created the film "Teen Sexuality in a Culture of Confusion," distributed by the Media Education Foundation.

"Including Samuel" has received support from the Institute on Disability, the Developmental Disabilities Council, the D1isability Rights Center, Granite State Independent Living, the New Hampshire Charitable Foundation, and the Episcopal Bishop of New Hampshire.

For more information about "Including Samuel," email Dan Habib at Danhabib@comcast.net. A preview of the film is currently in limited distribution.

The documentary *Including Samuel*, focuses on Habib's son Samuel, but includes segments on several additional subjects:

EDUCATING ALL CHILDREN. Beyond Access is a University of New Hampshire pilot project working with public schools to fully include students who experience the most significant disabilities. **Alana Malfy,** 17, attends Pembroke Academy Public High School, where she and her mother are finding that inclusion brings both educational rewards and social challenges.

> *"You know what? It's not easy getting along with other people."*
>
> *– Alana Malfy*

THE ROAD TO INDEPENDENCE. **Emily Huff, 20,** wishes there was a magic helmet that would let others experience the unreal voices, the hallucinations, the terrifying thoughts that invade her mind without warning. Emily and her mother Anne live together in Concord and are now embarking on a new journey toward an independence Anne worried might never be possible.

> *"I am in a doctor's office, and they are talking like they know every single thing about schizophrenia that is to be known. They don't! I'm like, "You don't understand anything. When you have seven people living in your head, then we can talk."*
>
> *– Emily Huff*

UNH TO OFFER SUMMER WORKSHOP ON AUTISM

The Institute on Disability at the University of New Hampshire will be presenting the eight annual Autism Summer Institute on August 14, 15, & 16. This unique three-day workshop is open to anyone interested in learning more about Autism Spectrum Disorders (ASD) from experts on the subject, including persons living with ASD. Topics will include strategies to help support the full participation of children in general education classrooms, as well as, to promote a better understanding of the emotional experience of ASD.

Keynote presentations will be offered by Stephen Shore, M.A., a Boston University doctoral student living with autism, Ros Blackburn, a lecturer from Essex England also living with autism, and Chris Kliewer, Ph.D., an Associate Professor in Special Education from the University of Northern Iowa. In addition, an exhibit displaying the works of internationally known artist with ASD, Larry Bissonnette, will be featured. Larry's life and work was recently profiled in the award winning documentary film, "My Classic Life as an Artist".

The fee for the Autism Summer Institute is $390 per person. Discounts for full-time students, family members of individuals with ASD, as well as individuals interested in attending keynote presentations only also are available. For more information or to register online, visit www.iod.unh.edu or call (603) 228-2084 with questions and to register by phone. The Institute on Disability at the University of New Hampshire was established in 1987 to provide a coherent university-based focus for the improvement of knowledge, policies, and practices related to the lives of persons with disabilities and their families. Its mission is to advance policies and systems changes, promising practices, education, and research that strengthen communities to ensure full access, equal opportunities, and participation for all persons.

SAVE THE DATE - FALL SYMPOSIUM - GOOD EDUCATION FOR ALL

Monday, October 23, 2006 at the Center of New Hampshire Radisson Hotel in Manchester.

SAVE THE DATE - SPRING SYMPOSIUM - GOOD EDUCATION FOR ALL

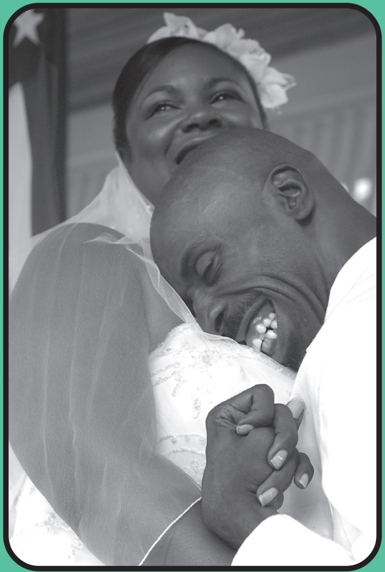
Tuesday, March 27, 2007 at the Center of New Hampshire Radisson Hotel in Manchester.

LEADING THE CHARGE. Keith Jones is a political activist in Boston who teaches hip-hop to youth with disabilities and educates businesses to be more inclusive. Jones speaks eloquently about the impact of his inclusive education on his life.

> ***"You cannot box people up in a room, 20 by 20, eight hours a day, and then ship them off into the world and expect them to have social interaction skills. It's not gonna happen."***
>
> *– Keith Jones*

A TRADITION OF INCLUSION. Nathaniel Orellana goes to the public Haggerty Elementary School in Cambridge, Massachusetts. His mother, **Marlene**, says that the principal Joseph Petner and his staff has made the school an ideal setting children with autism, like Nathaniel, and children with and without other disabilities.

> ***"Some children are going to require more resources to learn than other children. And that is where it becomes a civil rights issue."***
>
> *– Jan Nisbet, Director of the University of New Hampshire's Institute on Disability.*



DAN HABIB

Keith P. Jones and Kerlyne Pacombe during their wedding day on Saturday, July 23, 2005, at the Milton Hoosic Club in Milton, Massachusetts.


DAN HABIB

Emily Huff practices signing with her instructor Elizabeth Langille.

On Being a Target

Julia Freeman-Woolpert, Disabilities Rights Center

> *I didn't belong as a kid, and that always bothered me. If only I'd known that one day my differentness would be an asset, then my early life would have been much easier.*
>
> \- Bette Midler

Let's just put it right out there - Emily Huff is not a fan of inclusion for everyone. Years of painful and traumatic experiences make her an expert on the subject. As a student, she was, at various times, in regular classes, in out-of-district placements, and in alternative programs within the Concord School District. Emily, now 21, said for her full inclusion was not the answer, "If I had been mainstreamed, I wouldn't have lived."

