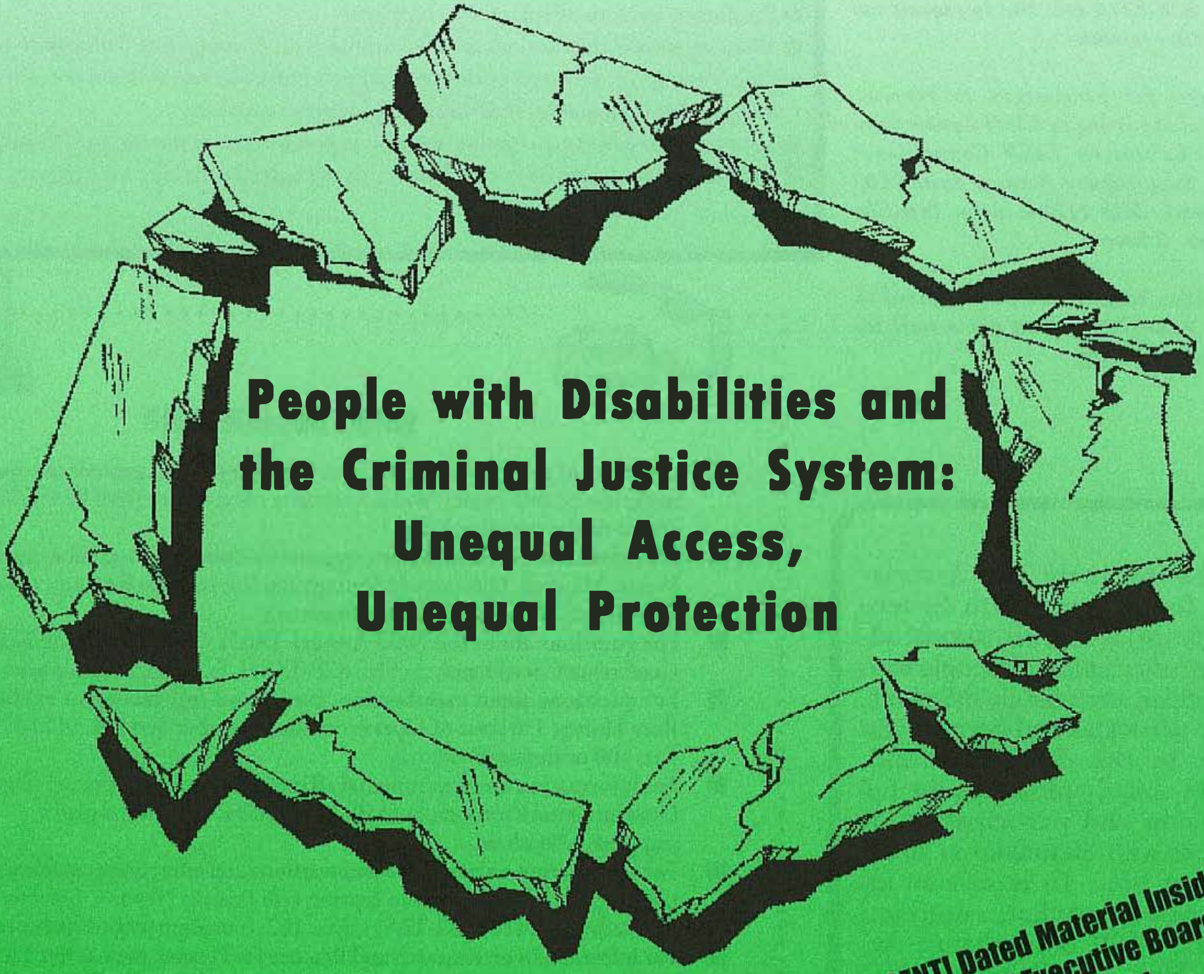
VOLUME 29 • ISSUE NUMBER 8/9 • AUGUST/SEPTEMBER 2003

TASH CONNECTIONS

Equity, Opportunity and Inclusion for People with Disabilities since 1975

Inside This Issue



People with Disabilities and the Criminal Justice System: Unequal Access, Unequal Protection

URGENT! Dated Material Inside! 2003 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 2003 Annual TASH Conference, 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: jruppmann@tash.org
- For information on newsletter submissions and advertising, marketing and promotions, 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: Fredda 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

THE 2003 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.

Five of the 15 seats on the TASH Executive Board will be re-seated at the December 2003 TASH Conference in Chicago. 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 9, or clearly write "ballot" on the envelope you use. Ballots must be received at the TASH office by October 31, 2003. Please use ink and vote for five candidates. Voting for more than 5 nominees will invalidate your vote.

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

Pat Amos

"Since the birth of my first child over a quarter-century ago, I've been drawn into an unexpected advocacy career. And like most TASH members, I cannot think of a better way to combine the personal with the political. As a famous *Pogo* quote says: 'We are surrounded by insurmountable opportunities.'

One opportunity I'd like to explore with TASH is the creation of new ways to support and benefit from our grassroots. Another is the organization of a unified push to end, once and for all, the use of restraints and other aversives.

I have enjoyed all the benefits of a long learning curve. To my oldest son I owe my knowledge of what autism is and especially what it is NOT. He and his friends have identified their issues as the need for a decent living wage and the need to stay out of institutional settings, and therefore he elected to volunteer with the International Workers of the World and for a prisoners' rights project. My daughter, who lives creatively with obsessive-compulsive disorder and "anxiety disorder," shows me what it means to move in a world with a different topography of peaks, valleys, and gravitational fields, while my second son's response to anxiety and recurring depression impressively demonstrates how much can be accomplished by standing on one's dignity and saying 'no' whenever appropriate.

I began my career as President and newsletter editor for the Greater Philadelphia Autism Society, and in the late '80s co-founded a statewide autism organization dedicated to inclusion. Subsequently I served with Pennsylvania's Developmental Disabilities Council, eventually sitting on the Executive Committee.

Among my favorite projects was a fellowship for emerging leaders with disabilities, supporting them to acquire the hammer of their choice to break through the 'glass ceiling.' For families just beginning their advocacy careers, a grassroots project offering networking and mini-money grants continues to help hundreds of small groups to soar.

In 1990, it was my pleasure to be a founding member of the Autism National Committee (AutCom), which owes much of its incubation to TASH. After serving on the Board and as newsletter editor, I became its second President after Herb Lovett. In 1998 I was honored to receive the first annual Herb Lovett Memorial Award.

Currently I am promoting TASH issues in my neighboring state of New Jersey, where we are involved in an intense struggle to pass a bill banning aversives and limiting restraints. Check out the web site, www.matthewslaw.bravepages.com (which was put up by my third son).

Back home, our inclusion movement has matured into Autism Living and Working, Inc. (ALAW). ALAW homes belong

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to those who live in them and direct their own services. Our goal is to leverage this pilot into systems change across disabilities labels.

I frequently draw on my graduate work in anthropology and the study of narrative to bring new insights to my trainings and writing, which focus on quality of life issues. TASH's clarity of vision has kept me going through the years, and I avidly seek the opportunity to 'pay it forward.'"

Wanda J. Blanchett

Wanda is an active TASH member who has boldly undertaken controversial issues of sexuality education, HIV/AIDS education, issues related to meeting the needs of non-heterosexual individuals with significant disabilities, and meeting the needs of people of color with disabilities and their families.

For over 15 years, she has worked in community and public school settings to promote the inclusion of individuals with disabilities in all facets of life. She has worked diligently as a direct service provider, teacher, and teacher educator to increase participation of individuals with special needs in their local communities and to improve educational programming and outcomes for people with disabilities.

Wanda's commitment to empowering persons with significant disabilities to determine their own destiny is informed by her work in the 1980s as a direct service provider for recently deinstitutionalized individuals in the state of Arkansas. Specifically, she helped to facilitate their transition into independent living settings, employment, post-secondary education and all other aspects of adult life that were important to them.

Wanda is an advocate for inclusive education and quality educational programming for students with special needs. Her pledge to improving educational programming and outcomes of students with disabilities dates back to her classroom teaching experiences in the Delta region of Arkansas.

As a practitioner, she taught students with disabilities in an elementary public school setting and served as a consultant to regular classroom teachers long before it was considered "best practice." She provided technical assistance to general education teachers that enabled them to meet the needs of their students with disabilities within the general education curriculum. Although Wanda found her role as a practitioner extremely rewarding, her desire to have a more direct impact on improving educational programming and outcomes of students with special needs led her into teacher education and research.

Wanda is currently an Associate Professor in the Department of Exceptional Education at the University of Wisconsin-Milwaukee where she is involved in urban teacher preparation and research. Her research focuses on issues of sexuality, urban teacher preparation, and the role of race, class and gender in special education. Additionally, she has published several articles in special education journals and made a number of presentations at TASH and other professional conferences. She is currently chair of TASH's Development Committee, a member of the Newsletter Advisory Subcommittee, and co-chair of the Sexuality and People of Color and Their Families conference strand.

Wanda has been a TASH Board member since 1999 and is interested in continuing to serve on the Executive Board for three reasons: she would like to utilize her practical and professional experience to further the mission of TASH; she wants to ensure that TASH continues to be viewed as a leading advocacy organization that is committed to diversity in all of its many forms; and she would like to work within the framework provided by TASH to challenge attitudes, institutions and policies that prevent individuals with significant disabilities from expressing themselves and achieving their goals.

Angela Burton

Angela Burton is no stranger to working with and on behalf of persons with disabilities. As a lawyer for children, Angela has been profoundly touched by the courage and perseverance of her clients and their families in the face of misunderstanding, insensitivity, and downright meanness that is sometimes exhibited by decision-makers and those in positions of power and authority when it comes to responding to the needs of individuals with disabilities.

Because of her experiences with the special education and juvenile delinquency systems, Angela has resolved to gain a more nuanced understanding of the lived experiences of children with disabilities and their families so as to become a better advocate and representative.

Currently an Associate Professor of Law at the City University of New York (CUNY) School of Law, Angela spent the

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last five years as director of Syracuse University's Children's Rights and Family Law Clinic. In that position, she not only increased her understanding of the complex legal aspects involved, but also gained a greater appreciation for the political and practical challenges and opportunities faced by persons with disabilities, their families, and their advocates.

"At the moment, my outreach and research is particularly focused on the plight of children with disabilities who find themselves caught in the tangled web of the juvenile justice system. Substantial numbers of children who end up committed to juvenile detention centers by the courts are either misdiagnosed or undiagnosed as experiencing various learning disabilities, and mental and emotional disorders. Most often, these children do not get proper services, education, or treatment while detained in these 'children's prisons,' and end up the worse for the experience." Angela hopes that her research will provide a basis for institutional accountability and stronger legislative protections for children with disabilities in juvenile detention centers.

