

TASH CONNECTIONS

Equity, Opportunity and Inclusion for People with Disabilities since 1975

Inside This Issue

- 2004 TASH Executive Board Election
- Making Social Relationships an Integral Part of Sex Education
- Respecting, Supporting, and Honoring the Sexuality of All People
- Listening to Women's Voices: Risk Reduction in Community Settings

URGENT! Dated Material Inside!
2004 TASH Executive Board Election Ballot

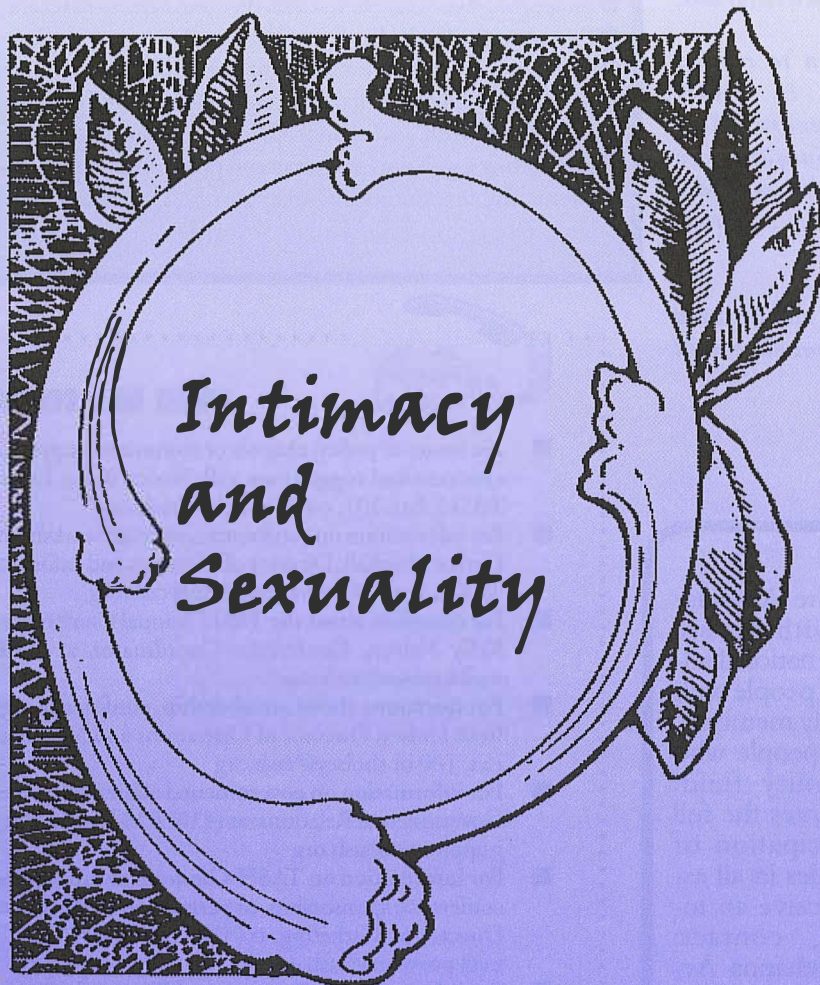


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Requests for permission to reprint material appearing in TASH Connections should be sent to: TASH Connections, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204, Attn: Priscilla Newton, Editor.

Permission requests can also be faxed to (410) 828-6706 or sent via e-mail to: pnewton@tash.org.

TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. **TASH** actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: **TASH**, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

TASH MISSION

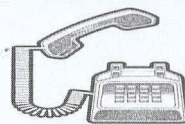
TASH supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

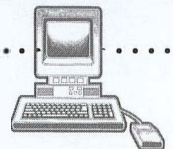
- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging;
- Are most likely to have their rights abridged;
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments;
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf;
- Historically have been labeled as having severe disabilities; and,
- Are most likely to need on-going, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates;
- Advocating for equity, opportunities, social justice, and rights;
- Disseminating knowledge and information;
- Supporting excellence in research that translates to excellence in practice;
- Promoting individualized, quality supports;
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports;
- Supporting legislation, litigation and public policy consistent with **TASH's** mission; and,
- Promoting communities in which no one is segregated and everyone belongs.



WHOM DO I CONTACT?



- For issues of policy, chapter or committee support, or general concerns and suggestions, call: Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail: nweiss@tash.org
- For information on conferences, regional workshops, or technical assistance, call: Denise Marshall, Director of Meetings and Information Resources, at (410) 828-TASH, Ext. 103, e-mail: dmarsh@tash.org
- For questions about the **TASH** Annual Conference sessions and presenters, call: Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail: knelson@tash.org
- For questions about membership, conference registration or exhibiting, call: Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- For information on governmental affairs, call: Jamie Ruppmann, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: [jrppmann@tash.org](mailto:jruppmann@tash.org)
- For information on **TASH Connections** submissions and advertising, conference sponsorship, or permission to reprint, call: Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail: pnewton@tash.org
- For information on **Research and Practice for Persons with Severe Disabilities** (a publication of **TASH**), call: Freda Brown, Editor-in-Chief, at (718) 997-5243, e-mail: fbrowncuny@aol.com
- Don't forget to visit **TASH's** web site at <http://www.tash.org>



**FROM THE EXECUTIVE
DIRECTOR**

By Nancy Weiss

Exercise your right to vote!

In just a few weeks, many of us will be called upon to exercise one of our most important rights and responsibilities as citizens. As we quickly approach another national election, I urge each of you to take the opportunity to vote this November. Information is available about local, state and national candidates for office and their positions on the issues from a number of sources. Jamie Ruppmann, TASH's Director of Governmental Relations, provides some useful resources for obtaining voter information beginning on page 4.

A good opportunity to "practice" selecting the candidates of your choice is offered right now through your participation in the election of TASH Board members. Four Executive Board members will be elected for terms that will begin at the 2004 TASH conference (November

17-20, in Reno) and continue until the 2007 TASH conference. The primary roles of the TASH Executive Board are to:

- ❖ Make major policy decisions for the operation of the organization;
- ❖ Plan for TASH's future;
- ❖ Assist in building TASH's membership and impact;
- ❖ Participate in maintaining TASH's fiscal viability;
- ❖ Approve TASH's annual budget and monitor TASH's financial status;
- ❖ Clarify and promote TASH positions on a range of timely topics, and be proactive in determining the need for new or revised resolutions and position statements;
- ❖ Support TASH values in theory and practice, in both personal and professional arenas; and
- ❖ Promote valued perceptions of people with disabilities, respectful supports, and progressive policy and legislation.

To accomplish these objectives, Board members stay abreast of the needs and concerns of members, chapters, and committees. You will find the self-mailing ballot on page 11. Take a few minutes to review the statements of the excellent candidates who are running for the Executive Board this year, and return your ballot to the TASH office before the deadline.

Thank you for taking an active role in selecting new Executive Board members!



TASH Receives 2004 President's Award from National Down Syndrome Congress

At its Annual Awards Banquet in Milwaukee, the National Down Syndrome Congress presented its President's Award to TASH. The award citation reads:

"For tenacious commitment and leadership in advancing and disseminating best practices to improve the quality of life for individuals with significant disabilities."

Judy Martz (r), President of the National Down Syndrome Congress, presented the award to Jamie Ruppmann (l), TASH's Governmental Relations Director, who accepted on behalf of TASH.

TASH: Public Policy in Action

ACCESS AND EDUCATION ARE EMPHASIZED AS THE DISABILITY COMMUNITY GETS READY TO VOTE

A growing number of projects and activities are focusing on making sure that individuals with disabilities are informed about the people running for office in their states and the positions of the national candidates. Equally important is the right of each citizen to access the polling places and vote.



ROLL THE VOTE

Roll The Vote is a nationwide effort to link voters with the Federal Election Commission's National Mail Voter

Registration Form. This form can be used as a voter registration tool when downloaded on plain paper, completed, signed and mailed using first class postage.

❖ The Election Assistance Commission, an independent, bi-partisan agency authorized by the Help America Vote Act (HAVA) has a good website that offers updated information about many voter registration and access issues. The address of this site is <www.eac.gov>

❖ The League of Women Voters has developed an informative *Voter's Guide to the Help America Vote Act* -- go to "where we stand" on their web page. They also offer extensive information about voting -- click on "voter information." The League's web address is <www.lwv.org>

❖ United Cerebral Palsy (UCP) has launched the "Don't Block My Vote" campaign to help assure that people with disabilities, their families and supporters have the access they need to fully participate in elections.

Voters with disabilities often go to the polls only to find that even though federal law requires all polling places to be accessible to people with disabilities, problems still exist. Inaccessible polling places, voting machines, and ballots too often force voters with disabilities away from the polls.

Sadly, the extra effort, frustration and humiliation many people with disabilities endure to exercise their right to vote prevent many from voting at all.

According to United Cerebral Palsy, more than 20 million eligible voters with disabilities did not cast a vote in the 2000 election. Through DontBlockMyVote.org, UCP is encouraging eligible voters to participate in this year's election, while building support for full funding for the Help America Vote Act (HAVA). For more information, visit <www.DontBlockMyVote.org>

❖ The American Association for People with Disabilities (AAPD) has established a special web site and voting project that can be

accessed at:
<www.aapd-dc.org/dvpmain/newdvindex.html>

AAPD's Disability Vote Project is focused on meaningful election reform, efforts to get out the disability vote, access to polling places and voting systems, and encouraging service providers to people with disabilities to comply with the provisions of the National Voter Registration Act. In addition, AAPD is encouraging people with disabilities to run for office and to get involved in the political process for the candidates of their choice.

❖ And, finally everyone is urged to find out about each candidates' positions and views on matters of importance to TASH members. Contact information for the Presidential Campaigns:

BUSH-CHENEY '04
Phone: 703.647.2700
FAX: 703.647.2993
BushCheney04@GeorgeWBush.com

KERRY-EDWARDS 2004, INC.
Phone: 202.712.3000
FAX: 202.712.3001
TTY: 202.336.6950
www.johnkerry.com/contact/

You will find responses received from President Bush and John Kerry to a set of questions posed by the American Association of People with Disabilities (AAPD) on the TASH website.

For more information about TASH positions and public policy, contact Jamie Ruppman, Director of Governmental Relations, jruppman@tash.org
410- 828-8274, x104.



Honor a Loved One through a Tribute Gift to TASH

Many of us make charitable gifts to memorialize a loved one or honor a birthday or anniversary, the help of a teacher or advocate, or another important event. We hope you will think of TASH as a special way of thanking someone or commemorating these times.

Many people specify donations to TASH in lieu of flowers upon the death of a family member. Please consider a gift to TASH when you are looking for a way to honor the memory of a loved one.

When you make a memorial or tribute gift, we will thank you and send a special note to the honoree or the bereaved family.