To see Emily now, you would never guess what she's been through. For starters, she has friends. "I have six really good friends." Six is just the right number of friends for Emily: not too few, not too many. She and her best friend Misty, who lives in Maine, met at summer camp. They keep in touch by phone and plan to get an apartment together some day. She has made other friends through her part time job at the Movie Gallery. "That job rocks!" she enthused. "I have friends in that job. I can handle myself in that job. Socially, I think it's the best thing I've ever done for myself." She is especially appreciative of the difficult customers who have taught her a lot about handling conflict.

A student at Nashua Technical College, Emily is working towards a certificate in American Sign Language and plans to become an interpreter for the deaf. She first fell in love with the beauty and poetry of signing as a student in Liz Langille's 11th grade Basic Sign Language course. "I felt brave and free when I signed," explained Emily. "I've always felt like a little birdie with a cinder block tied to its foot."

Emily's life growing up was very different than it is now. For most of her childhood, Emily said her only real friends were her mother and her cat. In school she experienced "stigma and hatred and loneliness." Emily literally carries the marks of her mistreatment; she has a scar on her right temple, the result of being stoned on the playground by boys who tormented her. Emily explained, "When you're the larger girl, when you're the shy girl, when you are not an outspoken girl, when you are the sensitive one, when you're obviously the loner, you might as well have a red bull's eye painted on your back."

All through elementary and middle school Emily was regularly teased, bullied, and harassed. "Bullies are nasty people that make your life a living hell. And they can be absolutely brutal," she said. There were times she paid other kids to sit with her at lunch so she wouldn't have to eat alone. "It just hurt sometimes going down to that cafeteria and looking around and seeing an empty table in the corner."

In middle school, Emily was diagnosed with schizophrenia and was eventually placed at Spurwink, a day program an hour's commute from her home. The move was hardly a solution; at Spurwink very little education took place. The severity of Emily's illness at the time caused her to 'escape' the real world by sleeping. "(They) just let me sleep all day and passed me through my classes," said Emily.

When she was a sophomore, Emily left Spurwink and went to Advance, an alternative school located at White's Farm in Concord. Finally, she was in a program where she could learn and get support for her special needs without being tormented. Emily made the decision to openly acknowledge her mental illness. "I finally felt like I can't live this lie anymore." One day at lunch she told the girls she was sitting with about her illness; the girls promptly picked up their trays and moved to another table. In spite of their reaction Emily is not sorry about "coming out" about her mental illness. It marked a turning point in her life and helped her to accept herself as she is.

Now an outspoken advocate, Emily and her mother, Anne Huff, regularly present at conferences about mental illness. They have testified at legislative hearings about the need for mental health services. Last year photojournalist Dan Habib did a feature about Emily for the Concord Monitor. Emily also will appear in Habib's documentary film, *Including Samuel*, which explores educational and social inclusion of youth with disabilities. Emily hopes that by publicly telling her story maybe some of those who tormented her will recognize themselves and "it'll make them knock it off for the rest of their lives."

"When people say inclusion or mainstreaming is the *only* way, think of the kids and think of how much emotional pain you're putting them in," Emily cautioned. "Sure they're having the experience of being with the other kids, but it's a forced experience. They could become depressed because they can't fit in and because there's an aide with them or they're falling behind. I honestly think that in some cases, mainstreaming is not the answer. I was in pain and agony."

Though as a child Emily was not included, even when she was "mainstreamed," as a young adult she has found ways to actively participate in and contribute to her community. She has friends, she has a job, she has a future, and she has a passion for changing the world and making the community a gentler place for those who are different.

Stop It!

Kristine Bergstrom, JD, Disabilities Rights Center

For a Minnesota boy known only in court filings as M.P., life changed forever after his school counselor let slip that he had schizophrenia. Once other students found out about M.P.'s diagnosis, school became a dangerous and terrifying place. Students called M.P. "psycho," "weirdo," "mental kid," "special," and "idiot." Students also shoved M.P.'s head into the drinking fountain, slammed him into lockers, threw him to the floor, shoved, scratched, spit on, and cut him. In spite of numerous complaints by his parents to the school district, the harassment did not stop. When M.P.'s parents asked for a solution, the school district's only suggestions were that M.P. be partially home-schooled or attend an entirely different school for children with mental health issues. M.P.'s parents knew the school's solutions were no solution at all; they sued the district for failing to keep their son safe. Six years later, after two trips to the Eighth Circuit Court of Appeals, M.P.'s parents won the right to sue the school for not preventing M.P. from being bullied.

M.P. is not alone. Sadly, there are many students with disabilities who are denied the opportunity to learn because they are continually picked on, teased, or ostracized. This bullying may even lead to increased drop-out rates and absenteeism. Statistics collected by the U.S. Department of Education show that in any given year almost 10% of all children report being subjected to bullying while at school.

Today, parents with children who are being bullied do not have to go the extremes that M.P.'s parents did. New Hampshire law specifically requires school districts to adopt a pupil safety and violence prevention policy that addresses bullying. School districts are supposed to inform parents about the details of the school's anti-bulling plan at the beginning of each school year.

While each district is allowed to develop its own plan, there are some basic requirements that every district must follow. For instance, under the state law any school employee who witnesses or has reliable information that a pupil has been subjected to insults, taunts, or challenges, either verbal or physical, that are likely to intimidate or provoke a violent or disorderly response that violates the school bullying policy must report the incident to the school principal. This reporting requirement

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Warning Signs: A child who is being bullied, may exhibit one or more of these signs:

- Withdraws socially; has few or no friends.
- Feels isolated, alone and sad.
- Feels picked on or persecuted.
- Feels rejected and not liked.
- Frequently complains of illness.
- Doesn't want to go to school; avoids some classes or skips school.
- Brings home damaged possessions or reports them "lost."
- Cries easily; displays mood swings and talks about hopelessness.
- Has poor social skills.
- Talks about running away; talks of suicide.
- Threatens violence to self and others.
- Changes in eating or sleeping patterns.
- Takes, or attempts to take, "protection" to school (a stick, knife, gun, etc.).
- Displays "victim" body language – hangs head, hunches shoulders, avoids eye contact.