As a member of the Executive Board of TASH, Angela hopes to use her legal expertise to further the goals and mission of the organization, and will strive to learn from others on the Board and in the membership who have lived experience as persons with disabilities and as individuals working with and on behalf of people with disabilities. "If elected to the board, I will use my legal experience and knowledge to benefit the organization and the people it represents, and simultaneously become a better legal and political advocate on behalf of people with disabilities."

John Butterworth

"As a member since the late 1970's, TASH was central to developing a values base and understanding of the purpose of my work as a teacher and then program manager providing adult supports. I joined shortly after completing my Master's in Special Education at Peabody.

As a beginning educator who knew something about how to teach, TASH helped me understand what to teach and why. That change in perspective has continued to evolve, steadily and sometimes radically, with TASH as a continuing force that makes me ask 'why?' I was a founding member and have served as Treasurer and President of the New England Chapter. More recently I have been a co-chair of the Employment Committee and supported the employment strand at the conference.

My work has taken me from teaching young adults, to providing/managing adult day and employment services, to my current focus on research, training, and systems change. Along the way I have worked with schools and adult service providers to support individual and organizational change that is consistent with TASH values.

As Research Coordinator for the Institute for Community Inclusion at UMass Boston, I work on a wide range of projects that focus on expanding employment opportunities through policy change and effective services. This work addresses questions including: How do we get state agencies to take the goal of employment seriously, how can generic services like one-stop centers provide effective supports to all of their customers, how can local organizations reimagine themselves from a traditional facility-based service provider to supporting individual careers and other life goals, and how do we support individuals to clearly state their personal dreams and use them to drive their supports? All of these questions require debate, conflict, coalition building, and creativity, skills that TASH has always provided an effective forum for.

There is a perception among many that TASH does not do as good a job at representing and supporting adult issues, including employment. The truth, I think, is that adults have too many interests and it is harder to pin us down (everyone goes to school after all; we spread out after that), but I would expect to be a voice that helps keeps issues of adult life and the systems changes necessary to support personal dreams active.

My goals as a TASH board member are to ensure that the organization continues to challenge each of us to rethink our perspectives and focus, to expand the visibility of employment and related adult life issues in the conference, publications, and training, and to support opportunities for meaningful participation of members across all levels of the organization and particularly at the chapter level. TASH succeeds if it facilitates regular opportunities for dialog, disagreement, and controversy."

Jim Conroy

"Since 1970, my role in our field has been research. I want to support the TASH values of community, inclusion, and self-determination through my understanding of facts, evidence, research, litigation, and, at the end of the day, values.

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I have been a member of TASH since 1983. I graduated cum laude from Yale University in 1970 with a BA in Physiological Psychology. I received my MA in Sociology/Program Evaluation in 1982, and the Ph.D. in Medical Sociology from Temple University in 1992.

I did a research visit to Pennhurst State School and Hospital in 1970, which was designed for 700 people but at the time housed 3,400 - and that stunning experience remains a vivid motivator for me to this day. It broke my heart to see that enforced and massive misery - making lives that were "poor, nasty, brutish, and short" - in the richest nation on Earth.

I was Research Director at Temple University's University Affiliated Program in Developmental Disabilities for 17 years. Heading the Pennhurst Longitudinal Study, the largest and most comprehensive study of the impacts of moving from institution to community done up until that time, taught me the powerful value of community living.

Designing and conducting the Congressionally-mandated National Consumer Survey for the Administration on Developmental Disabilities, in which more than 13,000 Americans with developmental disabilities were interviewed face-to-face, taught me the extraordinary value of learning to listen to people about their satisfaction, hopes, and dreams.

Doing the evaluation of the original self-determination demonstration in New Hampshire, and then the National Impact Assessment for the Robert Wood Johnson Foundation's National Self-Determination Initiative for Persons with Developmental Disabilities taught that shifting power toward service recipients and their allies through self-determination does lead to better qualities of life, and yet is fiscally conservative.

I have served as an expert witness in some of the most noteworthy court cases in our field, including Pennsylvania's Right to Education litigation, *Halderman v. Pennhurst* and *P.J. v. Connecticut*. These experiences taught me to see the disability movement as a civil rights movement.

I've written and co-written 30 articles in professional journals, 11 book chapters, and 240 formal deliverable research reports to government agencies. My work has been publicized on *60 Minutes*, *ABC Evening News* with Peter Jennings, *NightLine*, *National Public Radio*, the *Philadelphia Inquirer*, the *New York Times*, the *Chicago Tribune*, public television, multiple radio interviews, and a variety of other media.

I believe my work on the outcomes of deinstitutionalization in America has been my definitive contribution toward better lives for people with disabilities. My more recent work on the outcomes of self-determination, however, may ultimately prove to be just as important.

I think I can be a valuable Board member for TASH."

June Downing

June is a lifetime member of TASH and a professor at California State University, Northridge. She is committed to creating the best learning environment for students with significant disabilities and their peers. To do so, she maintains high standards for teachers while helping them learn how to truly make all students, regardless of ability level, active members of fully inclusive classrooms. June does considerable inservice training, and has presented nationwide on inclusive and best educational practices to educators, family members, paraeducators, related service providers, and administrators. She shares her own experiences as a paraprofessional, teacher, work experience coordinator, and tutor to help others avoid mistakes she made, and to serve as a catalyst for creating change.

June strongly believes in the values of TASH and has been active at both the state and national levels. She was the Arizona TASH president for several years and was on the executive board of CalTASH as Past President. She has served on the Executive Board of TASH for the past 3 years and is actively involved in committee work related to Personnel Preparation and Related Services. Publications include three books and numerous articles and chapters regarding inclusive education, teaching students to learn in inclusive classrooms, and personnel preparation issues needed to support inclusive classrooms.

June is interested in disseminating TASH values to other organizations to which she belongs, to faculty at different universities, teachers, and family members. She serves as a family advocate and is continually amazed when families who have a member with significant disabilities is unaware of TASH as an organization. Through her work with families, school personnel, and others, she hopes to increase awareness of TASH and what is possible when the vision for everyone is positive and builds on strengths and dreams. June would like to volunteer her energy and her commitment to serve, to furthering the ideals that TASH represents.

Paula Kluth

"What an honor to be nominated for the TASH board. I have learned so much from TASH and

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its members over the years. It would be an honor to serve this organization and give back to a group that has given so much to me.

I began my relationship with this organization as an undergraduate student at the University of Wisconsin. Shortly after graduating, I started my career as a special educator and inclusion facilitator. I worked with students with a range of abilities, skills, needs, and gifts in both elementary and secondary schools. In this role, I learned how to teach in diverse, inclusive classrooms; plan lessons accessible for all; and co-teach with colleagues. After teaching for a few years, I continued to study dis/ability, education and curriculum.

I have a M.Ed. in Educational Policy (Human Rights/Civil Rights) from the Harvard Graduate School of Education and a Ph.D. in Special Education from the University of Wisconsin. I am also a former Assistant Professor in the Department of Teaching and Leadership at Syracuse University. I thoroughly enjoyed my time at Syracuse, especially my work with my wonderful colleagues, the Inclusive Education Teacher Certification program, and the Facilitated Communication Institute.

I am currently an independent educational consultant and researcher. My professional and research interests center on differentiating instruction, on supporting students with significant disabilities in inclusive classrooms, and on communication rights. I am especially interested in teaching with and learning from students with autism and am currently working on a 2-year grant project focused on providing inclusive schooling experiences for students with autism. Much of my interest in autism has come from working with and learning from fellow TASH members with the label of autism. I have learned so much about ability, inclusion, and dis/ability from Eugene Marcus, Susan Rubin, Jamie Burke, and Franklin Wilson.

I am interested in using my professional experience to further the creative political work of TASH and especially to help TASH further its mission of putting people with disabilities at the center of their own lives and at the front of the disability rights movement."

Liz Obermayer

Liz is a consultant for the Council on Quality and Leadership where she trains customers, people with disabilities, and sometimes parents on how to include people with disabilities in the work that they do. Liz also sits on different committees to represent The Council's point of view on issues that concern quality of life for people with disabilities.

Liz is a leader in the self-advocacy movement, serving as the Vice-Chair of the Maryland DD Council and the treasurer of People on the Go, the Maryland self-advocacy group.

Before relocating to Maryland, Liz lived in Boston, Massachusetts where she worked for the Department of Mental Retardation as a trainer. Liz's duties there was similar to what she does for The Council. She was key in starting up the self-advocacy organization in Massachusetts. In addition to her job, she was active on various committees and boards in Massachusetts.

Liz also brings to the table the experiences of being a consumer of services as she received supports from a provider in New Jersey. In her 9 years living in the state, Liz was very involved in the self-advocacy movement. She was active with South Jersey People First group from 1989-1994. Liz was on various other committees within the state to help either close institutions or help promote community living.

On the national level, Liz was Vice President of the national organization, Self-Advocates Becoming Empowered (SABE) from 1993 to 1996. She worked her way up from being on the Board of New Jersey TASH to currently serving on TASH's Executive Board. Liz was appointed by President Clinton to the President's Committee on Employment of Persons with Disabilities.

In 1998, Liz received the Elizabeth Monroe Boggs Award for Young Leadership. The award is given to young leaders in the field of developmental disabilities.

Lu Zeph

"It is an honor to accept the nomination to serve a second term on the TASH Executive Board. My name is Lu Zeph, and I have been an active TASH member for over 20 years. During that time I have served on a wide range of TASH committees and work groups. During the past three years, I have served as the Board liaison to the Governmental Affairs and Early Childhood Committees. I also serve on the Development Committee, the Conference Planning Committee and the Editorial Board of Research and Practice for Persons with Severe Disabilities. For the past year I have served as the Secretary of the Executive Committee of the Board.

My professional career spans over 25 years in the area of severe disabilities. I

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have been a teacher, early interventionist, administrator, and for the past 24 years, I have been a professor at the University of Maine teaching in the area of severe disabilities and disability studies. In 1992, I became director of The University of Maine Center for Community Inclusion, Maine's University Center for Excellence in Developmental Disabilities. The Center's mission is to bring together the resources of the community and the university in ways that result in improved quality of life for individuals with disabilities and their families. The Center, like TASH, brings together individuals with disabilities, family members, and a broad range of professionals and community members committed to creating inclusive communities based upon what can best be described as 'TASH Values.'

In addition, I have a strong interest in the area of public policy. In 1999, I was named a Kennedy Public Policy Fellow and had the privilege of serving for a year in Washington, D.C. as a congressional fellow with Senator Jim Jeffords, Chairman of the Health, Education, Labor, and Pensions Committee. I returned to D.C. during the 2000-01 academic year to serve as the Executive Director of the Joseph P. Kennedy, Jr. Foundation. These experiences underscored for me the need for TASH to be at the table when legislation and policy decisions are being made that affect the lives of individuals with severe disabilities. This is the perspective, knowledge, and commitment that I would like to be able to continue to bring to the TASH Executive Board.