Just let us know your preferences:

- ☐ Memorial Gift
☐ Other Tribute Gift (specify occasion or purpose):

Please send the acknowledgement card to:

Name _____

Address _____

City/State _____

Zip/Postal _____ Country _____

In Memory of/In Honor of: _____
 (Person's Name)

Special Message (if desired):

Your name and telephone #:

☐ Check enclosed ☐ M/C ☐ Visa ☐ Discover

☐ Card #: _____

Expiration Date: _____

Of course, the amount of your gift is always confidential. Unless you specify otherwise, a thank you for your tribute gift will be featured in the next issue of TASH *Connections*.

Donations to TASH are tax deductible and can be made using the form to the left, or electronically by going to: www.tash.org/donate/index.htm

You can fax information to us at 410-828-6706 or call Rose Holsey for more information at 410-828-8274, ext. 100.

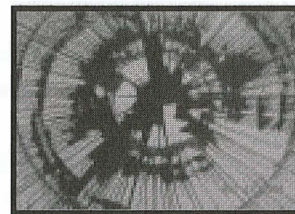
Below are the designs and text of the cards that we will send (text can be individualized as you prefer).

Text of Memorial Card:

In loving memory of _____ a generous donation has been made to TASH by _____.



The in-memory card is full color in a beautiful water color print. "Freedom Flight" designed by Jessica Vohs. To see Jessica's other work go to: www.jessicavohs.com.



Text of Tribute Card:
Congratulations! In honor of _____ a generous donation has been made to TASH by _____.

The in-honor card is full color in a beautiful abstract design by Lucy Aponte. To purchase cards by Lucy, e-mail: Luzaponte1@aol.com.



THE 2004 EXECUTIVE BOARD ELECTION

One of the most important things members of any organization are asked to do is to participate in selecting members of the Executive Board. Now is the time for you to decide who will help provide critical leadership in TASH's social justice movement for people with disabilities. Many important issues and challenges face us — your participation as a voting member of TASH counts more than ever.

Four of the 15 seats on the TASH Executive Board will be re-seated at the November TASH Conference in Reno. The individuals who appear on this year's slate have made significant contributions in the lives of people with disabilities and have demonstrated leadership in the disabilities movement.

Your vote is critical. Please use the postage-paid, self-mailing ballot provided on page 11, or clearly write "ballot" on the envelope you use. Ballots must be received at the TASH office by **October 18, 2004**. Please use ink and vote for four candidates. Voting for more than 4 nominees will invalidate your vote.

THE FOLLOWING ARE THE NOMINEES FOR THE TASH EXECUTIVE BOARD OF DIRECTORS:

Carol Berrigan

"I feel honored to be nominated for the TASH Board. TASH, of which I am a lifetime member, has been a part of my life since the organization's beginning.



For three decades I have worked with the Center on Human Policy, a Syracuse University-based policy, research, and advocacy organization involved in the national movement to ensure the rights of people with disabilities. The Center has been connected with TASH from its creation.

The Center is involved in a broad range of local, state, national, and international activities, including policy studies, research, information and referral, advocacy, training and consultation, and information dissemination. I, as part of the staff, have a commitment to promote

inclusive education, employment opportunities, and full community participation for people with disabilities. In conjunction with parent leaders, I helped organize parent advocacy groups to educate and encourage many parents to join the movement. We regularly stage conferences with national leaders, sharing their wisdom and inspiration.

As well as being a part of the Center on Human Policy, I have been a faculty member of Syracuse University's Division of Special Education and Syracuse University's Division of International Programs Abroad. Campus graduate courses I taught involved designing inclusive education. I was also a consultant to school districts in New York State as well as in other states.

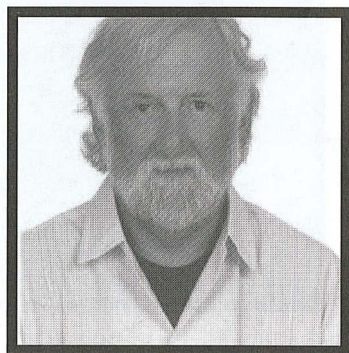
Beginning in 1984 and continuing to 2002, I directed a graduate summer course abroad entitled, '*Education in Italy: An Inclusive Approach*.' In 1983, I had a series of discussions with Gunnar Dybwad (of distinguished memory). For years, Gunnar Dybwad was a mentor to many leaders in the field of the special education. From him, I learned that Italy has the best national policy in the world for including all students in regular classrooms. Inclusion in Italy occurs without regard to the severity of disability and includes appropriate supports. This information inspired me to design my own course. For several years I have presented at TASH on the education system of Italy and have written several articles on related themes.

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2004 TASH BOARD ELECTION

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In August, 2002, I retired from teaching. I still continue to be a part of the Center on Human Policy, and particularly to the Center's Advocacy Board. The Advocacy Board is composed of people from the community who perform the invaluable service of keeping the Center on Human Policy grounded in the every day experiences of people with disabilities and their families. An additional role of the Advocacy Board is to bring about significant changes in our community. Keeping with that tradition, I pledge a life-long commitment to advocate for individuals with disabilities and their families."



Lyle Romer

"Like almost everyone else, I

find it difficult writing things about myself. And, since I don't want to completely bore anyone, I have the additional burden of trying to be interesting as well as informative. So, my apologies upfront if I fail at either or both of those objectives.

In some sense I grew up with TASH, at least professionally. Although 2 members of my family experience developmental disabilities, I had little contact with the professional side of things until I was about 25. In 1973 I

had just moved to Oregon from New York with my wife, Mary, and my then 2 year-old son, Justin. Having no reasonable prospects upon arrival in Oregon I took on various jobs, U.S. Forest Service fire crew, welder and house painter.

As a house painter, I was working on what I later found out to be a group home for 10 women that had opened only months prior. One thing led to another and Mary and I became substitute and, eventually, full-time house parents. I'm sure I need remind no TASH members of how humbling it is to look back at our past. I bring this up because as an enormous bonus, we found our selves working for Bud Fredericks, one of the founding members and past president of TASH. I feel a little like I am telling you I come from good stock, and that is entirely a reflection on the good fortune I had to learn from someone like Bud.

I started graduate school about a year later and I remember hearing about all these people going to a conference being held by a new group, The American Association for the Education of the Severely and Profoundly Handicapped (language conveys so much more than the words themselves, doesn't it?). Of course, this was the first TASH Conference. I didn't get to go that year, but I have made most of the conferences since then.

Along the way I continued my run of good luck, continuing to work with Bud, and also Rob Horner, Tom Bellamy and Norrie Haring. This gave me chances to work with people with disabilities where they went to school, where they worked and where they lived. After 30 years working primarily in research and policy,

either for a university or state government I, and Mary, are now managing a supported living agency just south of Seattle, Washington.

I am committed to TASH and to offering to run for the board for some of the same reasons I choose to leave my previous position and become the director of Total Living Concept. While it may not sound like the most sensible reason to change my job, a lot of it had to do with my impatience. I know to some people this is a flaw, but I remember the fragment of a quote about how you can't grow crops without turning over the dirt. I wanted to do something again that directly made a positive difference in the lives of people with disabilities.

I am again part of a truly wonderful group of people at TLC, who all have one thing in common -- a burning desire for social justice. They, and I, don't use that term, but it's also what we at TASH are all about. We think we will all live in a better world when no one has to live in that world alone, without friends, without hope; anyone, ever. Certainly we do most of our daily work with people who experience disabilities. But how could we ever limit our concerns to one group of people without diminishing our values? TASH has never been afraid to say what it stands for and I admire that in a person and an organization.

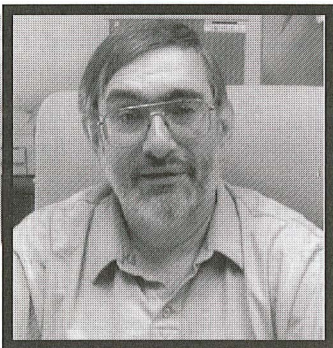
I want to be on the TASH board because one of its greatest responsibilities is to be an exemplar and a model for the values and principles for which TASH stands. I don't kid myself that I embody or even possess all the good things TASH stands for, but being

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2004 TASH BOARD ELECTION

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able to work with and learn from other TASH members through service on the board would continue my opportunities to learn from people who feel this passion for social justice everyday. As it says in our mission statement at TLC, I will pledge my mind, my heart, my passion to the values TASH works to achieve. It is an honor to be asked, and a challenge I will readily accept if offered the chance."



Jeffrey Strully

"I have been a long-time member of TASH and a

board member for the last three years. Over the years, I have served on the conference planning committee, as well as personally being a presenter at numerous TASH conferences.

I am currently the Executive Director of Jay Nolan Community Services, a not-for-profit human service agency located in California that provides personalized and individualized supports to people with autism and other developmental disabilities so that they can lead valued lives in the community. I have been involved with people with developmental disabilities for over 32 years in a variety of different capacities and environments throughout the United States. I have had the honor of

speaking throughout the U.S., Australia and England on issues of inclusion, friendship, family-related issues, supported living, organizational change, and person-centered planning/support. In addition, I have authored several articles on inclusion and friendship with Marsha Forest, John O'Brien, and Bill and Susan Stainback.

However, most people know me as a parent. I have spoken about our family's journey for inclusion in our neighborhood school, relationships outside of school, attending college, moving into one's own home, careers, jobs and owning businesses. These are some of the issues which we have worked on and struggled with over the years.

The most important issue that I have had the honor of being involved with has been the value and importance of friendships in the lives of all people. It is this subject that so many people continue to want to see happen, but it continues to be lacking in the lives of many people.

I would like to see TASH continue to be a beacon in the professional, parent and consumer communities for those things that are important to our members such as inclusion in schools, person-centered planning, quality lives, empowerment and choice. I would hope that TASH would focus more of its efforts on the plight of adults with developmental disabilities. That is not to say that we shouldn't be concerned about what is happening in our schools. We definitely need to advocate for quality and effective education for all learners.

As an agency director, there are many issues that administering a not-for-profit organization needs to be aware of and concerned about. I would hope to continue to bring my skills and knowledge in this area to assist the TASH central office staff as well as the Board in these matters.

Finally, TASH needs to continue to push the envelope. Whether it is generating income so that people with disabilities can accumulate wealth, attending and graduating from college, home ownership, sex, love, and marriage (maybe not in that order), friendship, or another area, I want to see TASH be in the forefront of these issues so that ALL people will lead wonderful, valued lives."

Nancy Ward

"I am Nancy Ward and I am currently the Self-Advocacy Specialist for

Oklahoma People First, which is sponsored by the Oklahoma University Health Sciences Center, in Oklahoma City. Locally, my role is to teach those with disabilities to speak up for themselves. Also, I promote self-advocacy by educating society about people with disabilities. Nationally, I am a trainer and management team leader for the Medicaid Reference Desk and the Project Vote Programs.