From the website of the Department of Health and Human Services, National Mental Health Information Center at http://www.mentalhealth.samhsa.gov/publications/allpubs/SVP%2D0056/.

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also covers employees of companies that contract with the school district, such as bus drivers. Note that there is no requirement that the person reporting the incident witnessed the incident personally. Reliable information that an incident of bullying occurred is enough to trigger the reporting requirement. Once an incident is reported, principals must report the bullying to the parent or legal guardian of all pupils involved within 48 hours after the incident happens.

What happens after the bullying is reported varies from school district to school district. However, a good bullying prevention plan includes a clear definition of bullying, formal and informal reporting procedures, and consequences that are consistent and based on the frequency, seriousness, and duration of the bullying behavior. To ensure that all reports are taken seriously, schools should follow set investigative procedures once an incident is reported.

Once a school determines that one child has been bullying another, the school should have a range of interventions for the bully and the victim that match the seriousness of the behavior. For the bully, these options can include a behavior intervention plan, increased staff monitoring of the offender, behavior contracts, and restraining orders. All school staff should be involved with monitoring a bully in order to ensure that the behavior does not continue. Victims of bullying should receive support services that include: staff support, friendship building and social skill instruction, and self-esteem building exercises.

What can parents do when their child is being bullied at school? Parents should start by letting their children know that the bullying is not their fault, and that the child doesn't have to face the bullying alone. Parents should report the bullying incident to the school principal immediately. During that first contact, parents should ask for a copy of the school district's anti-bullying policy. It also is important to document both the harassment and the contacts to the school about the incident. This documentation will be valuable evidence if the parents ever need to prove the bullying in court.

Parents should be careful about advising their child to fight the bully or trying to bring the bully and victim together to "work things out" themselves. Bullying is a problem that requires an adult solution—preferably by a trained educational professional. However, parents can encourage their children to be assertive, to walk away from bullies, and to get help from a trusted teacher or adult if necessary.

Tom Owen and Jen Ricci having a wonderful time on a date.

Love.com

Thomas Owens, Jr.

Hello my name is Tom Owens Jr. I am 50 years old and have cerebral palsy. I live a very active life; I am involved with several organizations that assist people with disabilities and spend my days surrounded by friends and family. Finding things to do and people to spend time with is not a problem, but at night I am usually alone. It's the one time during the day that I am lonely. Then one night I received an email from my sister about a website for people with disabilities.

Www.lovebyrd.com is where my Internet dating journey began. At first I was quite skeptical, but I was willing to give it a try. Considering that I had just about given up on meeting someone special, I figured that I had nothing to lose. I paid $9.96 for my monthly membership and set up my personal profile. You can add pictures, which really helps with your search. Some profiles don't have pictures; so you're rolling the dice there, so to speak. The first few weeks I sent messages and got no responses. I was about to give up when I received the message that changed my life.

I had found a "match" and I was excited! Not only was Jen beautiful, but we also had so much in common. Like me she has cerebral palsy and a big bonus, she only lived an hour away. How rare to find someone with wonderful qualities who was also local. We started off slowly, sending each other daily messages. After a week we decided to make a big leap in online dating and exchanged our personal email addresses which made it easier to write each other.

Through our emails we asked each other all kinds of questions and really got to know one another. The months passed and we decided to make another leap - the old line, "Can I have your phone number?" It was great to hear her voice; she was a real person who was just as interested in me as I was in her. Things between us kept getting better and better. We had known each other now for nearly a year when I decided to make the biggest of all moves in online dating - "Lets meet each other."

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OURSPACE: Overcoming the Obstacles of Being Online

Matthew Gianino, Manager of Marketing & Communications, Institute on Disability

A few clicks of the mouse are all that is needed these days to bring the world to your doorstep. In the last 10 years, the Internet has become the most widely used tool in the world to communicate, as well as to access information, goods, and services. Here are a few quick Internet stats: Amazon.com did $8.5 billion dollars worth of business in 2005; Yahoo.com has over 105 million visitors each month; and in the last six months, the number of Internet users in the world has eclipsed 1 billion. Thousands of marriages and lifelong friendships have been initiated by online matchmaking services.

There is no denying the unprecedented global impact of what a keyboard, mouse, and monitor can do when plugged into a cable or phone line. The lightning speed and instant gratification of the Internet has made the world a much smaller place, but it also has posed new challenges and risks. It is important to understand these risks and learn what you can do to minimize them.

MySpace.com not only has grown exponentially in popularity, it also has become the most referenced website in the current online safety debate. With over 70 million registered users it is the second most popular website in the world. MySpace.com is a free Internet resource where users publish their own webpage that typically includes personal interests, photos, and messages. The ease with which anyone

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I was really nervous to ask her, but I figured it was worth the risk. I had never found a woman I had so much in common with. I waited for her emails everyday with so much anticipation. We had been emailing religiously and talking regularly on the phone. We had sent each other several pictures and exchanged gifts for birthdays, Christmas, and Valentine's Day. We even had each other as screensavers on our computers. Our emails always ended with, "I love you."

We both wanted to make this more than an email relationship. She agreed to meet me. We knew how special each of us was to the other and what a rare occurrence this was in both of our lives. We were going for it!

The meeting place, Square One Mall in Saugus, Massachusetts; the time, high noon March 20th, 2006 - the first day of spring. How symbolic is that? I arrived first and I am not going to lie, I was really NERVOUS! Suddenly I saw her coming around the corner and then she was right in front of me. What a moment for the both of us. We hugged and talked.