In many ways, I believe that TASH and I have grown-up together. Like so many others, TASH provided a place to replenish when the struggle to create change became overwhelming. TASH has always been there for me...the people, the values, and the commitment to 'do the right thing,' even when it was difficult. It has been a privilege to serve on the board for the past three years, and to have the opportunity to give back to an organization that has given me so much. If re-elected, I will continue to contribute to ensuring that TASH continues to do the same for others in the future."

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We hope that all TASH members will participate in this year's election. We're aiming for as inclusive a process as possible! The five candidates who are selected will be announced in the November issue of TASH Connections. We appreciate your participation!

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THANK YOU!

Our thanks to TASH Executive Board members Barbara Ransom and Dick Sobsey for their invaluable assistance in co-editing this issue of TASH *Connections*.

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:

Viktoria A. Brown
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June Downing
Young Ae Ko
Eppie Maidenbaum
Kathy Peckham-Hardin
Beverly Rainforth
Barbara Ransom
Joan Rosenblum
Jesse Vazquez
Julie Vrdoljak
Christine Yuelys-Miksis

And thanks to lifetime member

Kirk Huddleston

TASH also has a lifetime member option available. To find out more about how you can receive full international and chapter member benefits for your lifetime, contact Rose Holsey at 410-828-8274, ext. 100.

TASH 2003 Election of Five (5)

EXECUTIVE BOARD MEMBERS

Term of Office: 2003-2006

- OFFICIAL BALLOT -

There are five 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 2003 TASH Conference to be held in December in Chicago, Illinois.

Ballot Instructions:

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

☐Pat Amos

☐Wanda Blanchett

☐Angela Burton

☐John Butterworth

☐Jim Conroy

☐June Downing

☐Paula Kluth

☐Liz Obermayer

☐Lu Zeph

For information about the candidates, please refer to pages 3-8 of this issue of TASH *Connections*.

Mailing Instructions:

Ballots may be returned using this postage-free mailer, or originals of the ballot can be sent in an envelope. If you elect to use an envelope, please be sure the word BALLOT is printed on the front. If you use an envelope, please do not place anything other than your ballot inside; your envelope will not be opened until the counting of the ballots.

VERY IMPORTANT:
Only an original ballot will be considered valid.
Photocopies or faxes will not be accepted.

Ballots *must* be received at the TASH Central Office by October 31, 2003.

Mail your completed ballot to:
TASH, 29 W. Susquehanna Avenue, Suite 210
Baltimore, Maryland 21204
Attn: Ballot

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FOLD BALLOT HERE

2003 TASH
Executive Board
Election BALLOT

Due in Baltimore on
October 31, 2003!

TASH: The Action Starts Here ...

While it's true that TASH doesn't really stand for "*The Action Starts Here,*" TASH members know that it is TASH's clarity of vision and willingness to take action that distinguishes us from many other groups.

If TASH is one of the organizations nearest to your heart, please consider a contribution or a plan for giving to secure the future of TASH's commitment to progressive supports and included lives of value and meaning for all people with disabilities.

Your gift can guarantee that TASH will continue beyond our almost 30 years of leading the way to assure that:

- the rights of people with disabilities are protected;
- progressive research is assured the support and audience it deserves; and,
- individual and legislative advocacy is available whenever needed.

You are important to TASH's future. Please consider a gift by check or credit card. No amount is too small or will go unappreciated.

Do also consider:

- Contributions of stocks or securities
- Remembering TASH through your will or living trust
- Beneficiary designations of life insurance or pension plan proceeds
- Designating TASH as a "write-in" on your United Way form
- Gifts with retained income for you or others

Gifts to TASH are tax deductible. You can drop your gift in the mail today or call us to make a credit card contribution or to discuss your options for making a donation to TASH by calling Nancy Weiss at 410-828-8274, ext. 101.

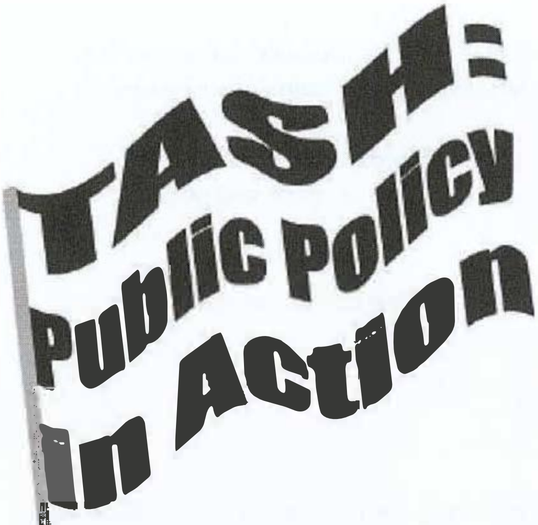
It's the 2003 TASH Town Meeting!

Join **Greg Smith,** Host of "*On A Roll - Talk Radio on Life & Disability*" for a rousing "Open Microphone" Discussion of Critical Issues

With invited guests:
Martin Gerry, *SSA, Office of Disability and Income Security Programs*
Pat Morrisey, *Administration on Developmental Disabilities*
Troy Justesen, *White House Liaison for The New Freedom Initiative*
And TASH leaders in the areas of
- *Governmental Relations*
- *Health Care*
- *Self-Determination and Rights*

Friday, December 12
12:00 Noon

TASH Annual Conference



A CALL FOR UNITED ACTION:

Advocates Visit Washington, D.C.

Pat Amos and Janice Roach are advocates for children and youth who have "walked the walk" for many years and, most notably, since February 6, 2002.

That's the date that Matthew Goodman died in one of the "neurohealth units" of Bancroft School in New Jersey. Janice Roach is Matthew's mother. Since Matthew's death, Janice has worked tirelessly to bring about reform in the care and treatment of youngsters with significant disabilities in New Jersey.

Pat Amos, past president of the Autism National Committee (AutCom) and herself a mother and outstanding advocate, has provided support and leadership to Janice and other parents in New Jersey and Pennsylvania to bring about reform through the passage of Matthew's Law in the New Jersey legislature. With New Jersey TASH and advocates from SPAN, the New Jersey parent resource center, they founded The Family Alliance to Stop Abuse and Neglect.

After 18 months of activity and research, The Alliance leadership came to Washington D.C. on September 3, 2003 to meet with and challenge key advocates in the disability community to join them in their efforts to eliminate the use of restraint, seclusion and punishment as an educational or therapeutic "treatment" of school age children and youth.

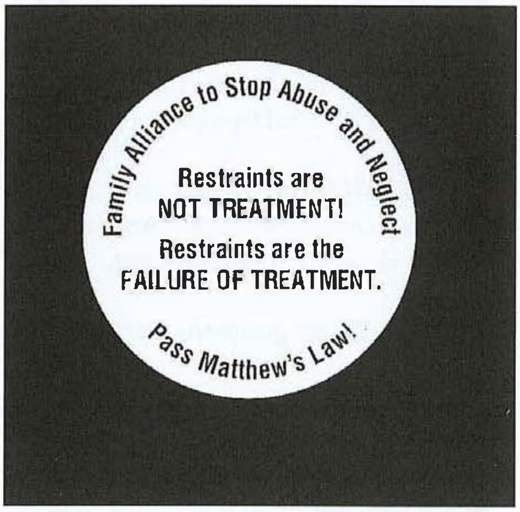
Pat Amos and Janice Roach visited the offices of the Children's Defense Fund, the National Association of Protection And Advocacy Systems, and the National Association of Councils on Developmental Disabilities.

In addition, Janice and Pat addressed a meeting of the Consortium for Citizens with Disabilities Education Task Force. Citing their difficulty in gathering data and resources to assist them in their fight for Matthew's Law, Pat Amos urged CCD member organizations to work to ensure data collection and reporting of the use of restraints and aversives:

"CCD organizations must clearly inform their members of where and how to file reports with P&As (protection and advocacy) and other appropriate agencies. Please maintain data bases of the stories and incidents that come to you," Pat said.

"Incidents are happening daily, stories get reported once in local newspapers, families raise concerns and tell stories on listservs, but too little of this data is captured," she added.

Pat and Janice presented information packets to CCD Education Task Force chairs to be shared with members. Included in the materials were a set of additional steps The Family Alliance is asking advocacy organizations to undertake in support of their goals. These include:



- ❖ Raise awareness by setting organizational priorities.
- ❖ Position this issue across and beyond the disabilities field.
- ❖ Support a wider spectrum of self-advocates to address the use of restraints and seclusion.
- ❖ Target the information needs of state legislatures.
- ❖ Consider more intensive support for state-level reforms.
- ❖ Work together to address the elimination of restraints, seclusion, and aversives using the national forums.

Next steps include the formation of a steering committee that will bring together like-minded organizations to develop national strategies and activities to work toward the banning of aversives, seclusion, and the inappropriate use of restraints as educational "intervention" or "treatment" used with children and youth who have disabilities.

For more information about The Family Alliance to Stop Abuse and Neglect and their work in New Jersey, visit their web site at http://www.matthewslaw.bravepages.com

For information about this or any other advocacy or policy issues of interest to TASH members, contact Jamie Ruppmann, Director of Governmental Affairs, at jruppmann@tash.org. Be sure to visit the public policy section of our website: www.tash.org

RPSD-*Connections*

RPSD-*Connections* is focused on bringing the latest research from TASH's journal, Research and Practice for Persons with Severe Disabilities, to *Connections* readers. Our goal is to summarize some of the articles that are newly published in RPSD to help keep you abreast of the latest available research and information.

The following article summary was prepared by a graduate student at Simmons College in Boston. If you would be interested in summarizing an article for publication in this column, please contact the RPSD office at 718-997-5315, or send an e-mail to <fbrowncuny@aol.com>

Fredda Brown, Editor, and June Downing, Associate Editor, RPSD

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Fisher, M., & Meyer L. (2002). **Development and social competence after two years for students enrolled in inclusive and self-contained educational programs.** *Research and Practice for Persons with Severe Disabilities*, 27, 165-174.

Summary prepared by: Michele Mayer, M.Ed., Simmons College and HMEA, Boston, MA

Background

Almost twenty years after the development of inclusive programs for children with severe disabilities, disagreement still exists as to whether inclusive classrooms can meet the needs of students with the most intensive support needs. Opponents argue that it is difficult for general education teachers to completely address the needs of students with severe disabilities, and that concentrating services within a self-contained setting leads to better use of the specialized resources that these students require.

Recent studies have begun to indicate that students with severe disabilities who receive services within an inclusive setting are demonstrating educational gains. Longitudinal data comparing outcomes of students served in inclusive classrooms versus those served in self-contained classrooms are limited.

Purpose

This study evaluated the effects of educational program placements (inclusive versus self-contained) on students with severe disabilities of varying ages. The purpose of the investigation was to compare the effects of attending inclusive versus self-contained programs on two validated measures of child development across a 2-year time span.