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2004 TASH BOARD ELECTION

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I have been active in the self-advocacy movement for 25 years. I have received many awards and certificates for my contributions to the movement. I was honored in 2000 as one of the 20 most influential national leaders in the disability community. I was a founding member and chairperson of Self-Advocates Becoming Empowered (SABE), the national self-advocacy organization. I have been involved with Regional SABE and Southern Collaborative, which are self-advocacy groups within my geographical region.

I am considered to be a national disability policy expert and tireless leader who has supported the development of numerous self-advocacy organizations. My participation throughout the years has taken me to every state in the nation, except two, and to four (4) countries; Canada, China, Japan, and England.

I am willing to commit to the requirements of an Executive Board Member. If elected, I would be honored to serve the term to the best of my abilities."



Donna Wickham

"As a TASH member for over twenty years, I've witnessed changes in

how we operate and who leads, but the thing that has remained constant is a vision for improved quality of life for children, youth and adults with labels of severe disabilities. I am honored to be nominated to serve on the board with such an important vision and mission. If elected I would be proud to continue that mission.

Over the years I have been involved with TASH in several capacities. I have been involved in the formation of two state chapters, and served on the Kansas TASH board when it was first formed and later as Treasurer. I worked on the OSEP-funded national technical assistance center for children and youth with deaf-blindness (currently NTAC). Later, I was an Alice Hayden recipient after completing my doctorate at the University of Kansas.

As a board member, I would be interested in the Membership and Chapter committees. Specifically, I am interested in exploring ways that TASH might increase its role in professional development and ways to network members in states. In my consulting work around the country, I am always surprised to find families and teachers who are unaware of TASH resources.

During my professional career, I have been a classroom teacher and technical assistance provider and coordinator after earning my masters degree in severe disabilities from the University of Missouri. I have also been a university instructor, consultant and grant administrator after earning my doctorate in education from the University of Kansas.

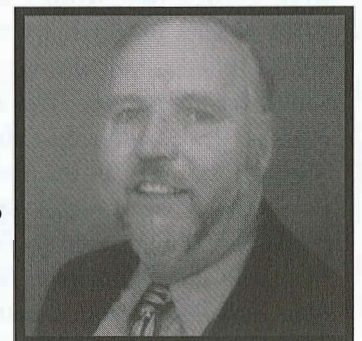
Most recently I have accepted an Associate Director position with the Inclusive Large Scale Standards and Assessment Center at the Interdisciplinary Human Development Institute, University of Kentucky. In that capacity, I work with state departments and teachers as they implement alternate assessment. I also continue to teach new and currently practicing teachers in Kentucky.

My professional interests include positive behavior supports for students with challenging behaviors, instructional skills that new and practicing teachers need to teach students with significant cognitive disabilities, alternate assessment, accessing the general education and inclusive education.

I share the beliefs and values of TASH. I believe that TASH can continue to be a resource to families, educators and professionals for children, youth and adults with significant cognitive disabilities. I believe I can make a contribution on the TASH Board. I thank you for considering me for the position."

John Williams

"I am pleased to put my name in nomination to serve on TASH's board. I bring to the Board more than a quarter of a century of experience in the



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disability movement as an advocate and an award-winning journalist.

My first contact with disability issues began in 1978 when I started working as the director of communications for the American Coalition of Citizens with Disabilities. There, I worked on issues dealing with the education of children with disabilities, accessible transportation, and raising awareness about the high unemployment level of people labeled with severe disabilities.

One of my proudest achievements at ACCD was co-authoring a book with Dr. Frank Bowe. *Planning Effective Advocacy Programs* provides readers with information on working with the media, raising money, building coalitions and developing advocacy groups. My work at ACCD also involved securing federal grants and foundation donations. Through our leadership, advocacy efforts and media work, ACCD raised disability issues to a national level.

Since 1978, I have written more than 1,600 articles on disability issues. I am a former award-winning weekly columnist for *Business Week* and *Business Week Online* magazine. In addition, my articles on disability issues and assistive technology products have appeared in *People Magazine*, *The Washington Post*, *The New York Times*, *Mass Transit Magazine*, *The Los Angeles Times*, *The Wall Street Journal* and *Chicago Tribune*.

I write a monthly column for *Orbit Magazine* and a quarterly column for *Careers and the Disabled*. I am the founder and former publisher of *Assistive Technology News*, a tabloid newspaper covering assistive technology products and disability issues.

In 1982, I coined the phrase 'Assistive Technology.' I am credited with raising awareness of the benefits of assistive technology to an international level.

I bring to TASH's board a unique knowledge of federal legislation dealing with disability issues, extensive knowledge of assistive technology products, familiarization with over 100 manufacturers of assistive technology, knowledge of the needs of people with disabilities and ways assistive technology products can assist them, recognition as a writer and advocate, and experience in marketing and public relations.

As a writer, I interviewed high profile individuals like President George Bush, former President Bill Clinton, former Vice President Al Gore, Senator Hillary Clinton, former Attorney General Janet Reno, Clint Eastwood, former Governor Jesse Ventura, former Congressman Newt Gingrich, former Senator Max Cleland, Congressman Jim Langevin, Vinton Cerf (one of the founding fathers of the Internet), country western singer Mel Tillis, Microsoft's CEO Steve Ballmer and physicist Stephen Hawking.

The *Business Week Online* column which I wrote won the Easter Seals Equality, Dignity and Integrity Award, the Stuttering Foundation of America's 2000 Journalism Award,

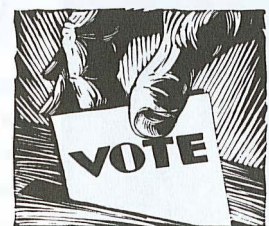
and the California Media Access Award. The technology column also contributed to *Business Week Online* receiving the New Media Excellence Award in 2000, the Easter Seals leadership corporate award in 1999, and for McGraw Hill Publishing Company receiving the American Foundation for the Blind's Lifetime Achievement Award for my 20 years of writing about products benefiting blind people. In November 2000 I received the Charles Van Riper Lifetime Achievement Award for my work in writing about stuttering and leadership in promoting opportunities for people with speech impediments.

I was an environmental writer, and I have covered NASA, the Congress and the Pentagon. I have written five books and edited several others, one on the environment, one on poetry and a NASA publication on *A History of Sunspots*. My latest book is *Assistive Technology: Expanding a Universe of Opportunities for People with Disabilities*.

I am married, and my wife and I have two children. I graduated from King's College in Wilkes-Barre, PA in 1967 with a Bachelor of Arts degree in Philosophy."



We hope that all TASH members will participate in this year's election. The four candidates who are selected will be announced in the next issue of TASH Connections. We appreciate your participation!



TASH 2004 Election of Four (4)

EXECUTIVE BOARD MEMBERS

Term of Office: 2004-2007

- OFFICIAL BALLOT -

There are four positions for members of the TASH Executive Board to be filled this year. Positions will be filled via ballot by dues-paying TASH members (one each) in accordance with the Association's By-Laws. The Executive Board members-elect will begin their terms at the Annual Board Meeting held in conjunction with the 2004 TASH Conference to be held in November in Reno, Nevada.

Ballot Instructions:

You should vote for a total of **FOUR** nominees. Ballots containing more than four votes are invalid. Please mark your ballot in ink.

- | | | |
|-----------------------------------------|---------------------------------------|----------------------------------------|
| <input type="checkbox"/> Carol Berrigan | <input type="checkbox"/> Jeff Strully | <input type="checkbox"/> Donna Wickham |
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For information about the candidates, please refer to pages 6-10 of this issue of TASH *Connections*.

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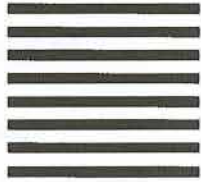
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Thank you!

TASH's work is dependent on the financial assistance of our donors and members. We wish to acknowledge the generous donations of the following individuals and organizations:

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Now Available! Assistive Technology Manufacturers Directory: *Expanding a Universe of Opportunities for People with Disabilities*

John Williams, award-winning journalist, author and publisher of *Assistive Technology News* and Howard McClintic, Executive Director of the CTC Foundation in Washington, D.C. have just released an information-packed and valuable resource, *Assistive Technology Manufacturers Directory: Expanding a Universe of Opportunities for People with Disabilities*. This Directory is the most comprehensive listing of worldwide manufacturers ever printed. The publishers will release periodic updates to the Directory, ensuring its content will be a valuable resource for years to come.

For a limited time, the publishers are offering a special purchase price to TASH members. The cost of the Directory, regularly \$99, has been reduced to \$65! In addition to the almost 600 manufacturers listed (contact listings include fax numbers and e-mail addresses), and coding to indicate the disability area(s) covered (M = Mobility, S = Sight, H = Hearing, etc), there are 22 informative technology-related articles in the Directory, authored by John and senior corporate leaders from Microsoft, IBM, Kurzweil, and many others. New articles will also appear regularly on the *Assistive Technology News*-CTC Foundation website, www.atn-ctcf.org.

The Directory can be purchased in several formats, including book form, CD or online access for one or more licensees. Purchasers of the Directory range from the disability offices of the government of New Zealand and Crete to the Smithsonian Institution in Washington. Directory advertisers include Bank of America, Dynavox and many more.

To discuss the various features of the Directory or to place an order, contact Howard McClintic, mcclint@ctcgc.org, telephone 202/312-2913 or fax your request to 202/312-2925. The discount to TASH members is available through the end of the 2004 conference, so hurry and place your order today!

Making Social Relationships an Integral Part of Sex Education

BY CHARLES DUKES

Sexuality involves more than sexual intercourse. In fact, the idea that individuals with significant disabilities need only "sex education" can at times act as a barrier to quality information about intimate relationships and other issues extending beyond the basics of sex education. Sex education is the foundation for providing information about one's sexuality. A comprehensive sexuality-education program should include discussions of relationships, communication, and respect (Wiley & Terlosky, 2000).

Notwithstanding such ideas, many hold narrow notions about sex education, especially for those with significant disabilities. There is the question of consent, capacity to participate (both from the cognitive and physical standpoints), and the myths surrounding individuals with significant disabilities. The ability to enjoy a sexual life is not only dismissed for people with significant disabilities, but sex education is seen as completely unnecessary.

Part of this widespread discharge of ideas may come from a common belief that "if one encourages individuals with significant disabilities to access sex education programs, then one is in essence encouraging sexual intercourse." It does make good sense to include a discussion and explanation of sexual

intercourse, but the issue of sexuality is much broader and more inclusive than simply intercourse. The reduction of sex education to facts about the human body, sexually transmitted diseases, sexual abuse and pregnancy leaves an entire "world" of issues and concerns uncovered.