At first conversation was a little difficult due to our speech impediments, but with time we became more comfortable. It was a wonderful three hours. We had lunch, walked around the mall, and talked. She kept telling me how handsome I was and I told her she was perfect for me. It was like a dream come true. At the end of the afternoon we held hands for a while and said goodbye until next time. When I got home I told all my friends about her and showed them the wonderful pictures we had taken of each other. I immediately emailed her and we planned for our date for the next week.

I have cancelled my membership with lovebyrd.com, not because of anything negative I just don't need them any more. I see a wonderful future and who knows what's next. Recently Jen and I have been discussing her moving to New Hampshire so we can be together every day. I hope and pray this will happen. My advice for anyone who has never tried this before - GO FOR IT. Be careful and use your best judgment, but still do it. I was alone with no hope, about to give up, and I am now in love with a wonderful, beautiful, and intelligent woman. The future looks bright!

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can post and access personally identifiable information, has made MySpace.com a favorite haunt of identity thieves and child predators. Increasing concerns have led computer and Internet corporations, including MySpace.com and Microsoft, to launch initiatives to make the World Wide Web safer for everyone.

The Internet also has been a bonanza for marketing firms and other companies and individuals to gather information that enables them to target specific audiences. Using ethically questionable technology they are able to track the browsing habits of countless online users. Not only can they monitor individuals' websites, they also can infiltrate a computer's memory to retrieve web-surfing history and other information. This technology, in addition to invading privacy, can harm computer performance, increase the amount of junk e-mail and potentially place personal information into the wrong hands. Fortunately, firewalls and other protective computer software are continually being developed to combat this problem.

Besides reducing nuisances like spam (unwanted solicitation e-mails) and pop-up ads, having up-to-date antivirus software and practicing "web smarts" can help to ensure a positive online experience. Here are a few key practices to remember for Internet safety:

- Never post personally identifiable information online, particularly in chat rooms, personal webpages, or blogs
- Never post bank or credit card information on the Internet unless you are using a secured site set up by a reputable vendor.

NH Developmental Disabilities Council Seeking Input on 5 Year Plan

The New Hampshire Developmental Disabilities Council has recently established proposed goals and objectives for its new five-year plan. The Council would like the input of people with developmental disabilities, families, professionals in the disabilities field and the general public. The draft plan can be found on the Council's web site at www.nhddc.org, or a copy can be requested by calling the Council at (603) 271-3236.

Please forward any comments to the Council by Monday, July 10th. The Council will consider all public input prior to submitting its final plan to the federal government.

The Council is looking for opportunities to meet with groups around the State interested in people with developmental disabilities to discuss the plan and hear comments. Representatives of the Council are available to attend meetings of family support, self-advocacy or other disability-related organizations around the State between now and July 10th. Please contact Carol Stamatakis at the Council if you would like to make arrangements for a Council representative to attend a meeting in your area.

I AM ALONE

– Hazel Savage

I am alone
a phone
I have to talk with someone
but oh, so alone
to travel along the highway
to go and do a little sightseeing
all the noises I hear from friends and strangers
is a cheery "hello" - bellowing in unison!
calling, calling, hear the echoes
loud and clear, so far and few!
You catch the voices' tone
Lots of time on your hands to moan and groan
picking up pebbles - oh,so lonesome!
Just to hear the skipping and rippling
sounds of water bringing forth
Still feeling terrible loneliness
No matter what - just being alone
I am alone

Hazel Savage, a Concord resident, has been writing poetry for 30 years. She says poetry helps her keep going when she is down and depressed, and helped her cope with the pain of numerous hospitalizations.

- Invest in and regularly update antivirus software on your computer. McAfee and Norton Antivirus are two of the more user-friendly and reliable anti-virus products. Many high-speed Internet service providers offer antivirus software free to subscribers.
- Establish a firewall, a security measure to prevent unauthorized users from gaining access to your computer. This is especially important if you access the Internet over a wireless network. The latest version of Microsoft Windows includes this as a free feature.
- Do not keep any website membership usernames and passwords on your computer. If necessary, keep a hardcopy of this information in a safe and discreet place in your home.
- Do not share any online usernames or passwords with other people.
- Check for software updates regularly, particularly for Microsoft Windows and the antivirus software you use.

Being able to see the view from the top of Everest in seconds or downloading the latest episode of a television sitcom, all from the comfort of home, were the stuff of science fiction twenty years ago. Today the Internet is the portal to a wider world for millions of people. But it is important to keep in mind that the World Wide Web isn't a company or a single super-computer. It isn't owned or operated by any government or individual entity. It is means by which one out of six people in the world are freely interconnected. It is this "freedom" that inherently poses challenges that need to be addressed proactively. With a little homework and a reasonable amount of time and effort invested, the many "pros" can easily outweigh the few "cons" of utilizing and sharing countless online resources. And the amazing thing is that we are only just beginning to realize the potential of this incredible technology.

Talking with Your Kids about Sexuality: Do I Really Have To?

Katherine McLaughlin, Sexuality Education/Trainer for Planned Parenthood of Northern New England

Many parents of children with developmental disabilities often wonder whether they really need to talk about sexuality. They may not think of their child as a sexual person because of their disability, or they may feel afraid that talking about the topic will spark their child's interest in sex and cause them to start having sex. It is vital for parents to talk about this topic with their children. Why? Because we are all sexual beings!

Even though the media has a narrow view of who is considered sexual, we really are all sexual beings. The media would have us believe that only thin, blonde, physically fit, tall, young, able bodied people are sexual. We need to remember that all people – including people with disabilities – are sexual.

People with developmental disabilities are often left out of the conversation about sexuality, even though they too have thoughts, feelings and concerns about sexuality, just like everyone else. Not only are their parents reluctant to talk about sexuality with them, many individuals with disabilities are socially isolated and miss the informal learning that comes from hanging out with friends. Young people learn about sexuality by talking with friends about who they have a crush on, or how their bodies are changing as they're going through puberty.