Method

Forty students with labels of severe disabilities, ranging in age from 5 to 18 years, participated in the study. Half of the students were served in inclusive classrooms, where their IEP objectives were integrated into the routines of the general education classroom. The other half of the students received their services in self-contained classrooms. These classrooms were located in separate schools or segregated sections of the local school building. Both urban and suburban settings were included.

For purposes of comparison, two measures of child development were selected. The Scales of Independent Behavior (SIB) was used as a measure of developmental functioning. The SIB (Bruininks, Woodcock, Weatherman, & Hill, 1984) is a rating scale completed by a teacher or other knowledgeable adult, and measures level of independent performance across four major curricula clusters: Motor Skills, Social Interactions and Communication Skills, Personal Living Skills, and Community Living Skills. The SIB also yields a full-scale "broad independence" score that was used for comparisons in this study.

The second tool selected for use was the Assessment of Social Competence (ASC) developed by Meyer er. al. in 1985. The ASC is also a rating scale in which the respondent scores the students' social competence skills along a continuum indicating whether the skill has been directly observed, reported by others, or never observed.

Both evaluation tools were administered at the beginning of the investigation, and then were repeated two additional times at the end of each subsequent school year. According to initial assessment information, there were no differences in skill levels between the students from the inclusive classrooms as compared with those students who were in the self-contained classrooms at the outset of the two-year study.

Results

Both groups achieved higher scores on both the SIB and ASC when Year 3 scores were compared with Year 1 scores. However, the

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RPSD Article Review:

Development and social competence after two years for students enrolled in inclusive and self-contained educational programs

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gain in scores on the SIB for the inclusive group was found to be significantly greater than the gain in scores for the self-contained group. Likewise, both groups also scored higher on the ASC in Year 3 than in Year 1. Again, the increased scores for participants in the inclusive group were found to be greater (although not statistically significant) than the scores of the participants in the self-contained group. When the SIB individual cluster scores were examined, the Personal Living Skills cluster and the Community Living Skills cluster scores were found to be higher for the inclusive participants than for the self-contained participants. No significant differences were found between groups on the Motor Skills cluster, the Communications cluster, nor the ASC.

In summary, all students, irrespective of classroom setting, made significant gains between Year 1 and Year 3 on the assessment measures. However, those students receiving services in inclusive settings were more likely to make greater gains than those students receiving services in the self-contained classrooms.

<u>Practical Implications</u>

Contrary to the belief that concentrating special education services in segregated settings for students with severe disabilities will lead to more intense services and therefore, more favorable outcomes, this study suggested that students receiving services in inclusive settings made greater gains on validated measures of child development than similar students receiving services in self-contained classrooms. Educating students with severe disabilities in inclusive classrooms does pose greater challenges for school systems than educating students in self-contained programs. As this study suggests however, when school systems embrace inclusive practices for all learners, educational gains can be achieved, even by students with the most intensive support needs.

COORDINATOR FOR AUTISM PROGRAM

The Arc of Iberia, located in South Louisiana, is seeking a full time Coordinator to oversee and coordinate a newly developed Autism Program.

Responsibilities include developing individual plans of care, assessment of behavior and development of positive behavioral supports, and training and supervising staff in all aspects of individual care, including positive behavioral strategies. This position reports directly to the Program Director and is responsible for all aspects of programming.

Requirements are a Bachelor's Degree in a related field and 5+ years in a leadership position relating directly to autism. Progressive organization with full benefits package.

Send resume and cover letter describing specific training and experience in the above-mentioned responsibilities, as well as salary requirements, to Human Resources, P.O. Box 9610, New Iberia, LA, 70562. Resumes without a cover letter as stated will not be considered. EEOE.

ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of Research and Practice for People with Severe Disabilities (RPSD, formerly JASH) for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this:
Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To learn more about TASH's Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100, or send an e-mail to rholsey@tash.org

Helping People Who Have Been Hurt:

Adaptations to Cognitive Therapies for People with Developmental Disabilities and Post Traumatic Stress Disorder

BY TERRI PEASE

Trauma, experiencing or witnessing life-threatening events or personal assaults, is all too common in the lives of people with developmental disabilities. By some accounts, the majority of people with disabilities will experience some form of sexual assault abuse, or other traumatic event, with as many as 15,000 people with developmental disabilities being raped each year.

Trauma may result not only from intentional violence, but from the imposition of aversive procedures, serious illness, losses of significant people — whether due to death, moving, or other life changes. Not everyone who goes through a trauma will go on to experience the emotional numbing, anxiety and intrusive memories that are common aspects of posttraumatic stress disorder or PTSD. Still, it is clear that there is a pressing need for strategies to help people with labels of mental retardation to recover after a traumatic experience.

There is virtually no research on treatment strategies for trauma survivors with mental retardation. Counselors and psychotherapists who work with trauma in the typical population must apply what is known about responding to PTSD in general when people with developmental disabilities come to them for help. This article summarizes some observations and conclusions from work with adult survivors of trauma who are people with developmental disabilities, and offers suggestions for modifying the most effective PTSD interventions used in typical populations.

Psychologists have known for more than a century that people can experience long lasting changes in their psychological status after a highly disturbing event. While for many years reactions to trauma were thought of as primarily emotional responses, current research on Post-Traumatic Stress Disorder makes it clear that physical and cognitive processes are as important as emotions in explaining the way that human beings endure and respond to extreme stressors. PTSD is a brain-based response to extreme events that frighten and overwhelm a person.

Whether the brain of a person with a particular form of developmental disability responds to stressors in the same way as typical brains, and whether the same kinds of interventions can help to relieve the physiological, cognitive and emotional symptoms of PTSD, are research questions that have yet to be answered. Even without specific studies of developmental disabilities and PTSD, it can be helpful to explore adaptations of interventions for trauma in typical populations to meet the needs of survivors with developmental disabilities.

Similar symptoms

The kinds of symptoms experienced by people with both developmental disabilities and PTSD (including aggression, disruptive/defiant behavior, self-harm, agitation, jumpiness, distractibility, sleep problems, depressed mood) are so broad and so familiar, that they may be taken as being general problem behaviors, or as inevitable and non-specific features of the person's underlying disability. However, they may in fact be no different from the following three groups of symptoms described in any person who experiences trauma.

The core symptoms that mark PTSD include (1) compulsive re-experiencing of the traumatic event [disruptive behavior, jumpiness, distractibility]; (2) avoidance, numbing and detachment [aggression, defiant behavior, distractibility, sleep problems]; and (3) psychobiological symptoms affecting sleep, arousal level, sensory sensitivity and cognitive/attentional symptoms [jumpiness, distractibility, depressed mood].

Re-experiencing

A person who has felt terribly hurt, frightened or helpless may constantly remember what happened, and feel the need to talk about the event repeatedly. No amount of reassurance that a feared event is in the past will comfort the person, or relieve his or her distress.

Other forms of re-experiencing may include anniversary reactions, constant nightmares of the event, vivid memories that may be mistaken for hallucinations, and reenactment behaviors. It is very easy to mistake these symptoms of PTSD for behavioral problems without exploring their origins in one or more traumatic events, and to assume that extinguishing the behavior offers relief to the person that has been traumatized.

In people with developmental disabilities, re-experiencing may be labeled "perseveration," and treated with behavioral interventions designed to keep the person from talking about the event. Intrusive memories of a sexual assault, or reactions to traumatic triggers (things that remind the person of the trauma) may be misread as hallucinations. Constant vigilance, being always watchful in case the traumatic event may re-occur, may be mistaken for paranoia. Paying attention to

> *Intervening with a traumatized person with developmental disabilities requires first understanding the person's life circumstances to determine whether unraveling a way of coping, one that may be working in some way, is a help. Sometimes counseling is not the right intervention, especially if the person is still being exposed to the source of the trauma (an abusive caregiver, peer or parent, for example).*

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Adaptations to Cognitive Therapies for People with Developmental Disabilities

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these behaviors may keep those in close proximity to the survivor from having to constantly hear about the experience, or to reassure the survivor that the feared stimulus is not present, but we do not know that silencing the survivor relieves his or her constant fear and remembering.

Avoidance and numbing

The second group of PTSD symptoms reflect the person's attempts to keep the pain of the memories at a distance. Traumatized people tend to avoid situations that remind them of the place, people and/or circumstances of the trauma. Sometimes these are obvious triggers (the same room, riding a program van), but triggers can be very subtle and specific.

A person who was attacked in a room with white curtains may be triggered by a similar window, without being able to say that is the cause of his or her extreme emotion. Similarly, a person who has had a traumatic experience on the job, and who subsequently refuses to go to work, may be seen to have a behavior problem when, in fact, he is reacting in a way that is completely normal for a trauma survivor. In other cases, people who have access to drugs or alcohol may take them in an effort to mask the pain.

In some cases, trauma may have the effect of dividing the content of a memory from the feelings that originally went with it. For example, a woman who was raped was able to both compulsively remember and to avoid the memory. Telling the story repeatedly, she seemed "stuck" on a memory of the past event, but without much emotion. At other times, she experienced disabling fear and rage, without knowing what had frightened her. Such disconnection of the memory and the fear of a traumatic event can be confusing for family and staff, and can lead to the mistaken idea that the person is just re-telling a story "for attention."

Psychobiological Reactions

A third group of symptoms reflects the fact that the reaction to trauma is as much a physiological reaction as a psychological one. The experience of ongoing extreme fear and helplessness can cause lasting alterations in how the person's brain and body respond. The body's reaction to stimulation becomes unbalanced. Traumatized people have changes in their sleeping patterns; they may sleep a lot more, or be unable to sleep. They may become hyperaroused, always active, easy to startle, showing constant vigilance, seeking extremes of stimulation, getting themselves into danger. When a person with developmental disabilities seems always afraid and agitated without an obvious reason, one can misread the reaction as generalized anxiety, or attention seeking, without understanding that the origin of the reaction is a real physiological response to protracted fear.

Adapting Cognitive Interventions

Understanding these symptoms as evidence that people with developmental disabilities can be affected by the extreme stresses in their lives demonstrates that they can experience PTSD. These symptoms can lead parents, friends, other family members and caregivers to turn to counselors and psychotherapists for help in understanding and relieving the negative impact of recent or long-ago traumatic events. There is little research to guide counselors and therapists who want to help people in this situation. However, experience suggests some guidelines that counselors or therapists who are experienced in working with people with PTSD can use to guide their interventions.

Cognitive treatments for PTSD have become widely accepted as effective in reducing the distressing symptoms of PTSD and restoring the person's ability to function in personal, social and work life. Prolonged exposure therapies are supportive and systematic ways of helping the traumatized person to re-experience the situation that caused the trauma. In these therapies, the person is very slowly helped to remember the traumatic events and situations, and in some versions, to confront the actual situation in person.