Clearly, sex education programs should include an introduction to the previously mentioned issues, but sex education cannot be contained to a collection of training classes followed up by a post-test. This popular formula for "sex education training" does not begin to give justice to the importance and pervasiveness of sexuality in all of our lives.

While many will agree that individuals without disabilities should receive some form of sex education, there seems to be disagreement about the appropriateness of providing a sex education program to individuals with significant disabilities. In the past, education about sexuality was not considered until a person demonstrated some "unacceptable" behavior such as masturbating in public (Williams, 1991). According to this reactive view, an individual with a disability "gets" sex education to prevent any future "incidents." The discussion about the appropriateness of offering sex education programs to individuals with significant disabilities is made even more complicated by two related issues.

First, many consider individuals with significant disabilities to be asexual, not having the capacity or willingness to engage in sexual relations. Second, some view individuals with significant disabilities as having uncontrollable sex urges that will run rampant at the slightest provocation (Williams, 1991). These barriers to comprehensive sex education programming result in a number of individuals with significant disabilities essentially living without access to a major part of the human experience. Somehow the notion of ignoring the sexuality issue became popular, and continues to hinder those who provide support for individuals with significant disabilities. Ignoring sexuality issues or essentially providing "no support" is not support at all.

To consider sex education as separate from friendships, communication with others, and expression of a desire for close contact, renders sex education programming insufficient to help individuals with significant disabilities to truly understand and experience their sexual lives.

In an effort to better understand the current discussion about sex education programs, it is necessary to review some existing notions about sex education for individuals with significant disabilities. According to Huntley and Benner (1993) sex education is: The systematic dissemination of information regarding physical growth and development and systematic attention to the physical, psychological, and social sexual needs of each individual at his or her own level with the goal of facilitating whole and healthy personality development. A comprehensive sex education program should incorporate concepts such as contraception, reproduction, and sexually transmitted diseases. (p. 215).

This conception of sex education attempts to provide a meaning of the function of sexual intercourse and intimate contact. Here, the definition attempts to "meet individuals where they are." This is a common component of sex education programs for individuals with significant disabilities. The thought here is to ensure understanding of basic bodily functions and the potential consequences of engaging in sexual activity.

According to Wehmeyer, Sands, Knowlton, and Kozleski (2002), sex education is a means to ensure protection from sexual reproduction and abuse or to prevent the spread of sexually transmitted diseases. These two conceptions of sex education characterize many of the prevailing notions about the necessary content of a sex education program.

After considering the content of general sex education programs, it is important to consider the intent of the sex education program. On its face, it would seem that sex education programs are exactly what the title

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implies, but the deeper issue can be seen through the intended outcomes of the program. For example, certain curriculum will include or exclude certain topics (e.g., homosexuality or abstinence). The decision behind this inclusion or exclusion clearly communicates an expected outcome for individuals involved in the program.

A sex education program that includes abstinence, for example, informs individuals about the “advantages” of living without sexual intercourse (Kirby, 2000). The content of a sex education program may partially dictate future feelings and attitudes about sex. The curriculum used in sex education programs varies a great deal according to author, sponsorship, and intended audience. The point here is that while many programs do satisfy the basic requirements of facts, reproduction, and sexual abuse, excluding the teaching of the social skills necessary to support a sexual life may impede the development of the social networks necessary to support that life.

There are now more sex education programs available than ever before, yet there is still a great reluctance to actually support people with significant disabilities to lead sexual lives (Brown, 1994). To do this, educators must develop a sense of what the actual sexual needs and experiences of people with significant disabilities are, and then tailor programs to address these needs, rather than imposing the values of the non-disabled culture on individuals with significant disabilities (Whitehouse & McCabe, 1997). This calls for a fundamental change in the current practice of sex education programs.

Currently, many educators teach about sex as an isolated phenomenon from the greater social experience that we all benefit from as human beings. To consider sex education as separate from friendships, communication with others, and expression of a desire for

close contact renders sex education programming insufficient to help individuals with significant disabilities to truly understand and experience their sexual lives.

Robinson and Skinner (1985) claimed that sexuality is a significant and ever present part of all human beings, and is expressed in all daily activities (as quoted in McCabe, 1993). Sex education programs must serve as the foundation for individuals with significant disabilities to learn the essential facts about sex (e.g., reproduction and possible abuse). In addition to these facts, sex education programs provide an excellent opportunity to discuss the actions and events necessary to cultivate social relationships. It is almost impossible to separate the intimacy of some social relationships from the intimacy of sexual intercourse. If individuals with disabilities have access to a sex education program that is devoid of support for the creation and maintenance of social relationships, the program is essentially devoid of true meaning.

Individuals with significant disabilities do show an increase in sexual knowledge after receiving instruction in sex education (Caspar & Glidden, 2001). This finding is encouraging in light of the move from institutions to community living and the availability of community-based services. Individuals living, working, and recreating in the community can learn and increase their knowledge about sexuality. Beyond an increase in knowledge, there is still some debate on how individuals with significant disabilities can lead lives that include social relationships and sexual intercourse. Sexual activity is not an isolated behavior, but often occurs within an intimate relationship (Page, 1991). Further, all the issues surrounding sexuality are not isolated from the social experience of human beings.

The gap between teaching individuals with disabilities sexual knowledge and supporting a sexual life seems to be huge at present. To enable people with significant disabilities to effectively use the knowledge they have acquired regarding sexuality, they need information and opportunities to form relationships with others (Foxy et al., 1984 as quoted in Garwood & McCabe, 2000). It is important to acknowledge that sexual

behavior is not one activity; rather it involves social interaction, moral reasoning, empathic sensitivity, social responsibility, specific knowledge, skills, and physical capabilities (Page, 1991). In an effort to make social relationships an integral part of sex education, it is necessary to consider the following aspects of the social experience:

- 1) social interactions
- 2) environments, and
- 3) cross-environmental supports

Social relationships are based on the opportunity and ability of an individual to interact with another individual. The notion of a social interaction can be described as how often two individuals interact, how long each interaction lasts, what particular day(s) those interactions occur on, and so on (Kennedy, 2004). Essentially, social interactions constitute the foundation of social relationships. It is necessary for anyone attempting to live a social life to engage in interactions with others.

Individuals with significant disabilities who have opportunities to gain sexual knowledge need opportunities for formal and informal social interactions. The point here is not to argue for social interaction as a necessary and sufficient cause for sexual intimacy, but quite often sexual intercourse is viewed as an isolated event that occurs without reference to the greater social experience. This picture of sexual intercourse and sexuality in general does not place intimate relationships in the appropriate context.

Social interactions should be celebrated. For many, these interactions are highly anticipated. Interactions can take place in and around places of employment, social events (e.g., sporting events), and even typical community outings (e.g., visits to the grocery store). It is through these social interactions that all individuals encounter on a daily basis — and based on the high frequency of such contacts — that individuals with significant disabilities should be given “insight” about the many social opportunities that exist in the world.

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Social interactions can lead to many different types of relationships, with friendships being one of many possible results. McDonnell, Hardman, and McDonnell (2003) describe friendships in this way:

Friendship is a bond between individuals, i.e. favored companions who are emotionally connected to each other by mutual affection or esteem. Friendships develop as an evolutionary process. First, there is an awareness of common values, interests, concerns, or backgrounds. Then, individuals must have the opportunity to interact with one another to discover and explore these similarities. (McDonnell, et al., p. 60).

A sex education program that does not attempt to help individuals with significant disabilities make the greater connection to others and develop a full continuum of relationships does not allow for the full expression of social interaction. It is the social aspect of sexuality that acts as the foundation for more intimate relationships that are based on mutually satisfying interactions.

The environment or context in which sex education programming takes place is a central issue to the development of comprehensive sexual knowledge. For most, social contact (e.g., conversations about family and employment or making plans for an event) can occur at almost any time or any place. It is highly likely that many individuals have a number of social contacts in a number of different environments on a daily basis.

While many of these contacts do not constitute intimacy, it is possible that some of these contacts do reflect an intimacy that one individual shares with another. This level of intimacy does not begin with the first encounter or perhaps even the fourth or fifteenth, but the relationship evolves and becomes something fundamentally different. This kind of social contact cannot develop for

Sex education is essentially another aspect of our social world that must be directly taught and supported to truly have an impact on the social lives of individuals with significant disabilities.

individuals with significant disabilities if sex education programs do not go beyond the "training walls" and allow for interaction in a number of environments with a number of different people.

Where, when, and how sex education programs should occur for individuals with significant disabilities can be a challenge for those who narrowly define the meaning and significance of sexuality. Part of this challenge rests in the apprehension some feel about the outcomes for individuals who receive sex education.

According to Caspar and Glidden (2001), adults with developmental disabilities were found to have significantly less knowledge regarding sexual and sociosexual issues. They had fewer experiences of sexual interactions but, despite this, they were more likely to experience negative consequences of sex, including unwanted pregnancy and sexually transmitted disease.

If sex education programming does not easily "transfer" to other situations, then the programming should be expanded and enhanced to encourage outcomes that enable individuals with significant disabilities to not only learn about sex, but to benefit from this knowledge in the social world. The availability of sex education programs can be expanded but, just as important, it is necessary to consider the environment where such programming takes place. Individuals with significant disabilities need broad experiences with others in social situations to realize the true benefits of learning about sex. The environment is critical to the development of a comprehensive sex education program.

The quality and frequency of social interactions that take place as part of a result of sex

education programming is an essential consideration for individuals with significant disabilities. Another critical consideration is the environment in which programming takes place. It is not just the initial training environment, but also the opportunity to "be in and around" a number of places or social situations with the intent of developing and maintaining social relationships that may lead to more intimate relationships.

The final critical consideration is cross-environmental support. Sex education programming must be enhanced with "social support" outside of the training environment. Sex education is generally delivered in isolated situations from social experience. This isolation is further intensified by the inability of educators to be involved with the individuals outside of the training environment. This results in training taking place in one environment with one or two educators.

Once the individuals with significant disabilities leave the training environment, there is no one able or willing to "support" the use of the sex education content. It is necessary for individuals with significant disabilities to have the "support" of at least one individual besides the educator to help make the sexual training viable. In short, the missing piece of sex education programs is the continuation of this education outside of the initial education session.

Cross-environmental support requires one or more individuals to be familiar with the content of the sex education program. It also requires the ability and willingness of this individual to capitalize on the "teachable moments" to help solidify the "social side of sex." This support for the use of appropriate social behavior that may lead to appropriate sexual behavior (i.e., contact without exploitation) can be achieved with the assistance of a supportive individual to help clarify the social interactions that should take place before, during, and after sex education programming.