Without other sources for information, many people with developmental disabilities learn about sexuality from television, a source that often is inaccurate or misleading. In addition, the media's portrayal of sexuality can be negative. It is important for parents to give their children positive, healthy messages about sexuality, in language that they can understand. Not only does this conversation ensure that the information their children get is accurate, it also gives parents the opportunity to discuss their own values about sexuality.

Finally, sexuality education is an important factor in the prevention of sexual abuse. People with developmental disabilities are at risk of being sexually abused because they often are taught to comply, and they often want to please others. By better understanding sexuality and relationships, parents can help their children distinguish between what is healthy and what is not healthy. Most importantly, they can let their children know that it is okay to say "No" to unwanted touch.

Many parents have trouble talking with their children about sexuality, but for those who have children with disabilities, it can feel even harder. Parents may not know how to begin or what to cover. They may not know how old their child should be before they start talking, or they may fear that talking will encourage their children to have sex. Parents may have ambivalent feelings about sexuality and their own children.

It is important to know that talking with your kids doesn't put them at risk; it gives them knowledge that will help them make healthy decisions about sexuality. It may be difficult, but it is the right thing to do because your child deserves to be as self-sufficient, capable, and sexually healthy as possible. Help them get there. Talk about sexuality with your children. It may be one of the most important conversations you ever have.

For a copy of the GULP newsletter on "Sexuality and Developmental Disabilities, go to www.ppnne.org, click on "education", click on "for parents" or call Planned Parenthood's Education Department at 1-800-488-9638.

Planned Parenthood of Northern New England *offers the following workshops:*

- Talking one-on-one with People with Developmental Disabilities
- Helping Parents Talk with Their Children About Sexuality
- Sexuality Education for People with Developmental Disabilities: Leading Groups
- Leading Staff Training on Sexuality and Developmental Disabilities

For more information about these trainings or to schedule a workshop, please contact Katherine McLaughlin at 603-352-0934 or katherin@ppnne.org.

Tips For Discussing Sexuality

Katherine McLaughlin, Sexuality Education/Trainer for Planned Parenthood of Northern New England.

Many parents of children with developmental disabilities are uncomfortable discussing sexuality with their children. Here are some general tips for talking about this sensitive topic.

✦ **You may have to initiate the conversation.** Many children won't ask questions, so you may have to bring it up. Here are some ways to begin - "Now, that you're growing up, I want to talk with you about body changes." or "Some people have questions about sexuality like how are babies made? Will I ever find a partner? What is a condom? What questions do you have?"

✦ **Give age appropriate information.** It's important to talk about the sexuality topics that are appropriate to the child's actual, biological age, not cognitive age. For example, if your daughter is 11 years old, it's important that she learns about body changes to prepare her for puberty, even if her cognitive age is 5. The trick is finding ways to teach abstract concepts in ways that your child can understand.

✦ **Take advantage of "teachable moments."** The best way to start a discussion is to take advantage of "teachable moments," those everyday events are perfect conversation openers. If a neighbor is pregnant, talk with your child about it. A television show or music on the car radio may offer a context for a conversation about sexuality.

✦ **Simplify your responses.** When answering your child's questions, less is better than more. Begin with the simplest explanation and provide additional information if your child continues to be interested or asks questions.

✦ **Be patient.** Concepts will need to be covered more than once. Skills will probably not be learned after one discussion. Expect children to ask the same questions again and again.

✦ **Find ways to be concrete when teaching the topic.** Use drawings, photographs, videos anatomically correct dolls, and three-dimensional models.

✦ **Try to give a consistent message**. It can be confusing for children with developmental disabilities when their parents give one message and a teacher or provider gives another message. Work closely with the people in your child's life to establish and give consistent, positive messages about sexuality.

✦ **Try not to react.** If your child is doing something inappropriate or asks a shocking question, try not to react. Try to remain calm. Respond to the behavior, by naming it and telling the child what is or is not okay. Answer questions in a matter-a-fact way. How you respond sends a message about sexuality and tells your child whether you are an "askable" parent or not.

✦ **Provide for practice in a safe setting.** Some skills are easily broken down into smaller steps; others will present a greater challenge. For example, it may be fairly easy to teach a young adult how to use a condom correctly; teaching a young adult how to ask a partner to use a condom and what to do if the partner refuses may be much more difficult. Role playing can help prepare your child to handle situations. Pretending you are the partner and having your child ask about condom use provides an opportunity to practice responding to the partner's reaction.

✦ **There's nothing wrong with being embarrassed, and there's nothing wrong with telling your children that you're embarrassed.** This helps to make it clear to your child that the embarrassment belongs to you and not to them or the topic. You may even explain that your parents didn't talk with you much, if that is the case, and that's why you feel embarrassed.

✦ **Let a book say the embarrassing stuff.** That way, you and your child are a team, confronting and reacting to all of the embarrassing things being said in the book.

✦ **You don't need to know the answer to every question.** If you don't know an answer, you and your child can hunt for it together. Make use of local resources – libraries, doctors, nurses, Planned Parenthood Health Centers, etc.

✦ **If you're thrown by a question, you have the right to answer it later.** Sometimes children pose questions that we'd like to answer, but we may be so taken aback that we don't know quite how to respond. It's perfectly okay to say, "I'd like to answer that question, but first I need to think about what I want to say." Just make sure you answer the question later.