Anxiety management programs, including stress inoculation, help people to manage the distressing anxiety and other arousal symptoms associated with PTSD. These programs may also include education, relaxation, social skills techniques and distraction techniques. Eye Movement Desensitization and Reprocessing, or EMDR, a method of using eye movements and systematic recall of the event, has received a lot of attention as a method with promise, although controlled studies leave questions about the specific value of the eye movement intervention.

Each of these interventions typically involve a carefully planned program of facing small examples of the feared situation, learning techniques to manage and reduce fear by breathing and relaxation, and learning new social skills.

In group and individual work with adults with developmental disabilities who have PTSD symptoms, the following adaptations of cognitive strategies used with typical populations have helped to meet the needs of survivors with developmental disabilities. However, variability in developmental disabilities population means there is no one size fits all approach to such modifications. Creativity and flexibility based on careful assessment and knowledge of the individual, are key.

First, do no harm

Not all cognitive strategies that are applied in typical populations may be suitable for some people with cognitive disabilities. These approaches are based on the assumption that the person seeking treatment has a great deal of autonomy. Typical survivors usually can choose when to come and go, with whom they live, and select their occupations, companions, and healthcare providers. This is not necessarily the case of the person with mental retardation. Intervening with a traumatized person with developmental disabilities requires first understanding the person's life circumstances to determine whether unraveling a way of coping, one that may be working in some way, is a help. Sometimes counseling is nor the right intervention.

This is especially true when any person, with or without disabilities, is still being exposed to the source of the trauma (an abusive caregiver, peer or parent, for example). Offering psychotherapy to this person suggests that he or she should expect to feel better while

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continuing to be traumatized. The proper first intervention here is not to offer counseling to the person, but to remove the source of continuing harm.

Even in cases of domestic violence, where a person may not be ready to sever a relationship with a harmful partner or caregiver, providing alternative experiences and safe relationships that are free from abuse help the person to recognize and value his or her own right to safety, and must usually precede psychological interventions directed toward the person's traumatic/posttraumatic symptoms. Similarly, if the person's environment is unsupportive, repeatedly triggers memories of a past trauma, or is improperly medicating post traumatic symptoms, it seems wise to provide interventions to correct these situations before addressing traumatic symptoms.

Once environmental interventions have created a non-traumatic environment where healing may be a realistic possibility, counseling and therapy offer specific help to manage the three prime PTSD symptoms of constant remembering, pain avoidance and imbalance in distress responses. Four specific strategies are key.

(1) Learn from and strengthen the person's own cognitive strategies and coping attempts.
(2) Provide information that the person can use.
(3) Find the right vocabulary.
(4) Act as a "cognitive prosthesis," carrying out cognitive processes that are beyond the reach of the individual's capacities and experiences.

<u>Use the Person's Own Strategies</u>

Counseling with these survivors must be guided by the person's own spontaneous attempts to cope with stressors. People with developmental disabilities have a wide range of patterns of cognitive disability and function, life experience and learning, language and communication patterns, and capacity to engage in interaction. Therapeutic work benefits enormously from exploring the situations and circumstances under which the person has the greatest success in his or her life.

When it is recognized that a person has survived an extreme experience, asking "what did you do to feel better?" communicates optimism that the person has his or her own resources for healing. This question also gives the counselor insight into the person's understanding of her situation and the way he/she thinks and talks about her or own behavior.

While counselors who are unfamiliar with work with people with developmental disabilities may be told that a person "functions at" a specific age level, adults with developmental disabilities are not children. Child-focused strategies may have limited success, since the developmental differences associated with developmental disabilities rarely mimic the developmental patterns of typical childhood. More helpful is understanding that (for example) the balance between visual and auditory learning styles may be skewed in people with developmental disabilities more than in the general population; that a person with some genetic patterns (e.g., Down Syndrome) will be attuned to the details of an event and need more support to draw conclusions or generalizations about his or her experience or behavior, that people with other patterns (for example, Williams Syndrome) may have expressive vocabularies that suggest much greater understanding of a situation than is in fact the case. For most people with developmental disabilities who have experienced trauma, the best guide to counseling modifications comes from letting the person him or herself help you with words and behavior—find what helps them to feel better. Carefully reviewing school learning evaluations, psychological or neuropsychological test reports and using family members and staff as resources can give the counselor information that can help to tailor an individualized approach to counseling.

The real key to effective PTSD interventions for people with disabilities will be found when there is sufficient support and interest within the trauma research community to include people with developmental disabilities in their studies.

<u>Provide Information</u>

Giving people with developmental disabilities basic information about what therapy is, how it can help, and how they can either ask for it, or reject it, helps with restoring a sense of authorship and autonomy. In addition, understanding their symptoms in terms that make sense, and that focus on the symptoms' nature as an effort toward coping supports the survivor to have hope that he or she can learn to manage feelings and symptoms that can be distressing and confusing.

Explaining the person's symptoms and behaviors can have the very valuable effect of letting him or her know that reacting to being hurt or scared is normal. Many people with developmental disabilities come to believe that their problematic behavior and symptoms are their fault, and are associated with their developmental status. Knowing that anybody who is scared might "think about it a lot," and find that it "keeps coming back to mind" can be a great relief. Knowing that your feelings and reactions make sense, that they are normal, expected and ordinary—given the extraordinary events that caused the trauma goes a long way in itself to help ease the survivor's sense of isolation, difference and responsibility both for the trauma-causing event(s) and for the symptomatic behavior that followed. This is an especially valuable immediate intervention for people with developmental disabilities, since they may have had many experiences of being made to feel different.

<u>Find the Right Vocabulary</u>

People with even the most modest receptive language capacities can understand a great deal. Simple questions can be addressed to any person to whom we ordinarily speak. If we use

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language to ask a person to come to dinner, or to cooperate with being dressed, we can tell that person "I know you still feel scared. I think you have left over feelings from when you were scared a long time ago. I want to help you feel safe." We can explore a person's own coping strategies when we ask him to "show me what helps you when you feel really scared."

At the same time, it is important to know that many people with developmental disabilities use words in personal and idiosyncratic ways that can get in the way of clear understanding. Understanding the individual person's vocabulary is a simple and crucial step in helping to relieve the survivor's distress. For example, a young woman in a support group said that another person had "raped" her. The reaction to this disclosure changed after she was asked to tell "what kind of rape," a question that did not discount the importance of her experience, but allowed the group's leader to explore her experience in greater detail What she described was an intrusive kiss by another person unwanted and distressing to her, but not what we ordinarily understand by the stronger term. On the other hand, a different woman used the phrase "he went too far" to describe being raped

In both situations, understanding the person's communications allowed the group leaders to focus on what had actually happened (while remaining open to the possibility of other disclosures). Communication is enhanced if we ask questions in clear and accessible language. Instead of talking about "trauma," we can say "being very hurt and scared." Instead of saying "rape," we can say "being made to have sex, not stopping when you say 'no'." Instead of talking about flashbacks, we can say "remembering too much."

Similarly, using familiar concepts and clear explanations of symptoms and the healing process can be helpful. Compulsive re-experiencing can be described as "trying to fix the person who hurt you." Stress inoculation can be explained as a way "helping your scared feelings to get worn out. Then they won't be so strong." Adapting current skills can also help to achieve therapeutic aims. For example, a young woman who had severe PTSD symptoms was a Special Olympics swimmer. She was taught that relaxation breathing was like "air swimming," thus allowing her to use a skill she had mastered in the breathing and physical motions of swimming when she began to think about situations that frightened her. Practicing air swimming became an important part of desensitizing her and reducing her anticipatory panic.

<u>Act as a Cognitive Prosthesis</u>

In typical populations the person who comes for help with trauma related symptoms has absorbed a great deal of information about trauma and recovery from the popular culture. Television talk shows, popular magazines, and even TV dramas give people a general sense that a counselor or therapist is usually chosen by a person to help in restoring a sense of well being, and that telling one's story is a step on the way to feeling better. For people with developmental disabilities, the person in the role of counselor or psychologist may be understood as being an agent for ensuring better behavior, and conformity to the demands of the family or environment, rather than offering relief from emotional pain. Thus, the therapist has a new role in working with these clients.

Cognitive disabilities may limit a person's ability to deduce the "rules" of counseling, or to understand the purpose of the therapy encounter. In response, counselors and therapists may need to be quite clear and explicit about the reason for the meeting or meetings, and need to ask directly about the person's expectations of the purpose of the counseling relationship.

Just as a prosthetic limb provides support to allow a person who is missing a leg to carry out as many functions for himself as possible, the term "cognitive prosthesis" describes the therapist's role of filling in for cognitive capacities that the survivor is unable to do for him or her self. Therapists who work with typical trauma survivors often rely on their clients to think about and describe their experience, to link the events of their life in causal chains and to generalize the lessons of therapy to other life situations. This kind of thinking may be hard work and beyond the capacities of people with developmental disabilities. Still, these clients want to feel better too, but need more help to bring the relevant information to the surface, to make connections, to understand how a feeling in one situation is connected to behavior, or to understand how a therapy "homework" assignment can help bring relief.

The therapist acts as a "cognitive prosthesis" when she plays a role on both sides of the counseling relationship as counselor she asks questions, identifies feelings of subjective distress, points out feelings, plans practice sessions. Then as a cognitive coach, "stands beside" the survivor as they together react to what was said, and think through the feelings and responses.

The theme of all these modifications is to take seriously the suffering and distress of the person with developmental disabilities who has experienced the lasting effects of trauma, and who suffers from remembering. The real key to effective interventions will be found when there is sufficient support and interest within the trauma research community to include people with developmental disabilities in their studies. Until that happens, experienced clinicians will adapt what is known about trauma work in general to help bring healing to people with disabilities as well.

Terri Pease, Ph.D. is with the Partnership to Prevent Domestic Violence, 2 Lafayette Street, New York, N.Y. 10007.

Building Partnerships for the Protection of People with Disabilities: A Massachusetts Initiative

BY NANCY A. ALTERIO and
ELIZABETH D. SCHEIBEL

The Vulnerability of People with Disabilities

In 1998, the United States Department of Justice reported that some 54 million Americans have a disability. According to a study done in 2000, approximately 5 million crimes were committed against persons with developmental disabilities. The same study found that there were 1.4 million child abuse cases and one million elder abuse cases.[1]

Historically, crimes committed against persons with disabilities have not been recognized or reported to the appropriate authorities. Given the complex nature of these cases, prosecution rates have been extremely low. Reasons for underreporting and inadequate investigations have included lack of awareness, lack of effective coordination between law enforcement and human service agencies and reluctance by police, prosecutors and judges to rely on the testimony of a person with a disability.