Sex education programming for individuals with significant disabilities needs enhance-

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Making Social Relationships an Integral Part of Sex Education

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ment. The current state of sex education programming can be improved by considering three critical components: 1) social interactions, 2) environments, and 3) cross-environmental supports. This addition to sex education programming will provide individuals with significant disabilities and those that support them the additional information needed to recreate sex education programming into a comprehensive learning experience. Sex education is essentially another aspect of our social world that must be directly taught and supported to truly have an impact on the social lives of individuals with significant disabilities.

References

- Brown, H. (1994). 'An ordinary sexual life?': A review of the normalization principle as it applies to the sexual options of people with learning difficulties. *Disability and Society*, 9(2), 123-144.
- Caspar, L. A., & Glidden, L. M. (2001). Sexuality education for adults with developmental disabilities. *Education and Training in Mental Retardation and Development Disabilities*, 36(2), 172 - 177.
- Garwood, M. & McCabe, M. P. (2000). Impact of sex education programs on sexual knowledge and feelings of men with a mild intellectual disability. *Education and Training in Mental Retardation and Development Disabilities*, 35(3), 269 - 283.
- Huntley, C. F. & Benner, S. M. (1993). Reducing barriers to sex education for adults with mental retardation. *Mental Retardation*, 31(4), 215-220.
- Kennedy, C. H. & Itkonen, T. (1996). Social relationships, influential variables, and change across the life span. In L. K. Koegel,

R. L. Koegel, & G. Dunlap (Eds.), *Positive behavior support Including people with difficult behavior in the community* (pp. 287-304).

Kirby, D. (2000). What does research say about sexuality education? *Educational Leadership*, 58(2), 72-76.

McCabe, M. P. (1993). Sex education programs for people with mental retardation. *Mental Retardation*, 31(6), 377-387.

McDonnell, J. J., Hardman, M. L., & McDonnell, A. P. (2003). Family, friends, and society Supporting people with severe disabilities. In J. L. McDonnell, M. L. Hardman, & A. P. McDonnell (Eds.), *An introduction to persons with moderate and severe disabilities* (pp. 40-70).

Page, A. C. (1991). Teaching developmentally disabled people self-regulation in sexual behaviour. *Australia and New Zealand Journal of Developmental Disabilities*, 17(1), 81-88.

Wehmeyer, M. L., Sands, D. J., Knowlton, H. E., & Kozleski, E. B. (2002). The emergent self: Sexuality and social inclusion. Teaching students with mental retardation Providing access to the general curriculum. Baltimore, MD: Paul H Brookes.

Whitehouse, M. A. & McCabe, M. P. (1997). Sex education programs for people with intellectual disability: How effective are they? *Education and Training in Mental Retardation and Development Disabilities*, 32(3), 229 - 240.

Wiley, D. C. & Terlosky, B. (2000). Evaluating sexuality education curriculums. *Educational Leadership*, 58(2), 79-82.

Williams, S. (1991). Sex education. *Australia and New Zealand Journal of Developmental Disabilities*, 17(2), 217-219.

Charles Dukes is with the Department of Exceptional Student Education, Florida Atlantic University, Boca Raton, Florida. Comments about this article may be sent to Mr. Dukes at cdukes@fau.edu

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Respecting, Supporting and Honoring the Sexuality of All People

BY EDWARD WILLARD, JR.

Look at Suzy and Josh, aren't they cute?" "If you boys and you girls hold hands, the girl will get pregnant." "The overhead lights must stay on to keep the students from masturbating."

People might think of these statements and rules as arbitrary, strict, insulting and stupid as they relate to your average group of teenagers. And yet, when these same things are said in regard to people with disabilities, they can suddenly be passed off as "sensible" practices. All young people, including those with disabilities, are challenged with trying to have a natural and normal sexual life. For people who are gay or lesbian, multiply these challenges by two.

Many people look back on their late adolescence with fond memories of a springtime love affair. Flowers are blooming, sweet smells awaken your awareness of nature, and when that somebody special enters the classroom, you feel a connection with the universe.

Allow me to take you back to 1985 to a 94-bed private children's institution located in a small town in Texas. To protect the identity of the individuals, the two young men in this true story will be referred to as Frank and Tim.

For three years, the two had a typical friendship. There were days when they got along, and days when they could not tolerate one another.

When Frank entered the facility, it was well known that Frank had "homosexual tendencies." The staff was to be "on guard" for his "homosexual tendencies." It wasn't a normal concern for several students to bathe at once. But Frank was made to wait to bathe, last and alone. The staff feared he might look at the other young men and become aroused. Tim, on the other hand, kept his sexuality to himself.

A few months prior to Tim's twentieth birthday, he noticed that there was something different about the way he felt about Frank, who was 19. Deep down, Tim knew what these feelings were, and he knew that for him, these feelings were natural. He wanted to enjoy his feelings for Frank, but he knew he would be shunned and ridiculed if he expressed those feelings. So he kept his feelings under wraps. Besides, Tim was unsure if Frank felt the same way.

As time went on, the two men spent more and more time together, and their conversations became deeper. Tim began thinking about moving to a large metropolitan city, and he started talking to Frank about his plans to move.

They talked about how nice it would be to live in the same place. But neither of them dared discuss their feelings about each other while living in a facility where a simple kiss between a boy and girl would result in a weekend lock-down for the entire institution.

Still, on Sundays they would spend the entire day together. They would go to church together and then watch football in Tim's room in the afternoon.

Then one Sunday, Tim just needed to tell Frank how he felt. He took Frank's hand and simply said "I love you, Frank" to which Frank responded "It's about time we were honest with ourselves! You have become, like, the center of my world, and that's okay by me," said Frank.

They were both on cloud nine since finally confessing their love, but their joyfulness was clouded by a panicked fear of what would happen when they were found out. They tried to resist the behaviors that came naturally to people experiencing love and sexual attraction. But they found themselves kissing and sexually satisfying each other. After an afternoon of blissfully sharing this time together, they were caught.

They were both taken to the nurse's office and made to tell every detail of their afternoon together. The head nurse informed the director of the institution, and Tim and Frank were told that under no circumstances could they have any contact with each other. They missed each other so much, they even tried to deny being sexually attracted to one another, stating that they had been talking about girls and had simply become aroused.

What started out as a wonderful day for two consenting adults turned into a nightmare. Frank was kicked out of the institution, and Tim's parents were told to "report" to the institution to be told of "the event."

Here were two people who had developed a loving and nurturing relationship, and they were not even allowed to say good-bye to each other. Tim last saw Frank being put inside a van and being driven away. That was 19 years ago. Frank was taken to a nursing home, where he lived for 15 years. A year later, Tim moved to that facility in a big city that he had talked about -- but without Frank.

In the name of "professionalism" two individuals were emotionally scarred for life. And all because of the false belief that people with disabilities are things to be "fixed," especially those who are gay or lesbian.

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Respecting, Supporting, and Honoring the Sexuality of All People

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I want to talk about some responsibilities and obligations we have as professionals in the lives of people with disabilities. I write about those who are gay or lesbian because of the additional discrimination they face. At the very least, they get swept under the carpet.

It needs to be stated over and over again that people with disabilities are sexual beings, and they have the right to a sexual life. The responsibilities and obligations of professionals can and should be applied to all healthy and natural relationships between two consenting adults. Much more work is needed.

I have had the opportunity to work as a community-based provider. I always had this conversation with people coming into the program: "Should you have a relationship with another consenting adult, this will in no way jeopardize your services." I stressed that they should feel safe, and not be concerned with ever being asked to leave.

In my experience, many people with disabilities fear retaliation, being kicked out of their home, and being separated from their significant others. I feel, as professionals, we have the responsibility to facilitate loving and caring bonds between people.

I impressed upon the staff who worked under me three golden rules about fostering intimacy:

- ❖ First, do not patronize people's relationships. If somebody gives their loved one a kiss, avoid making remarks like "Robby and Dianne, that's so cute."
- ❖ Second, if two individuals want to go out to dinner or to a movie, we should assist in facilitating this activity.
- ❖ Third, when private time is wanted, it is given at the highest level of dignity and respect. Staff was instructed that sexual

activity in the privacy of one's bedroom is a confidential matter that stays in the individual's bedroom.

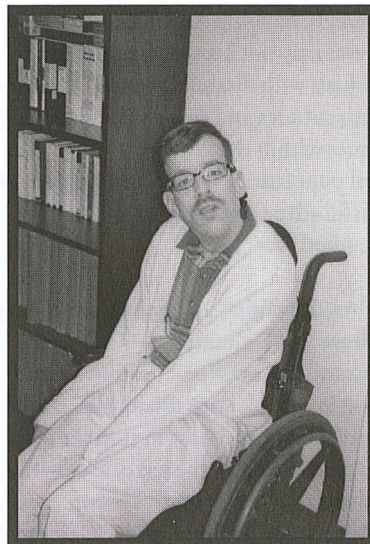
Situations like Frank and Tim's are still happening. We professionals are obligated to reduce the number of times we see these harmful practices. We are here to enhance the quality of life for the people that we support, and that includes respecting, supporting and honoring their sexuality.

About the author:

Edward Willard is the Co-Director of My Life Going FAR Project with TASH. Moving to Maryland from Austin, Texas, he has worked in the disability community for 15 years.

Living in a residential facility for four years, Edward feels that with appropriate supports, anyone can live in his/her community.

For readers who would like to start an ongoing dialogue about the topic discussed in his article, Edward invites you to contact him at Willard at ewillardjr@tash.org



ALASKA

The Special Education Service Agency (SESA) is recruiting for Education Specialists in the following specialty areas.

For more information about our organization and detailed position requirements, please visit our website at <http://www.sesa.org>

Autism

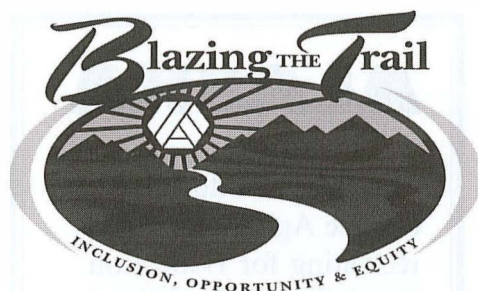
Qualifications: MA with emphasis on autism spectrum disorders; or MA with emphasis on moderate/severe disabilities and extensive coursework in autism; and three years teaching experience

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2004 TASH Annual Conference Reno, Nevada November 17-20

Topic Strands for Breakout Sessions

The following represents a tentative listing of topics highlighted in over 300 breakout sessions held as part of the 2004 TASH Conference.

For a complete description, including strand coordinators and specific sessions within each topic strand, please visit www.tash.org

Alternate and Standards Based Assessment

This strand deals with alternate assessment topics such as development, implementation, scoring, and instructional influence. As alternate assessment continues to be refined to reflect not only federal regulations but instructional significance, and as the data begin to inform as to the instructional impact as a result of assessment, these issues and the presentations that will address them are important for those who wish to improve educational outcomes for students with severe disabilities.