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- **You have the right to pass on personal questions.** One way to help children develop their own privacy standards is for them to see that you also have your limits.
- **Watch your body language.** Your words and body language should be giving the same messages. Don't grimace when you're saying, "What a great question!"
- **Each time you respond in a way that helps your child learn concretely and positively, it will get easier for you.** Try imagining the hardest question your child could throw your way and practice answering it.
- **Let your children "overhear" conversations.** Your child may be too embarrassed to discuss sexual topics, but they may not mind hearing a discussion about the topic.
- **Ask your child for their opinion.** A child's self-respect begins with the consideration they receive from others.
- **Have a back-up person for your child.** Ideally, we want our kids to talk with us, but they may be uncomfortable and need another option. Find someone who has similar values to yours that your child can go to if they have a question or a concern.

Remember conversations about sexuality are not one-time only talks. Keeping the lines of communication open will help your child learn, and will help you feel more comfortable talking.

Resources For Parents: Talking With Children About Sexuality

BOOKS for Parents

Sexuality: Your Sons and Daughters with Intellectual Disabilities.
Karen Melberg Schwier and David Hingsburger.

I Openers: Parents Ask Questions About Sexuality and Children with Developmental Disabilities.
Dave Hingsburger. Family Support Institute Press. 1993

Just Say Know: Understanding and Reducing the Risk of Sexual Victimization of People with Developmental Disabilities.
Dave Hingsburger. Diverse city Press, Inc. 1995

BOOKS for Children

Changes in You: A Clearly Illustrated, Simply Worded Explanation of the Changes of Puberty for Boys.
Peggy Siegel. Family Life Education Associates. 1992

Changes in You: A Clearly Illustrated, Simply Worded Explanation of the Changes of Puberty for Girls.
Peggy Siegel. Family Life Education Associates. 1992

An Easy Guide to Loving Carefully.
Lyn McKee, Winifred Kempton, and Lynne Stiggall-Muccigrosso. Published by the authors, 1997

It's So Amazing.
Robie Harris, Candlewick Press, 1999

It's Perfectly Normal.
Robie Harris, Candlewick press, 1994

Changing Bodies, Changing Lives.
Ruth Bell, Three Rivers Press, 1998

WEBSITES

www.ppnne.org
www.nichy.org
www.diverse-city.com
www.siecus.org
www.teenwire.org
www.sexualhealth.com
www.plannedparenthood.org
www.yai.org
www.qualitymall.org

VIDEOS

All of us: Sex Education for People with Developmental Disabilities, Part One, Talking Together: Finding the Comfort Zone.
Lucaswrites Educational Video Productions, Planned Parenthood of Santa Barbara and San Luis Obispo Counties, 1999.

Handmade Love: A Guide to Teaching About Male Masturbation.
David Hinesburger, Diverse-City Press, Inc, 1995.

Finger Tips: A Guide to Teaching About Female Masturbation
David Hinesburger, Diverse-City Press, Inc, 1995.

Under Cover Dick: A Guide for Teaching About Condom Use
David Hinesburger, Diverse-City Press, Inc, 1995.

Can Love Be A Goal on the ISP?

Jeffrey Williamson

Kathy Ordway and Jeffrey Williamson danced the night away at the NH Technical Institute's Spring Semi-formal in Manchester

Dead before now.

Close to gone.

Help me fix myself.

This makes me a person. I was almost like dead. Finally, someone added me to my body and now I am really applauding.

Last but not least, I am inside.

A simple wish is for a friend and a great friend as serious as we can find. May be easier now that I can talk.

I wrote these thoughts ten years ago when I first began communicating by typing on a keyboard. My simple wish continues to be for a friend as serious as we can find. The most important thing is, that now the dearest things to me are people who love me and want to know me. Not people who really don't care about me. Right now the future is mine for deciding, not some stranger who has me the whole three hours he is working. Friends are closer to reality now than ever before.

If love goes around, when does it return back? When you send love out, how does one get it back? Do you have dreams of love in your life? I do. First you need help stating this dream for love. Most of us never even have the chance to say, "I want love in my life." Saying it is only the beginning. Realizing this dream is a whole other challenge. Don't ever believe that kindness is a substitute for love. There are many kind people in my life, but ask them about love and you will get an answer about easy things like friendship.

Open up your minds to knowing that everyone has gifts to deliver if you are ready to receive them. Everyone has the power to receive them. Opening the gifts is more important. The gift is the person inside. Like the time when my mom received me was when I was born. She opened me again when I started to talk. The person called Jeff was always there, but nobody knew it.

Now people are realizing that the gifts I want in my life are the same as what others consider gifts. The gifts of love and deep friendship.

Jeffrey Williamson lives in Manchester, NH. He owns his own home and for the past 13 years has worked at CB Sullivan.

People First Focuses on Relationships

David Wetherow, Community Works

In October 2005 People First of New Hampshire held a day-long workshop, Navigating the Waters of Relationships. David and Faye Wetherow, founders of Community Works, led a guided reflection to help people envision how to seek, choose, sustain, and communicate in the relationships that are at the core of our emotional live. These include relationships with friends, trusted allies, lovers, and life partners.

Together we explored ways of discovering new people who share our interests, recognize our gifts, and value the same things that we do. We talked about the qualities we hope for in relationships - the things that help us feel safe, loved, and loving. We explored ways of finding out whether someone we care for has these qualities.

In the workshop we practiced new ways of communicating clearly and compassionately at times when we are feeling unsafe, confused, disrespected, or hurt. We talked about the importance of bringing our gifts of love and understanding to the larger community and the value of joining groups in our communities who share our interest in strengthening relationships and living in a more compassionate world.

More information about People First can be found on their website, wwwpeoplefirstofnh.org. To learn about David and Faye Wetherow visit their website at www.communityworks.info.index.htm.

Doug & Andrea Ewing kayaking as part of Northeast Passage's adaptive paddling program

Developing Relationships Through Recreation

Matthew Frye, B.S., CTRS, TREK Program Coordinator, Northeast Passage

Many of our most meaningful and lasting relationships are developed around the backyard, on the playground, and on the sports field. As adults, we continue to develop relationships at the gym, on the golf course, or in a racquetball court. When disability enters the picture many of these arenas for building relationships are abandoned.