When crimes were committed against persons with disabilities, the abuse was often not recognized as a crime by human service professionals and, therefore, not reported. When crimes were reported, they were often reported days or even weeks after the incident. As a result, crime scenes and physical evidence were destroyed. Testimonies were damaged by repeatedly interviewing the victim and perpetrator. Thus, these problems contributed to underreporting and low arrest and prosecution rates for persons who committed crimes against persons with disabilities.

Crimes committed against persons with disabilities have reached epidemic proportions in the United States as reflected in the following statistics:

- Children with developmental disabilities are about 4 times as likely as children without disabilities to be physically and sexually abused. One large study of about 50,000 children found that more than one-third of all school-aged children with intellectual disabilities had a confirmed history of maltreatment.[2]

- Only three percent (3%) of sexual abuse cases involving people with developmental disabilities will ever be reported.[3]

- Adults with developmental disabilities are at risk of being physically or sexually assaulted at rates four to ten times greater than other adults.[4]

The risk of sexual assault and abuse is increased because many of us — parents, advocates and caregivers — hold the common misperception that persons with disabilities are asexual, incapable of relationships and not able to engage in sexual acts. Frequently, persons with disabilities are raised in overly-protected or isolated environments where a lack of social exposure and interaction contribute to a misunderstanding of appropriate social roles and expectations, foster learned helplessness and encourage compliance. Persons with disabilities may also be inexperienced in self-defense and avoidance of violence mechanisms.

The Building Partnerships initiative has changed the way Massachusetts responds to crimes against persons with disabilities. It has afforded persons with disabilities equal access to the criminal justice system and the same protections and rights as other citizens of Massachusetts.

Consequently, on disclosing that she or he is a victim of sexual violence or abuse, persons with disabilities frequently are not believed. Even when such abuse is witnessed, a caregiver may not report it because of shock, fear for personal safety, reluctance to break the code of silence among fellow employees or simply a reluctance to become involved. The following stories of two victims highlight the vulnerability of persons with disabilities who are dependent upon a caregiver relationship.

Mary, a woman who has cognitive disabilities, is immobile, and non-verbal, was sexually assaulted by Ralph, her caregiver and a person who had worked with individuals with disabilities for more than twenty years. The sexual assault was witnessed by another direct caregiver but not reported for six days because the witness stated that she was afraid for her personal safety, shocked and surprised by what she witnessed. Because of the delay, the opportunity to collect DNA and other physical evidence critical to a successful prosecution of the case was lost.

Frank, a 23-year-old man with a label of moderate mental retardation, is non-verbal, communicates with a Lightwriter device, and has good receptive language skills. Frank needs staff assistance with transportation, food preparation, hygiene, communication and overall safety. When told that "Mike," a "veteran" service provider with over twenty-five years experience, would be working alone with him, Frank became upset, began to cry and disclosed by using his Lightwriter that "Mike" had sexually molested him the night

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Building Partnerships for the Protection of People with Disabilities

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before. Subsequently, two other persons with disabilities, also assisted by "Mike," disclosed that "Mike" also had sexually molested them.

These two cases have many unanswered questions:

- How many other persons with disabilities had "Ralph" and "Mike" sexually molested in their twenty plus years of working with persons with disabilities?
- How many of those victims could not disclose the assault because of their communication limitations?
- How many care providers were aware of or had suspicions of the abuse but did not report it?
- How many of those victims could and did disclose the assault but were not believed?

The Problem in Massachusetts

According to the United States Bureau of Census 2000, there are approximately 6.3 million people living in Massachusetts. Of those 6.3 million, there are 3.7 million individuals between the ages of 21–64, of whom 17.9% are persons with disabilities. There are 807,000 people ages 65 and over, of whom 37.8% are persons with disabilities. These statistics do not reflect those individuals with disabilities who live in institutional settings.

In 1997, a high profile case of severe abuse and neglect of two men with mental retardation made headline news in Massachusetts. Shortly thereafter, a scathing legislative report was published identifying serious problems with investigations involving persons with disabilities. The report also found problems with abuse, client mortality and communication and coordination deficiencies. This case changed the system in Massachusetts.

The Massachusetts DMR's Investigation Advisory Panel

In June 1997, in response to the legislature's report, Gerald J. Morrissey, Jr., Commissioner of the Department of Mental Retardation (DMR), appointed an Investigations Advisory Panel to determine how DMR could improve its investigative capacity and systems for protecting the safety and well being of the people it serves. The panel, chaired by Northwestern District Attorney Elizabeth D. Scheibel, concluded that most of the problems hampering the effectiveness of the civil investigations were systemic in nature and included a lack of referrals to the appropriate law enforcement and criminal justice authorities. In addition, there was an absence of formal procedures and cooperative agreements between law enforcement and human service agencies for the management and investigation of complaints of criminal conduct. This led to victims with disabilities not having equal access to the criminal justice system.

The Implementation Committee and Memorandum of Understanding

Shortly after the release of the DMR Investigations Advisory Panel's report, William D. O'Leary, then Secretary of Executive Office of Health and Human Services (EOHHS), recognized that the recommendations should be extended to cover all agencies that work with persons with disabilities -- DMR, the Disabled Persons Protection Commission (DPPC), Department of Mental Health (DMH) and the Massachusetts Rehabilitation Commission (MRC). May 1999 marked the first time that representatives of human service agencies and law enforcement came to the table with the primary objective of establishing a formal process that would ensure the swift and effective investigation of crimes committed against persons with disabilities.

Building Partnerships for the Protection of Person with Disabilities

The result is the Building Partnerships for the Protection of Persons with Disabilities initiative, funded by an Executive Office of Public Safety Byrne grant and housed at the Massachusetts' District Attorney's Association. This statewide initiative links law enforcement and human services in an effort to effectively address crimes committed against persons with disabilities. The partnership brings together the eleven district attorneys, state and local police, Disabled Persons Protection Commission and human service agencies and uses a multidisciplinary approach to address crimes committed against persons with disabilities.

The Building Partnerships initiative has been institutionalized through formal Memorandums of Understanding (MOU) with each district attorney, the Massachusetts State Police, the Disabled Persons Protection Commission and human service providers. It allows for the prompt identification, reporting, investigation and prosecution of cases involving persons with disabilities who have been victims of crime. As described in the MOUs, state police assigned to DPPC ensure effective screening and referral of crimes committed against persons with disabilities. Two state police liaisons assigned to each of the eleven district attorneys' offices have been identified and trained to ensure effective communication and integrity of the investigations. The goals of the multidisciplinary approach and Building Partnership initiative are:

- ❖ to provide protection, treatment and continuity of care of persons with disabilities;
- ❖ to increase awareness of crimes being committed against persons with disabilities;
- ❖ to increase communication and cooperation between law enforcement and agencies providing services to persons with disabilities; and
- ❖ to ensure that crimes committed against persons with disabilities are promptly reported, investigated by trained law enforcement personnel and prosecuted by experienced assistant district attorneys.

A steering committee was formed to facilitate the initiative's legislative, outreach and training activities. Through the efforts of the steering committee, thousands of law

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Building Partnerships for the Protection of People with Disabilities

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enforcement and human service providers have been trained on reporting, investigating and prosecuting crimes committed against persons with disabilities. The training provided to state and local police and civil investigators has been adopted by the respective training academies, ensuring consistency and quality investigations.

Legislation has been filed, calling for enhanced penalties for violent crimes committed against persons with disabilities. In addition, with the support of Massachusetts Continuing Legal Education (MCLE), a book entitled, "*A Practical Guide to the Reporting, Investigation and Prosecution of Crimes Committed Against Persons with Disabilities*," has been written and distributed in courthouses throughout Massachusetts.

Results of the Building Partnership Initiative

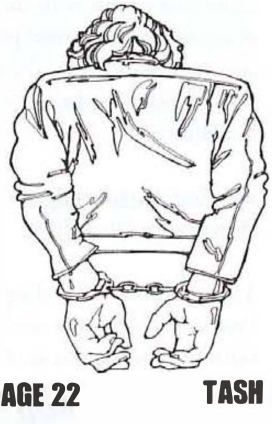
Thousands of reports of abuse against persons with disabilities are received monthly through a single point of entry – the DPPC – and screened by experienced state police detectives. Reports alleging criminal activity are now investigated by experienced law enforcement officials and prosecuted by specially trained assistant district attorneys. The success of the initiative is demonstrated by statewide statistics.

In fiscal year 1997, prior to the inception of the Building Partnership initiative, DPPC referred 32 cases to law enforcement. None resulted in prosecutions. With the implementation of the multidisciplinary approach, in fiscal year 2002, 622 abuse reports were investigated criminally, an almost 2000% increase. Those investigations resulted in at least 97 criminal complaints. Of those 622 criminal abuse reports, 307 were crimes of a sexual nature including rapes and sexual assaults.

These statistics do not necessarily indicate that crimes committed against persons with disabilities are increasing. Rather, those involved in the criminal justice system are doing a better job reporting, investigating and prosecuting crimes committed against persons with disabilities. The benefits are obvious — common goals and objectives; immediate action by the police and other agencies; immediate and effective communication preventing duplication; a network of consistent support and follow-up for the protection of persons with disabilities; reduction in the number of interviews of a victim; coordination between the state police, DPPC, service providing agencies and other law enforcement agencies; enhanced integrity, reliability and effectiveness of investigations and decision making; streamlined and increased referrals for criminal investigation and increased arrest and prosecution rates.

The initiative has changed the way Massachusetts responds to crimes against persons with disabilities. It has afforded persons with disabilities equal access to the criminal justice system and the same protections and rights as other citizens of Massachusetts. There is no doubt that this multidisciplinary initiative enhances the safety and well-being of persons with disabilities and provides the groundwork for effective prevention strategies.

The Building Partnerships initiative provides victims with disabilities the protection and services they need to pursue safe and healthy lives and enables communities to hold offenders criminally accountable for their violence. The success of the Building Partnerships initiative is best measured by the fact that Mary and Frank were freed from their abuse. Despite the many challenges in these two cases, the multidisciplinary investigations resulted in Ralph's conviction on two counts of rape and Mike's conviction of indecent assault and battery.



Nancy A. Alterio is Executive Director of Disabled Persons Protection Commission, Commonwealth of Massachusetts, in Quincy, Massachusetts. Elizabeth D. Scheibel is the Massachusetts Northwestern District Attorney.

Comments about this article may be directed to Ms. Alterio at (617) 727-6465, x. 219

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Three Little Words

BY DAVE HINGSBURGER

I was four years old. It may be my earliest memory. Certainly, it's one of my fondest. "No, you're wrong!" Three little words that told my mother that she no longer defined the world for me. I saw her as fallible. I saw myself as capable of expressing my own opinion. Sure I got spanked, but even as the blows fell, I knew that she was using strength, not logic. Red bummed but unrepentant, I slept that night knowing full well that I was separate from those who made me. I was, unquestionably, unique. It was an awesome feeling.