Autism: Continuing Our Understanding

Strand Sponsors: Jessica Kingsley Publishers and Youth Advocates Programs, Inc.

You can't open a newspaper or magazine without seeing an article on autism spectrum disorder. The rise is alarming. Families, individuals, educators and professionals need the latest on strategies to support and educate individuals with autism. This strand will help us to think about and develop effective and efficient strategies.

Accessing the General Education Curriculum for Students with Significant Disabilities

Strand Sponsor: Institute on Disability, University of New Hampshire

This strand will help participants learn

1) why students with significant disabilities should be learning general education curriculum content, 2) a process for planning students' participation and supports, 3) specific examples of student participation and learning at both the elementary and secondary levels, and 4) methods for conducting ongoing authentic assessment of student learning.

Advocacy/Changing Attitudes

Inclusion may not become a reality for individuals with disabilities until advocates change attitudes and create understanding of the issues within the general population. This strand will focus on successful advocacy strategies and methods for change.

Aversives, Restraint, and Seclusion: Ending the Abuse and Changing the Culture

This strand will offer practical advice and training for people with disabilities, families and professionals on how to stop the cycle of force and coercion in the use of aversives and the misuse of restraint and seclusion. Sessions will bring public awareness and justice to this long-hidden systemic abuse, will provide information about creating safe, respectful,

and positive culture of education and service delivery.

Community Living

Strand Sponsor: The College of Direct Support

How do you embrace choice and control on a daily basis? Join this strand to hear from individuals and support agencies taking part in the journey of individualized supports. Presentations include person-controlled housing, circles of support, individual supports, capacity building, and advocacy.

Communication

People with varying disability labels are often perceived as being incompetent or less able because of the inability to speak. This strand focuses on the value that all people can be competent communicators, given the opportunity to develop methods of communication, quality education, environmental awareness, and individualized accommodations and supports.

Early Childhood: Promising Practices and Directions

The fields of early intervention and early childhood education are confronted by a myriad of unique and challenging issues. This strand will help participants understand, within a family context, how to foster state-of-the-art inclusive care and education for young children with disabilities.

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Topic Strands for Breakout Sessions

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Employment

Strand Sponsor: Institute for Community Inclusion, University of Massachusetts, Boston
Reaching the vision of valued work for all is a collaborative effort that requires attention to emerging support strategies, organizational change, and systems change at the state and federal levels. This strand profiles the process of transforming traditional organizations, supporting individuals through values-based planning, creative supports, and emerging strategies such as self-employment, and state level initiatives for change.

Facilitating Friendships

As advocates for inclusion, we cite friendship as a huge benefit of inclusive education. And while this is absolutely true, there is a growing concern among families and educators that far too many students still do not have the rich and fulfilling social lives they desire. This all-day strand is designed to explore the attitudinal and educational barriers to friendship that continue to exist, even in schools.

Families

Strand Sponsor: Cal-TASH
This strand will include a family gathering to discuss current issues facing people with disabilities and their family members. Join family members, self-advocates and professionals as we share our challenges and successes. Sessions throughout the conference are coded to indicate that they have a family focus.

Guardianship Alternatives

This strand includes sessions that discuss guardianship as the last civil rights frontier, an exploration of strategies for self-determination, issues related to wills and trusts, and practices in alternatives to legal guardianship.

Hearing Different Voices: Listening to the Field in Teacher Prep

This strand emphasizes that to fully move in a direction which supports inclusive education,

teacher preparation programs must be informed by a diverse range of voices, including schools, the students, families, other professionals, and our own colleagues.

IEP Development

Research and evaluation data demonstrate that students with disabilities who are included in general education classrooms make better gains than those in pullout or otherwise segregated programs. More importantly, students who are included and have access to the general education curriculum show a strong trend toward improved outcomes (academic, behavior, and social). This strand will focus on crafting individual IEPs that increase access to the general education curriculum in meaningful ways.

Instruction for All Learners

TASH members believe that it is time to focus on good teaching, on rich and varied instructional styles that engage students at multiple levels, and on classroom communities that are supportive, kind, and respectful of all students. This strand focuses on inclusive practices as part of good teaching strategies for all.

International Inclusive Education

This strand provides a forum for international and multi-disciplinary dialogue on inclusive education for all educators and educational policy-makers concerned with the form and nature of schools. Specific examples from around the globe will be highlighted, with ample time for discussion amongst participants.

The Imperative for Sustaining Community: Revisiting the Very Real Risks of an Institutional Comeback

This strand is once again dedicated to the memory of Burton Blatt, Gunnar Dybwad and Herb Lovett, all loving souls and forceful advocates for better lives for people with disabilities. Continuing its work from the 2003 Conference, this strand resumes with critical discussions on the issues facing states as they implement the New Freedom Initiative and address serious funding crises that truly threaten the foundation of

community services and supports for individuals with disabilities across the age span.

Inclusive Postsecondary Education

New ideas for accessing post secondary education by students with significant disabilities are emerging. This strand will address the latest questions and challenges regarding students who want to continue their education in inclusive environments beyond grade 12.

Inclusive Recreation

This strand offers opportunities to learn tools for inclusive recreation in the schools and community. Recreation is another way for people to connect with the community so everyone is accepted, belongs, and is a valued community member. Sessions will feature information on inclusive recreation opportunities.

Literacy

Literacy is a critical life skill. The past decade has marked a shift in research, practice, and learning. This strand will offer participants the opportunity to become familiar with current research, best practices, and outcomes related to literacy instruction for all learners.

Microboards: A Tool for Living a Self-Determined Life

Strand Sponsor: Networks for Training and Development

This strand will share personal stories and information about microboards: the philosophy behind the concept, development strategies, as well as the challenges and successes in the operation and support of them in Canada, the United States, and the United Kingdom.

Peer Supports

Inclusive schooling refers to a wide variety of experiences in which students with and without disabilities are brought together for valuable learning activities. The creation of an inclusive school environment occurs when students not only learn together, but also learn to respect and value each other's differences. This strand will

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Topic Strands for Breakout Sessions

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highlight strategies that facilitate meaningful interaction amongst peers.

People of Color Labeled with Severe Disabilities and Their Families

While the disability rights movement has made significant progress over the last couple of decades in securing and ensuring the human and educational rights of individuals with severe disabilities, many individuals of color and their families have not benefited from the social and educational movements that have taken place. The purpose of this strand is to identify specific issues and concerns regarding people of color with severe disabilities and their families.

Positive Approaches to Supporting People with Complex Needs and/or Problem Behavior

This strand will include presentations that focus on concepts, principles, and strategies for implementing positive support approaches in school, home, and community settings.

Research

Over one-third of the breakout sessions this year are research-based and many presenters are authors and/or editors of TASH's premiere journal, *Research and Practice for Persons with Severe Disabilities* (RPSD). Sessions throughout the conference are coded and indicate a research focus.

Rural Issues

Rural schools across the country are challenged to deliver high quality supports to students with severe disabilities. Small schools located great distances from population centers often do not have experience with or ready access to specialized expertise necessary to meet the needs of these students. This strand will focus on issues that rural districts face, and exemplify creative strategies that have been successfully used in several states.

Self-Determination

This dynamic strand features sessions on cultural and systemic changes and new tools for promoting self-determined lives.

Sexuality

Sexuality and sexual expression are natural aspects of life. For many individuals with disabilities, societal ignorance and external controls have prevented them from gaining access to complete information regarding sexuality and from expressing themselves sexually. These sensitive and critical issues require awareness, respect, competence, and a commitment to empower all people to act upon their interests and choices.

Systems Change for Effective Inclusive Education

Changing systems at the district and building levels require a change in the way both general educators and special educators teach and collaborate. In this strand, several different approaches to address the barriers and identify solutions so that students with disabilities can be included as members of their school districts will be presented.

The Spiritual Threads of Our Lives

Many of us describe our daily lives with descriptors that include spiritual beliefs and values. This strand offers an assortment of expressions of spirituality. Various presenters offer participants moments of movement, reflection, meditation and practice that spring forth from their spiritual centers.

Transition

This strand focuses on cutting edge practices for youth with disabilities in transition, including non-school options for 18-21 year olds, innovative urban education approaches, and funding mechanisms.

Values/Systems Change

The mission of TASH is to stretch boundaries and eliminate obstacles to inclusive lives. The realization of this requires an unwavering commitment to values and a relentless pursuit of systems change. This strand highlights successful strategies for change.

2004 TASH Conference Tentative Agenda

Tuesday, November 16th

5:00 p.m. - 7:00 p.m. Registration Open

Wednesday, November 17th

Pre-Conference Activities

8:00 a.m. - 11:00 a.m. Registration Open

2:00 p.m. - 7:00 p.m. Registration Open

8:00 a.m. - 4:00 p.m. Exhibitor Set Up

10:00 a.m. - 4:00 p.m. TASH TECH Full Day Pre-conference Workshops

12:00 p.m. - 4:00 p.m. TASH Chapter Leadership Day

5:00 p.m. - 7:00 p.m. Opening Reception in the Exhibit Hall

5:00 p.m. - 7:00 p.m. Exhibits Open

Official Conference Begins

Thursday, November 18th

8:00 a.m. - 5:30 p.m. Registration Open

8:00 a.m. - 5:30 p.m. Exhibits Open

8:30 a.m. - 10:45 a.m. Breakout Sessions

11:00 a.m. - 12:45 p.m. General Session

12:45 p.m. - 1:45 p.m. Exhibits and Roundtable Luncheons or Lunch on your own

2:00 p.m. - 5:30 p.m. Breakout Sessions

5:30 p.m. - 7:00 p.m. Reception

Friday, November 19th

8:00 a.m. - 1:00 p.m. Registration Open

8:00 a.m. - 5:00 p.m. Exhibits Open

8:30 a.m. - 12:00 p.m. Breakout Sessions

12:15 p.m. - 1:15 p.m. Exhibits and Roundtable Luncheons or Lunch on your own

1:30 p.m. - 5:00 p.m. Breakout Sessions

5:30 p.m. - 7:00 p.m. Reception

Saturday November 20th

8:00 a.m. - 10:00 a.m. Registration Open

8:00 a.m. - 12:00 p.m. Exhibits Open

8:30 a.m. - 9:30 a.m. TASH Committee Meetings

8:30 a.m. - 10:30 a.m. Poster Sessions and Continental Breakfast

10:30 a.m. - 3:00 p.m. TASH TECH Full Day Workshops

“How about starting a group for women?” Early in 1998, this question was posed by an administrator of a large agency that provides services to people with intellectual disabilities. The agency was concerned about the safety of several women who displayed risky sexual behavior. We quickly agreed, considering it an opportunity to provide a service that did not exist in Alaska. After all, what could be so hard?