At Northeast Passage, we strive to keep people happy, healthy, and active through participation in recreation. We offer recreational opportunities across a wide array of activities and seasons with the ability to adapt all of our programming for a spectrum of abilities and needs. We offer cycling, sled hockey, scuba, water skiing, golf, cross country skiing, hiking, court sports, and paddling activities. Northeast Passage has resources to help individuals participate in a myriad of other recreational endeavors from hangliding to photography. We also have hundreds of pieces of adaptive equipment that can be rented and used when and where a person wants.

While our events and activities may differ greatly, the one constant is two or more people participating together, either cooperatively or alongside one another. This is the first step to creating a meaningful relationship. Something as basic as throwing a baseball back and forth has implications beyond fun and games. You can't play catch if you don't trust the other person to throw the ball back. You must also trust that person to not throw too fast or too high. This simple trusting connection may be the seed that grows into a friendship.

Beyond a sense of trust, recreation offers camaraderie. Two strangers arriving at a scuba class immediately know that they have something in common. As their participation in the class progresses, they have shared fears, challenges and successes to spark discussion. It takes much more than a shared interest in one activity to create a meaningful relationship, but shared experience can create a connection in which more shared interests can be discovered.

Northeast Passage invites you to come enjoy the physical, cognitive, emotional, and social benefits of recreation. Whether you have a new disability, lifelong disability, or no disability, we want you to get active and create new relationships.

Northeast Passage is a program of the University of New Hampshire's Department of Recreation Management and Policy. More information is available at www.nepassage.org or by calling Northeast Passage at 603-862-0070.

The Guardian's Role in Supporting Meaningful Relationships

Linda Mallon, JD, Executive Director, Office of Public Guardian

How do guardians resolve the dilemma of wanting to encourage meaningful relationships while also trying to protect their wards from the risk of harm? (Ward is the legal term describing a person under guardianship.) The opening section of New Hampshire's guardianship law offers guardians both a philosophical approach and a purpose "to promote and protect the well-being of the ward…to provide safeguards for civil liberties and…to encourage the development of maximum self-reliance in the individual." (NH RSA 464-A: 1)

Guardians have a responsibility to make decisions on behalf of their wards that protect their rights of independence and self-determination. The Office of Public Guardian's (OPG) Code of Ethics, authored by Michael Casasanto, Mitchell Simon, and Judith Roman in 1988, details these responsibilities. The Code, which was ultimately adopted by the National Guardianship Association, describes general rules for proper decision-making, including a duty to support the wishes and preferences of the ward whenever possible. If a ward's wishes cannot be determined, or if supporting these wishes would cause substantial harm, then the guardian's duty is to make a decision that is in the person's best interests.

To carry out the responsibilities of guardianship, it is important for the guardian to establish a relationship with the individual and become thoroughly familiar with the person's history, needs, and goals. Guardians who are family members or friends already have this knowledge. For public guardians, getting to know the individual requires a substantial investment of time, research, and documentation in the first months of a new guardianship. This understanding enables the guardian to advocate for an individual based on his or her unique circumstances.

In addition to developing a relationship with the ward, it is important for the guardian to support other meaningful relationships in the individual's life. The presence of family and friends is essential to the quality of anyone's life. Unless it would be harmful to do so, the guardian should support the individual in maintaining those relationships. Despite the fact that certain rights are limited or removed when a person is found legally incapacitated by the probate court, many fundamental civil rights remain. These include the right to choose friends and sexual partners, the right to privacy, freedom of religious expression, freedom from abuse and neglect, and the right to reside in the least restrictive available setting.

A guardian's responsibility to promote meaningful relationships must be balanced with the duty to take reasonable measures to protect the ward from harm and exploitation. Sometimes it is very difficult for a guardian to know where to draw the line when the person is in a vulnerable situation. Each situation should be addressed individually, taking into account the person's wishes, the extent of the risk, the value and dignity in allowing some level of risk, and ways in which the potential for harm could be reduced. The National Guardianship Association has built on the foundation established by OPG's Code of Ethics by adopting Standards of Practice for Guardians. These Standards offer a "toolkit" approach to the everyday practice of guardianship and provide helpful guidelines. Both the Code of Ethics and Standards of Practice can be accessed through a link on the NGA website, at www.guardianship.org.

There are times when a guardian is completely comfortable with facilitating meaningful relationships in the individual's life and other times when a leap of faith is required to accept the risks associated with relationship building. However, because personal relationships bring a richness and quality to every life, as guardians, we must do all we can to promote opportunities that enable those we support to develop meaningful relationships.

RELATIONSHIP RESOURCES

ADS Center
11420 Rockville Pike, Rockville, MD 20852
stopstigma@samhsa.hhs.gov
1-800-540-0320 (English/Spanish)
http://www.stopstigma.samhsa.gov/
SAMHSA's Resource Center to Address Discrimination and Stigma provides practical assistance in designing and implementing anti-stigma and anti-discrimination initiatives.

The Asset-Based Community Development Institute
The Institute for Policy Research
Northwestern University
http://www.northwestern.edu/ipr/abcd.html
The Institute is built upon three decades of community development research by John Kretzmann and John L. McKnight

Axis Consultation and Training, LTD. (Norman Kunc and Emma van der Klift)- http://www.normemma.com/

Beach Center on Disability
University of Kansas, Haworth Hall
1200 Sunnyside Ave., Room 3136
Lawrence, KS 66045-7534
785-864-7600, Fax: 785-864-7605
TTY: 785-864-3434
Email: beachcenter@ku.edu
http://www.beachcenter.org/

Brain Injury Association of New Hampshire
109 N. State Street, Concord, NH 03301
603-225-8400
http://www.bianh.org/
BIANH has a wide range of resources and services, including the Connections Program, a support system through phone contact to individuals or family members who are experiencing brain injury or stroke.