I had almost forgotten it. Lost in the busyness of adult life, I made decisions based entirely from my own thoughts and feelings. I could determine the good people from the bad people. The angels from the devils. And more importantly, right from wrong. I came to take this for granted.

It was in Windsor. I had been asked to do an abuse prevention class for people with developmental disabilities. I had a simple-minded approach for people who had for centuries been thought to be "simple minded." I taught them to say "NO!" loudly and clearly to abuse and victimization. I was having fun. So were they. Seventy people with disabilities shouted the word "No" to my prompting. Role plays were done. Games were played. And then the lights came up, it was over.

In my little corner of the world, it had been a success. As people with disabilities, my audience, were milling about waiting for rides to come, parents to gather, I saw a woman, who looked to be around 24 years old.

She sat, alone. Thinking. I loved it. I like to see people with disabilities ponder what they have learned. Review the things that they have experienced. Her face darkened. She looked at me with what approached ... hostility. That she was angry was clear. I wondered what had bothered her. But that lasted only seconds. I was quickly gathering up my gear, ready to escape for a quick beer and then bed.

She rose and began to approach me. I sped up. I wanted to get out of there. I had done what I had been paid for, it had been a long day, I wanted just to go. But the crowd at the door, the mess of people meeting people, blocked my exit. She arrived before I could leave.

"Hey," she said having forgotten my name. I am not happy to admit that I tried to ignore her. Tried to get away.

"HEY!!" she said more loudly. I turned to face her. "Yes?" I asked.

"This was all wrong," she said and began to cry -- only a little. I put my best, "I'm listening" face on. I paid for four years of education in psychology to learn that face. I like to use it.

She didn't speak. She waited for me. "What was wrong?" I asked. "I said 'no' and he raped me anyway. It doesn't work the way you said it does. This was all wrong."

Before I could answer, she was walking away from me. She was done. I stared at her retreating form. Stunned by her assertion.

A few feet away from me she turned. She wasn't crying now, she was smiling. I waited. She thought for a second and then she said, "I didn't think you people could be so wrong." Then she turned and walked away from me.

My briefcase was packed and I hurried to walk beside her. For a second we simply walked together. I didn't know what to say and it didn't matter. Without looking at me again she said, "Are you mad at me?"

I assured her I wasn't. She walked away saying, "I've never told anyone they were wrong before." I asked her if it felt good. She said that it did.

I don't know who she was before she came to my workshop. I don't know what she had experienced. But I knew that she left fully apart and distinct as an individual. She had been able to separate herself from me. From what she was learning. She was able to evaluate, from her own experiences, the information that came towards her. She was completely able to determine that her life had taught her something more than what I ever could have. She knew that she was right and I was wrong. That night she was able to assert that people like me, people who were supposed to be smarter, wiser and stronger, could be completely wrong. She left a person, an individual.

For me, it happened when I was four. For her, it happened when she was twenty four. The only thing that really mattered was that it happened.

It wasn't until I was nearly six that I learned that I could be wrong. Really wrong. That how I saw the world, how I viewed other people, was not always right. I have been reminded of that a thousand times. I was reminded of my fallibility that night. I have never taught that class the same way again. She changed me.

I wonder, now, who she will be in a couple of years. I'm guessing she will be awesome. It took her a while to catch up. To assert herself. To become separate from those who have supported her. To be right, or indeed wrong, on her own terms. But now that she had, I'm guessing that nothing will stop her. To be sure, individuals who can tell us we are wrong are more difficult to serve. From my experience, though, they are a heck of a lot more fun to be around.

Growth is what it's supposed to be about. For them. And most decidedly, for us.

Dave Hingsburger is a writer, activist, and consultant on issues related to sexuality, communications, and behavior supports. Comments about this article may be addressed to <daveandjoe@sympatico.ca>

2003 TASH Tentative Conference Agenda

Tuesday, December 9th	
Registration Open	5:00 p.m. – 7:00 p.m.
Wednesday, December 10th Pre-Conference Activities	
Registration Open	8:00 a.m. – 11:00 a.m. 2:00 p.m. – 7:00 p.m.
Exhibitor Set Up	8:00 a.m. – 4:00 p.m.
TASH TECH Full Day Pre-conference Workshops and Special Symposiums	10:00 a.m. – 4:00 p.m.
TASH Chapter Leadership Day	10:00 a.m. – 4:00 p.m.
Opening Reception in the Exhibit Hall Exhibits Open **Official Conference Begins**	5:00 p.m. – 7:00 p.m.
Thursday, December 11th	
Registration Open	8:00 a.m. – 5:30 p.m.
Exhibits Open	8:00 a.m. – 5:30 p.m.
General Session	8:30 a.m. – 10:00 a.m.
Breakout Sessions	10:15 a.m. – 12:30 p.m.
Exclusive Exhibit Time (Lunch on your own)	12:45 p.m. – 1:45 p.m.
Breakout Sessions	2:00p.m. – 5:30 p.m.
Reception	5:30 p.m. – 7:00 p.m.
Friday, December 12th	
Registration Open	8:00 a.m. – 1:00 p.m.
Exhibits Open	8:00 a.m. – 5:00 p.m.
Breakout Sessions	8:00 a.m. – 11:30 a.m.
TASH Town Meeting	11:45 a.m. – 1:15 p.m.
Breakout Sessions	1:30 p.m. – 5:00 p.m.
Reception	5:00 p.m. – 7:00 p.m.
Saturday December 13th Poster Sessions and Saturday Institutes	
Registration Open	7:30 a.m. – 10:00 a.m.
Poster Session Set UP	7:30 a.m. – 8:00 a.m.
Poster Sessions and Breakfast	8:00 a.m. – 10:00 a.m.
Exhibits Open	8:00 a.m. – 1:00 p.m.
Saturday Institutes	10:00 a.m. – 1:00 p.m.

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B CONFERENCE REGISTRATION CIRCLE ONE:

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C

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• **Chapter Leadership Day.** (Wed) no fee, but registration is required	N/C	N/C	+N/C

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United Nations Study on Violence Against Children

BY DICK SOBSEY

TASH was selected as an Advisory Panel Member to ensure the interests of children with disabilities

The World Health Organization (WHO) indicates that about 57,000 children die in reported homicides each year, not counting those who die in war and other armed conflict. The WHO report goes on to point out that the number of unreported homicides of children may be even larger. Violence is one of the most serious problems facing the world's children, and children with disabilities experience violence much more frequently than other children.

A special session of the United Nations General Assembly was scheduled for October 2001 to celebrate the ten-year anniversary of the Convention on the Rights of the Child. Children from around the world were invited to address the General Assembly to talk about the most important issues affecting their lives. The tragic events of September 11, 2001 resulted in a decision to delay the meeting until May, 2002.

Finally, children from many countries and heads of state of more than 70 countries joined their United Nations delegations, along with representatives from more than 800 non-governmental organizations (NGOs) and a wide variety of invited guests as diverse as Nelson Mandela and Bill Gates. The agenda was set to review progress and chart new directions as follow-up to the 1990 World Summit on Children.

A number of supporting events were held to discuss issues of vital concern, including a topical meeting on "Protecting Children from Violence." The moderator, Thomas Hammarberg, Representative of the Prime Minister of Sweden, pointed out that children from around theworld consistently identify violence as their top concern. Most in attendance agreed that violence against children is a massive problem with grave consequences. As stated by Andre Roberfroid, Deputy Executive Director of UNICEF, "It is everywhere... At the same time, it is very hard to do anything about it, not least because it is often hidden... in families or in institutions."

Apprehension about violence may have been heightened by the events that had delayed the meeting, but the concern was not new. Nevertheless, children and their advocates had repeatedly and eloquently expressed their concerns about violence for years. In response, the General Assembly had already authorized a major study to determine the effect of violence on the world's children. Mary Robinson, the UN High Commissioner for Human Rights, announced the study that had been introduced in the General Assembly at the end of 2001 and approved in April 2002 to be conducted by her office, UNICEF, and the World Health Organization.

The U.N. Resolution calls for an in-depth study on violence against children, and suggests that the U.N. Secretary General appoint an independent expert to direct the study in collaboration with the Office of the High Commissioner for Human Rights, the United Nations Children's Fund and the World Health Organization.

The planned study began to take shape. The panel called for an advisory panel comprised of representatives of non-governmental organizations to guide the study and the appointment of an independent expert to lead the study. The advisory panel was established late in 2002 and the independent expert was appointed early in 2003. Professor Paolo Pinherio from the University of Sao Paolo in Brazil was appointed to serve as Special Rapporteur and Independent Expert. Professor Pineiro is a human rights lawyer with considerable experience in international human rights issues. With only about two-dozen members of the NGO advisory panel to represent the diverse interests of children from 190 member nations, there were many organizations competing for a few seats at the table.

TASH Involvement

To ensure that the interests of children with disabilities are given careful consideration in the UN Study, TASH joined with several other groups to jointly nominate a potential advisory panel member. I was pleased to be nominated to the NGO Advisory Panel jointly by TASH, The Canadian Association for Community Living, Inclusion International, The Arc of the United States, and the JP Das Developmental Centre at the University of Alberta. I was honored to receive word that I was selected to serve on the advisory panel. In addition, another group represented on the 24-member advisory panel, Disabled Children's Action Group of the South African Federal Council on Disability, will help ensure that the committee gives appropriate attention to the needs of children with disabilities.

Some of the other NGOs that have representatives on the advisory panel include: Center for Justice and International Law, Centre of Concern for Child Labour (India), Children's Rights Alliance for England, Defense for Children International, Center of Legal and Social Studies on Childhood and Youth (Argentina), Global Initiative to End all Corporal Punishment of Children, Human Rights Project (Bulgaria), Human Rights Watch, International Society for the Prevention of Child Abuse and Neglect, the International Institute for Child Rights and Development, International School Psychology Association, Resources Aimed at the Prevention of Child Abuse and Neglect (South Africa), Save the Children (Norway), World Organization Against Torture, World Vision International, and International Federation of Social Workers.

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United Nations Study on Violence Against Children:

TASH Selected as Advisory Panel Member

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The study has the potential to have a long-term influence on children's rights and a number of other concerns that affect children in general and more specifically children with disabilities. In addition, through its participation in this project, TASH may be able to forge working alliances with children's rights organizations that will carry forward to additional areas of common interest.

The final list of issues that will be identified by the study has yet to be determined, but some of the topics likely to be included are the effects of war on children, exploitation of child labor, child slavery, family violence, inhumane punishment, institutional neglect and abuse, deprivation of the necessities of life and development, and child prostitution. Some of these topics suggest obvious links to issues and values that have long been a concern to TASH.