Listening to Women's Voices: Risk Reduction in Community Settings

BY KAREN M. WARD and
REBECCA L. BOSEK

We had been providing specialized support services for males who exhibit risky, inappropriate, or sexually offensive behavior since 1992. Our agency, the Center for Psychosocial Development, is the non-profit service arm of the University of Alaska Anchorage Center for Human Development—A University Center for Excellence in Developmental Disabilities: Education, Research, and Service (UCEDD). We mistakenly thought all we needed to do was to adapt the interventions that worked with the men.

Our general approach is to conduct risk assessments, hold weekly psychosocial skill training groups, and provide specialized clinical case management. Within a few short months, we began to provide services for women.

What we both missed and had not reckoned on was the voices of the women. They let us know, in a variety of ways, what they needed to live safely in community settings. Our curriculums were criticized, the women's self-management of behavior during the group setting was negligible, and attendance dropped off. We quickly realized that if we did not change things, we would not have any services to offer.

We held a series of focus groups. We listened carefully to the voices of the women and incorporated their suggestions.

To date, our risk reduction services reflect what we have learned from the 40 women who have attended the Center for Psychosocial Development Clinic.

The women have histories of severe psychological, physical, and sexual abuse. They have labels of intellectual disabilities, along with difficulties in adaptive behavior, social communication, and interpersonal relationships. Many display ongoing mental health symptoms, exacerbated by their abuse.

The women require services to keep themselves safe, and when they exhibit risky behavior directed against others, to reduce their risk to potential victims. The general efficacy of our approach is demonstrated by the following outcomes:

- 1) none of the women had experienced additional rapes;
- 2) none of the women had legal charges of prostitution or other forms of sexual misconduct against them;
- 3) many of the women experienced decreased supervision in home, employment, and community settings; and
- 4) the majority of the women had increased opportunities for social interactions with peers.

Focus Groups

We conduct focus groups with the women every six months to maintain the quality of our risk reduction services.

Five questions are asked:

- 1) What do they like about services?
- 2) What do they dislike about services?
- 3) What aspects of services do they want to stay the same?
- 4) What aspects of services do they think should be changed?
- 5) What suggestions do they have to make services better?

The results of our initial and ongoing focus groups

identified six main themes that the women considered important, both in receiving services and developing risk reduction skills. These six main themes are:

- 1) create a welcoming environment and early access to the building; 2) physical cues and identification of feelings; 3) simple multi-sensory risk reduction strategies; 4) public versus private talk; 5) taking safe risks; and 6) opportunities for practice.

While not an exhaustive list of the topics covered during psychosocial skill training groups, these are the themes that the women considered critical both to creating a safe atmosphere and for learning safety skills. Also, the topics are conducive to individual skill training and can be taught by family members and agency service providers when group psychosocial skill training is not available.

Welcoming Environment

Feedback from the women suggested that our physical environment was not as welcoming as it should be. Due to time constraints, the room was not accessible until directly before group, there was no access to the kitchen for drinks, and there were few opportunities for social interactions with peers.

We remedied this situation by making sure that the room was available at least 30

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Listening to Women's Voices: Risk Reduction in Community Settings

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minutes prior to group, a large bowl of popcorn and healthy drinks were in the room, and the women had opportunities to socialize. Staff working in a nearby area provided informal supervision, answered questions, and provided requested assistance.

Mary* had recently moved to Alaska. She had limited social communication skills, was isolated, and lacked friends. She used to enter the group room, take a bowl of popcorn, put her head down, and pretend to read a book. Staff noted that Mary appeared interested in the other women, but seemed uncertain about how to interact with them.

For several weeks, staff randomly entered the room prior to group and made sure that Mary was included in the conversations. When Mary appeared to be expressing an interest in getting to know one particular group member, staff assisted the two women to arrange an outside bowling trip, an activity both women enjoyed.

During the bowling activity, staff made sure that Mary and the woman had multiple opportunities to talk to each other. Prior to subsequent groups, Mary and her new friend were observed talking to each other. They planned and participated in several additional activities together.

Feelings

Our second area of needed change was that many of the women had difficulty identifying the physical cues for their feelings, along with naming the feelings that corresponded to these cues. The women reported that on many occasions they attempted to disclose and talk about their abuse, but their feelings were ignored, minimized, or discounted. As a result, they did not feel respected or supported by others.

**All names are pseudonyms and examples have been modified to protect confidentiality.*

Assisting the women to learn to identify the physical cues for and name their feelings provided the means by which they could accurately relay what was happening internally, a critical communication skill.

Julie participated in a focus group. When it was her turn to discuss what she liked best about the group, she stated that she liked matching the look on her face to the feeling that she had inside her body. When asked why she felt that this was important, Julie said that when she was raped, she felt uncomfortable talking about what happened, so she would smile when this topic was mentioned. Julie reported that since she smiled, staff did not take her rape seriously or feel that it upset her. She said that, since she had learned to match her facial expressions to her feelings staff were taking her much more seriously.

Multi-Sensory Risk Reduction Strategies

Across the years, many women have provided feedback on their preference or multi-sensory activities instead of information that is presented through lectures. The women told us that multi-sensory activities provided information in a more enjoyable format and made it easier to remember the information.

Now, we use art projects, crafts, games, and movies to present information. During an activity, participatory discussions are used to connect the activity to safety skills, emphasize critical points, and provide concrete examples. When completed, the activities are taken home and displayed in an area where they serve as visual prompts related to safety skills.

Games

The women were learning the four personal safety steps of: 1) Say "No," 2) Leave the area, 3) Talk to a safe person, and 4) If the response of the first person is not safe, talk to someone else. The women were divided into two teams, and each team came up with a name. A series of increasingly difficult vignettes was read. Each team was given an opportunity to respond and discuss how the four personal safety steps could be applied to that situation.

While facilitating the activity, staff provided information that if a woman was frightened or was unable to use the four personal safety

In order to provide risk reduction education, it is critical that a close partnership exists between the women and staff providing services. The women we have worked with have made it clear that they are a part of the process, need connections with the larger community of women, and require services that fit their needs.

steps, she was not responsible for any abuse that occurred. Also, staff talked about the importance of always letting safe people know if abuse occurs, as perpetrators sometimes "trick" women into thinking that they are responsible or caused the abuse.

Arts and Crafts

The women constructed large stoplights and glued red, yellow, and green cotton puffs on the circles for the three lights. The colored circles of the stoplight were applied to situations that could occur in dating relationships: 1) Red-Stop! Get Away and Get Help, 2) Yellow-Take Your Time and Proceed with Caution, and 3) Green-Go! This is Safe.

Staff facilitated a discussion around how situations sometimes change, and much conversation revolved around themes related to changing personal actions to reflect changing circumstances. Again, staff reminded the women that if, in spite of their best efforts abuse occurs, the responsibility for the abuse rests with the perpetrator.

Public vs. Private Talk

Additional feedback from focus groups suggests that the women often had difficulties discriminating public from private talk and actions. Often this revolved around the degree to which they felt they were expected to tolerate the social and sexual behavior of peers. The women reported they regularly felt uncomfortable with the actions of others in social situations, but were hesitant to assert themselves due to fears that they might offend the person or be rejected. Narrative storytelling with increasingly complex themes was incorporated into services as a means to

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Listening to Women's Voices: Risk Reduction in Community Settings

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provide information in a non-threatening and simple format. Often, the core of the story revolves around situations that the women have either previously heard about or experienced.

The women were presented with a story about a male acquaintance (someone they had met a few times) who sat next to them at a dance. When a "fast dance" started, the man stood up and began dancing in a sexually suggestive manner in front of them. The women were asked how they would feel (body cues and identification of feelings), and most women responded that they would feel afraid or uncomfortable. When asked what they would do, most of the women reported that they would move to a different seat.

The women were asked a series of increasingly difficult questions adding more complexity to the narrative (e.g., the male is handsome, offers to pay for dinner, has physically or sexually victimized other women). In these types of narrative stories, the needs of the women are identified and incorporated into the story (the woman is lonely, wants to date someone, the male is popular) and safe responses are stressed.

Safe Risks

Many of the women expressed pride that they had extensive information about what they should not do to remain safe in community settings. We spent a lot of time teaching these skills and cautioned them repeatedly to suppress certain unsafe behaviors. However, we found that the women generalized this information even in social situations that had minimal risk attached to them. This severely limited their chances to safely meet new people, form new relationships, and increase their opportunities for participation in social activities.

As a result, many of the women were left feeling lonely and isolated. To alleviate this

situation, we started to include teaching examples that portrayed situations where women learned to assess the degree of risk and respond accordingly.

The staff facilitated a discussion on the differences among strangers, acquaintances, friends, and dates. Different situations were reviewed, as relates to these categories of relationships. Many of the women do their grocery shopping at a local store, which has cooking demonstrations and free samples of food.

Connie was asked if it would be safe to take a free sample of food. At first, Connie vehemently stated that she could not take a free sample of food at the cooking demonstration, as a stranger was offering it. Some group members thought that it was safe to take a free sample of food if it was offered as part of a cooking demonstration and the stranger was wearing a grocery store uniform. This was defined as a safe risk. Also, the women discussed how it would not be safe to take free samples of food from other strangers either in or outside of the grocery store. This was defined as an unsafe risk.

The women were discussing times when strangers may turn into acquaintances. Kim began talking about a man named Curt, who was receiving services through the same agency as she. Kim stated that she was interested in getting to know this man, but was a little annoyed that he repeatedly called her "babe." Several women knew Curt and told Kim that he was a safe person for her to get to know. Based on their information, Kim decided that talking to Curt was probably a safe risk. When questioned, she concluded that she would treat this as a "Yellow Light-Take Your Time And Proceed With Caution" situation. Kim asked Curt to call her by her name, but he continued to refer to her as "babe." In subsequent groups, Kim modified her initial opinion of Curt and decided that he was not a safe risk, since he did not respect her request.

Practice

Lastly, feedback from the focus groups reflected the women's interest in having time to practice learned skills in community

settings. The women described this as a fun way to spend time with peers, as well as a means to further learn about safe and unsafe situations.

The women planned and implemented an activity involving a picnic by the lake. The women observed several nearby couples engaging in varying levels of intimacy. A discussion was held regarding how it is difficult for some of the women to have private time with a partner, due to a lack of privacy in their homes. The women talked about whether it is acceptable to hold hands or kiss a partner in the park, and the majority of the women felt that this is not a problem.

Next, a series of questions was asked about whether it is acceptable to have any further forms of sexual contact in the park, and specific examples were given. Several women felt that it is acceptable to have sexual relations in the park, as long as others are not able to observe them. Subsequent discussion revolved around how respectful partners do not request sex in public locations and that there may be social and legal consequences when people have sex in public.