Community Works
http://www.communityworks.info/index.htm
David and Faye Wetherow's website

Disability is Natural - http://www.disabilityisnatural.com/
Very person and family-centered website

Inclusion.com
Canadian website that includes person-centered planning material, training events, and the Marsha Forest Centre. http://www.inclusion.com/

The Krempels Brain Injury Foundation
PO Box 4388, Portsmouth, NH 03802-4388
603- 433-9821
http://www.krempelsfoundation.org/
The Krempels Foundation has grants and operates SteppingStones, a day program for people who have had brain injuries. It has recently launched an oral history project of SteppingStone members. Audio interviews in mp3 format are on their website.

The Minnesota Governor's Council on Developmental Disabilities
http://www.mncdd.org/extra/publications.htm
Has many publications including *Friends, A Manual for Connecting Persons with Disabilities and Community Members*

Northeast Deaf & Hard of Hearing Services
125 Airport Road, Concord, NH 03301
603-224-1850 or TTY 224-0691
info@ndhhs.org
http://www.ndhhs.org/
New Hampshire's "one-stop" resources for services specific to the Deaf and Hard of Hearing community and for information about hearing loss. NDHHS has monthly social gatherings.

The Riot – "Self Advocacy, it's a riot!"
http://www.theriotrocks.org
A national, free e-newsletter from the self-advocate leadership network at HSRI. The April 2006 issue is on love. Don't miss page 2 for a column by our own Marian West.

Social Role Valorization home page
http://www.socialrolevalorization.com/

Unlimited Connections
A dating service of the Rhode Island ARC
http://www.bvcriarc.org/services/recreation/unlimited_connections.htm

Is One the Loneliest Number?

Linda B. Bimbo, M.S., Institute on Disability

Spending quiet moments alone in solitude should not be interpreted as social isolation. Aloneness is not the same as loneliness. You should be able to enjoy your own company. But while it is possible to be your own best friend, you shouldn't be your only friend.

LINDA BIMBO

Julie Whittington with one of her beautiful quilts.

Julie Whittington, a grandmother and fantastic quilter, has suffered with depression for many years. Before she sought treatment, she would spend days alone struggling to take care of her daily needs, isolated from her friends and family. Now she uses one of her quilts, pieced together during her recovery from a deep depression, as a vehicle to speak with other older adults about depression and the need to stay involved with others.

As sociologists have pointed out, as we age, our roles change. Once we were workers, now we're retired; once we were parents, now our children are on their own; and once we could remember things and see or hear better, now we need help with daily activities. For many aging Americans a change in roles leads to a change in the social activities they are engaged in.

For older adults with depression, Alzheimer's disease, or other dementia, the social isolation that often accompanies these diseases, can make the situation worse. Depression in the elderly is often dismissed as "part of growing old." It is important to recognize that depression is not part of the aging process. In serious cases, depression can pose a significant health hazard in the elderly by exacerbating existing physical problems or boosting the risk of suicide.

By the age of 65, according to the American Medical Society, 18 to 28 percent of the elderly in the United States suffer significant symptoms of mental illness. The most common problems of older adults are dementias such as Alzheimer's disease, anxiety disorders, depression, and cognitive or mood disorders often caused by physical problems, such as heart disease or poor nutrition. Mental illnesses, at any age, can and should be properly diagnosed and treated.

The good news is that being alone and loneliness are not the same thing. Whether someone lives in their own home or in a group setting there are many opportunities to become or remain active in social programs and activities. Julie often works on her quilts, alone, in the quiet of her own home. It allows her to concentrate. She also teaches others how to quilt and shares her love of quilting.

SAVE THE DATE

The New Hampshire Developmental Disabilities Council's 12th Annual Direct Support Professionals' Conference - "Creating A Better DSP" will be held October 27 & 28, 2006 at the Grand Summit Hotel and Conference Center in Bartlett, NH. Last year's popular keynote presenter, Peter Leidy, is coming back. If you are a DSP now is the time to let your agency know you would like to attend. The conference brochure will be available on the Council website – www.nhddc.com - after August 1st. For more information please contact the New Hampshire Developmental Disabilities Council, 21 South Fruit Street, Suite 22, Concord, NH 03301-2451, (603) 271-3236 or email Bonnie Addario at baddario@dhhs.state.nh.us.

DISABILITIES RIGHTS CENTER, INC.
18 Low Avenue, Concord, NH 03301-4971
Voice and TDD: (603) 228-0432 ✦ 1-800-834-1721 ✦ FAX: (603) 225-2077
TDD access also through NH Relay Service: 1-800-735-2964 (Voice and TDD)
E-mail: advocacy@drcnh.org ✦ Website: www.drcnh.org
"Protection and Advocacy System for New Hampshire"

The Disabilities Rights Center is dedicated to eliminating barriers to the full and equal enjoyment of civil and other legal rights for people with disabilities.

INSTITUTE ON DISABILITY/UCED – UNIVERSITY OF NH
10 West Edge Drive, Suite 101, Durham, NH 03824-3522
Phone (Tel/TTY): (603) 862-4320 ✦ Fax: (603) 862-0555 ✦ Website: www.iod.unh.edu

Institute on Disability/UNH – Concord
56 Old Suncook Road, Suite 2
Concord, NH 03301
Phone (Tel/TTY): (603) 228-2084

Institute on Disability/UNH – Manchester
250 Commercial Street, Suite 4107
Manchester, NH 03101
Phone: (603) 628-7681

The Institute on Disability advances policies and systems changes, promising practices, education and research that strengthen communities and ensure full access, equal opportunities, and participation for all persons.

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Dignity, full rights of citizenship, equal opportunity, and full participation for all New Hampshire citizens with developmental disabilities.

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