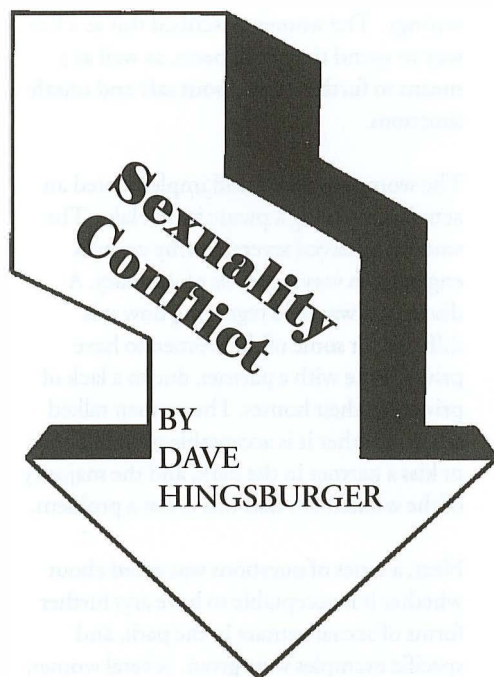
Conclusion

Over the last six years, we have learned much from the women who have received services. In order to provide risk reduction services, it is critical that a close partnership exists between the women and staff providing services. The women we have worked with have made it clear that they are a part of the process, need connections with the larger community of women, and require services that fit their needs. By "listening to their voices" we have heard what they need and learned what works.

Karen M. Ward is the Director of the Center for Human Development: A University Center for Excellence in Developmental Disabilities (UCEDD), in Anchorage, Alaska. Rebecca L. Bosek Ph.D. is the Clinical Director of the Center for Psychosocial Development Clinic.

Comments about this article may be directed to Karen Ward at afemw@uaa.alaska.edu





The sexuality of people with intellectual disabilities is fraught with anxiety. There are realistic concerns which cause families and agencies to fear for the safety of a person with a disability. There are also fraudulent issues which lead to over-protectiveness, limitations on rights, and draconian measures to assure chastity.

The mix of real concerns and fraudulent issues often leads to conflict between parents and agencies, boards of directors and front line care providers, and between individuals with disabilities and all who support them.

These conflicts are difficult to sort through because emotions run high, with everyone believing that they are acting in the best interest of someone else. Someone once said, "...save me from the people who want to save me from myself." This is never more true than with the issue of people with disability and sexuality. Two conflicts need to be closely examined.

First, there may be conflict between an agency and family over the sexuality and sexual rights of an individual in care. Second, conflicts often arise between a family and an agency which the family sees as too restrictive regarding their son or daughter.

To discuss these conflicts, situations will be presented in the form of four questions that have been asked of sexuality consultants regarding various issues.

Agency and Family

The person I support wants to attend a sex education class, but her parents (or guardians) have said "No." What should I do?

Before answering this question, it is best to look at parental concerns in context. Many parents of children with labels of intellectual disabilities were told by doctors and other professionals that their child will not grow, learn, date, or marry. For these parents sexuality was dismissed early on and they put a considerable amount of effort into just parenting their children.

Remember, it often takes longer for people with intellectual disabilities to learn and, therefore, parents and guardians worked hard at teaching all the basic skills. To hit them years later without preparation with the issue of sexuality can be cruel.

One mother said, "The child that could date and marry is dead. I buried that child. I mourned that child. I moved on. Now for me to come to accept that my child may be sexual requires a resurrection ... and I'm just too tired for that." Approaching families regarding the sexuality of their son or daughter needs to be done cautiously and carefully, recognizing that this is a highly emotional issue for reasons other than sexuality per se.

The approach for sex education needs to be made on common ground. Why are parents fearful of sexuality? Abuse. Pregnancy. Exploitation. Disease. Parents should be concerned about these issues. Indeed, so should any support agency.

Sex education should be offered as a means of protecting the individual from harm. Let parents know that the risk, for example, of victimization is high and that the agency wants to do everything in its power to assure that people are protected. One of the best ways to do that is to have people with

disabilities well informed and educated about sexuality. When both agency and family agree that sexuality poses risk and that sex education is a risk reducer, then full discussion can begin.

However, if after all approaches to the family have resulted in their statement that they will not allow their son or daughter to attend a sex education class, they should be required to sign a statement that they had been informed about the vulnerability of their son or daughter, that sex education is considered best practice for the prevention of problems, and that they assume full responsibility for the decision.

The individual I support has a boyfriend. The parents have asked us to break up the relationship, as they do not approve of their child having sexual interest in another adult.

Let's be clear. Agencies, under no circumstances, can abuse people in care. If a parent asked a staff member to slap their son or daughter because the parent believes in corporal punishment, parental consent would not make striking a person with a disability acceptable.

If a parent asked staff to call their son or daughter a hurtful, demeaning name, it would not make it acceptable for staff to call a person with a disability a name. Parents are not always right. Since we know that we cannot physically abuse a person with a disability, nor can we verbally abuse a person with a disability, it should also be clear that we cannot emotionally abuse a person with a disability. Agencies and staff know that using the full force of agency power to break up a consenting relationship between two people with disabilities is at the very least emotionally abusive. The agency cannot comply with parental wishes.

One parent brought considerable pressure on an agency, going so far as to have a government official call and ask the agency to comply with the parent's wishes. The government official was asked to provide a letter stating that it is acceptable for the agency to emotionally abuse those in care

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Sexuality Conflict

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before the agency took action. The letter did not come. The agency did not follow through.

As angry as a parent may become, agencies must conceptualize themselves as being in full opposition to all forms of abuse.

I want my child to attend a sex education class, but the agency says that they do not offer such a service. I've tried to find someone else in the community to do this, but find that as soon as they know my child has an intellectual disability they back away from service. What should I do?

There are times when parents need to be strong advocates. To be an advocate, parents need to be informed. Knowing, for example, that 80% of women with disabilities and 56% of men with disabilities will be sexually molested or raped by the age of 18, and that 90% of those who abuse people with disabilities are in care-providing roles, is powerful. Also knowing that the research says that sex education is a good way of reducing the risk of victimization, is transforming.

Agencies are responsible for providing best practice. The research on the abuse rates of people with disabilities is not new. In fact, we've known for over a decade that the situation is grim. Agencies need to be able to enunciate what they are doing to reduce the risk of abuse or they will be liable should abuse happen within the confines of their agency.

Twenty years ago there were few credible sex education curricula available that targeted the learning styles of people with disabilities. This is no longer true. In fact, there are many good curricula, and in many ways the curricula for individuals with disabilities are better than those for the typical community.

Given knowledge of best practice and knowledge of the means to provide best practice, agencies should be aware that parents will hold them responsible should tragedy occur when tragedy could have been avoided.

The agency which supports my child has a policy that does not allow for sexual expression, even for dating. I want my child to grow and develop and have all her needs met. What can I do?

Once again, advocacy through information is important. Many agencies don't want to bring up the issue of sexuality policy because it seems too daunting process. However, agencies like The Association for Community Living in Springfield, Massachusetts, have published their policies so that other agencies can have a template for developing their own policy. A parent's best ally here is the self advocate movement. The self advocate movement can actively challenge an organization's restrictive policies based on the rights of the people being supported.

If there is no self advocate movement available, help your son or daughter to develop the skills necessary to approach the board of directors of the agency that provides service to her or him. It is much more difficult for a board of directors to look at a person with a disability in the eye and say, "You will never be loved." than it is for them to dismiss you as an eccentric and bothersome parent. If your adult son or daughter comes to understand his or her rights as both a citizen and a service recipient, he or she may be able to forge change for all being supported by that agency.

The conflicts in the area of sexuality are extensive, and these are but a few of the issues that come up. However, both parents and agencies need to know when to be strong and when to refuse to back down. Yes, sparks will fly, but sometimes sparks provide enough light to illuminate the darkness of prejudice.

Dave Hingsburger is a consultant, lecturer, and widely published author. He has extensive experience working with people with disabilities, and specializes in the provision of education and consultative services in the areas of sexuality and challenging behaviors. Comments about this article may be sent to Mr. Hingsburger c/o Diverse City Press, diversecitypress@bellnet.ca

TASH Will Honor Norrie Haring through this Year's Legacy Series. We Seek Your Input!

At this year's conference in Reno, TASH will hold our second annual Legacy Series Special Session - a session dedicated to the life, work and impact of Norrie Haring. Norrie is a TASH founder and lifetime member who remains active in TASH and serves as an inspiration to many TASH members. Norrie's work and thinking continues to have important positive impact on the lives of people with disabilities and their families.

We are looking for input from TASH members. If Norrie touched your life or influenced your thinking, please send us a paragraph or two relaying your reflections. These memories will be incorporated into the session being planned in Norrie's honor. Whether you knew Norrie personally or whether his work had impact on your thinking from afar, we'd like to hear from you. We would be very appreciative if you would e-mail us a short statement about what Norrie and his work have meant to you.

The Legacy Series will be continued at future TASH conferences. If you would like to participate in planning for this year's session, or if you have suggestions of visionaries whose work, memory, and influence you'd like to see celebrated in the future, please let us know. Send an e-mail to Nancy Weiss at nweiss@tash.org.

TASH NEWSLETTER

Policy Statement

It is TASH's mission to eliminate physical and social obstacles that prevent equity, diversity and quality of life for children and adults with disabilities.

Items in this Newsletter do not necessarily reflect attitudes held by individual members or the Association as a whole. TASH reserves the right to exercise editorial judgement in selection of materials.

All contributors and advertisers are asked to abide by the TASH policy on the use of people-first language that emphasizes the humanity of people with disabilities. Terms such as "the mentally retarded," "autistic children," and "disabled individuals" refer to characteristics of individuals, not to individuals themselves. Terms such as "people with mental retardation," "children with autism," and "individuals who have disabilities" should be used. The appearance of an advertisement for a product or service does not imply TASH endorsement. For a copy of TASH's publishing and advertising policy, please call 410-828-8274, ext. 102.

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 () Administrator/Other
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 () Advocate/Friend
 () Behavioral Specialist
 () Case Manager
 () Early Childhood Services

() Educator/Teacher (K-12)
 () Government Personnel
 () Legal Services Provider
 () Occupational/Physical Therapist
 () Parent/Family Member
 () Personal Assistant
 () Professional/Public Policy Advocate
 () Professor/Instructor-College/University
 () Psychologist
 () Regular Education Teacher/Administrator

() Related Services Provider
 () Self-Advocate/Person w/ Disability
 () Social Worker
 () Speech/Language Pathologist
 () Special Education Teacher
 () Special Education/Support Specialist
 () Staff Development/Trainer
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