For example, while institutional abuse and neglect affects children with and without disabilities as has been graphically illustrated by exposés of Romanian, Russian, and Chinese orphanages, children with disabilities are disproportionately affected by institutional abuse. If excessive and inhumane punishment violates children's rights, why should the use of aversive procedures or inappropriate restraint and seclusion of children with disabilities be acceptable? If deliberate deprivation of the necessities of life is crime against children, withdrawal of treatment from infants with severe disabilities might also be seen as criminal.

In other areas, the interaction between disability status and the effects of violence on children may be less obvious but equally important. For example, war and other forms of collective violence, as it has been labeled by the World Health Organization, have devastating effects on all children, but its effects on children with disabilities are particularly damaging. Children and adolescents with communication or intellectual disabilities have been shot and killed in various parts of the world because they have failed to obey the commands of soldiers who ordered them to stop or to put their hands behind their head. Children with developmental disabilities have also been victims of landmines and terrorist bombs, in part because they have a more difficult time learning the danger signs than other children learn to reduce their risk.

Children with disabilities are also more vulnerable to war's effects on infrastructure disruption. This includes physical, economic, and social infrastructure. The disruption of electrical service may be a serious inconvenience for many, but it is potentially fatal for those who depend on respirators or other medical technology. The development of new e-bomb technology, which uses an intensive electromagnetic pulse to destroy electronic components in an area the size of a city while doing minimal structural damage, has the potential to selectively eliminate people who are technology dependent since even battery-powered backup systems would be destroyed.

War also disrupts and sometimes virtually destroys the economic infrastructure. Necessities of life such as food and medication often become scarce. Children with disabilities are rarely given high priorities for these items.

While considerable attention has been given to the role of eugenics in the Nazi euthanasia programs of World War II, their own records indicate that a crisis in the health care delivery system played an equal role. The depressed economy following the first World War had left the German health care system stretched to its limit between the wars. This problem reached the breaking point when the Nazi decertification of Jewish physicians seriously depleted the labor supply. The system was thrown into chaos when Germany went to war, greatly increasing demands for health care. The horrifying solution to this problem was to free up 330,000 chronic health care beds by active euthanasia and deadly medical neglect. According to the Nazi's own record, they achieved their goal. War crime records suggest 275,000 children and adults with disabilities were murdered in the process.

While the horrors of the Nazi regime may have been a unique anomaly, the underlying principle is not. The effect of war on over-taxed or marginal economies is inevitably to divert medical and other essential resources from the most vulnerable members of society. In wealthy industrialized economies, these effects may be less deadly but they are no less real.

Whether war is necessary and justifiable or not, labor, commodities, and money devoted to it inevitably result in diversion of resources from other endeavors, and the most vulnerable members of society often pay the highest price. As suggested by former President Jimmy Carter in his 2002 Nobel Peace Prize acceptance speech: "War may sometimes be a necessary evil. But no matter how necessary, it is always an evil, never a good. We will not learn to live together in peace by killing each other's children."

Perhaps the most devastating effects of war on children with disabilities come from the effects on the social infrastructure, primarily families and communities. Families may need to have one parent, an older sibling, or a member of the extended family in the home to provide care for a child with a disability while other family members earn a living. War may take the father, older siblings, and extended family members away from the community, leaving the other parent alone to manage an impossible situation. She may have to leave her children unsupervised and uncared for while she works, gets water or food, or carries out other essential activities. The results have sometimes been tragic, and have led to increased use of inhumane practices such as tethering children with disabilities.

War also transforms children into refugees or orphans. Children with disabilities face special problems as refugees and orphans. They face many more barriers to immigration than other children, and orphans with significant

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United Nations Study on Violence Against Children:

TASH Selected as Advisory Panel Member

Continued from page 27

disabilities are sometimes very difficult to place in families.

TASH Members Can Help

To help ensure the success of this study, we need to enlist the help of individual TASH members as well as various TASH committees. It is important to capture the voices of children with disabilities and young adults with disabilities who can tell us how violence affected them as children.

If you are interested in learning more about the United Nations Study on Violence Against Children, would like to find out how you can help with the study, or would like to check on the progress of the overall project and specifically on work being done related to children with disabilities, a web site is being established for that purpose. The URL is: http://www.ualberta.ca/~jpdasddc/affiliate/UNSVAC.htm.

The UN Study will provide a unique opportunity to ensure that children with disabilities receive due consideration in worldwide efforts to protect children from violence. In order to achieve the best outcome, however, I need help from TASH committees and individual TASH members. Much of my work with the Advisory Panel involves collecting and organizing information provided by others. Basic information about the study appears on the website. In the weeks and months to come, new sections of this site will indicate how anyone interested in the study can provide input.

Dick Sobsey is a member of the TASH Executive Board, and Director of the JP Das Developmental Disabilities Centre at the University of Alberta, Canada.

Grim News for Children with Disabilities Around the Globe

Belgium 2002. A father is charged with strangling his 9-year old son who had autism.

Columbia 2001. Gang violence kills the intended target's daughter who had developmental disabilities.

Canada 2001. A 14-year-old girl with Rett syndrome is fatally poisoned by her mother.

England 2002. A 17-year-old with developmental disabilities is burned to death in an arson fire.

Guatamala 2002. A 13-year-old girl with Down syndrome is tied to her bed, soaked with gasoline, and burned to death by a group of men who invade her house and abduct her mother.

India 2003. Government initiates study to determine the extent and effects of tethering -- leaving children with disabilities tied to a tree or other fixed object while parents spend the day away from home. In other parts of India, children with disabilities are being sold for export to the Middle East where they are exploited as beggers, often after being maimed to "increase their value."

Isle of Man 2002. A 16-year-old girl with spina bifida is strangled. An acquaintance is implicated.

Italy 2003. A mother suffocates her adult daughter who had autism in Ferrara only a few days after a retired army doctor shot his son, who also had a label of autism. Earlier this year, a physician published an article on the string of parents in Italy who previously murdered their children who had autism.

Jamaica 2003. Keating Committee Report tabled in Parliament in July describes widespread abuse and neglect of children in care facilities. The *Jamaica Gleaner* describes the "rape, carnal abuse, batterings, physical restraints and harsh punishment" as "sheer hell." Thirty-seven percent of these children in institutional settings have significant disabilities, and the report indicates these children receive the worse treatment.

Japan 2002. A father is charged with strangling his 14-yearold son who had been diagnosed with high-functioning autism.

Nepal 2002. A child with developmental disabilities dies in a bombing in a political conflict.

Spain 2000. A 9-year-old girl with cerebral palsy is killed by her brother with a Samurai sword.

Thailand 2000. A fifteen-year-old girl with cerebral palsy is strangled by an acquaintance.

Taiwan 2003. A study of child prostitutes finds that 5.4% have mental disabilities and an additional 29.4% have borderline intellectual disabilities. It also found that 6.3% had complete Fragile-X chromosomes and an additional 5.5% had partial fragile-X mutations.

United States 2003. A mother and her boyfriend are charged after a 4-year-old with developmental disabilities dies from beating and scalding. In another case, a foster mother is charged after the 28- pound body of an-eight-year-old girl with multiple disabilities was found in a garbage truck.

Wales 2000. A 10 year-old girl with autism and her 14-year-old brother who had developmental disabilities are beaten to death with a hammer by their father, who later kills himself.

West Bank 2001. Guerillas invade a home and kill an 11-year-old girl with developmental disabilities.

Around the Globe 2003. Approximately 300,000 children are currently serving as involuntary soldiers in conflicts in 33 countries around the world. These boys and girls, sometimes as young as eight, are typically treated as the most expendable soldiers. Many are beaten and raped by their fellow soldiers. Thousands of those who survive are abandoned after they sustain severe disabilities.

Around the Globe 2003. Children with disabilities continue to die in "wilderness therapy" boot camps from the use of aversive procedures and restraints.

The Victimization of Individuals with Fetal Alcohol Syndrome/ Fetal Alcohol Effects

BY KATHRYN ANN KELLY

When a crime is committed against a person with Fetal Alcohol Syndrome (FAS) or Fetal Alcohol Effects (FAE), it is highly unlikely that the criminal justice system will react to protect and serve the victim. Cases in which the disability can generally be seen or surmised by police and prosecutors — blindness or deafness, for example — have at least a possibility that the criminal justice system will respond with the vigor and force used to protect and serve victims without disabilities. Although the disabilities caused by Fetal Alcohol Spectrum Disorder (FASD) are not as obvious as blindness or an inability to walk (indeed, they are usually not visible except to the trained eye), they warrant particular attention when the individual with that disability is the victim of a crime.

There Is No Safe Level of Alcohol a Mother-to-be Can Use Before and During a Pregnancy

FAS and FAE (referred to collectively as Fetal Alcohol Spectrum Disorder (FASD)) affect two to three million adults and children in the United States.[1] Police, prosecutors and the general public know very little about the disability. Further, there is a widespread but mistaken assumption that FASD is limited to children whose mothers were seriously and repeatedly intoxicated during pregnancies. Damage from even small quantities of alcohol occurs because of the mother's unique metabolism and her liver function at the time of the pregnancy. Many mothers stop drinking only after they know they are pregnant, but damage to the developing fetus may already have been done. The Surgeon General's recommendation is that a woman refrain from drinking during pregnancy and even earlier if she is planning to become pregnant.[2]

Although police and prosecutors may realize that alcohol use during pregnancy can cause birth defects, few law enforcement officials have any idea that the birth defect is a pattern of tell-tale facial features: a smooth philtrum (the space between the nose and upper lip), a small head, eyes that are short in length, a flat midface and a thin upper lip.

Children and some adults with Fetal Alcohol Syndrome may have these distinctive facial features, however, these facial features are never present among individuals with Fetal Alcohol Effects. It is important to note that there are other physical problems impacting on eyes, ears, bones and heart.

The most important disability caused by a mother's prenatal use of alcohol is seriously debilitating and yet, invisible to the naked eye — organic brain damage. The organic brain damage associated with FASD often impairs the individual's executive brain function -- the ability to understand and adapt to the world.

Individuals with Fetal Alcohol Spectrum Disorder frequently have problems planning and organizing information and daily life, have trouble comprehending the consequences of their behavior, find they have difficulty drawing conclusions from past experience, have trouble understanding social cues and norms of behavior, and have difficulty controlling impulsive conduct. These individuals typically have an excessive desire to please others, an attitude which may lead them to take (or acquiesce in) actions that are harmful to their own interests.

Frequently those with FASD also have a below average I.Q., but most do not have a label of mental retardation. Whatever their I.Q., their level of social functioning is usually substantially lower than other individuals with the same I.Q. Most individuals with an average I.Q. lead productive and organized lives. Individuals who have an average I.Q. but who also have brain damage caused by alcohol in utero, often struggle unsuccessfully to deal with the usual demands of life.

The characteristics of Fetal Alcohol Spectrum Disorder — invisible to police in a brief interview — could be quite obvious to a perpetrator who lived with or knew the victim. A criminal case in which FASD is present, more often than not, requires special care and handling. Charges against an individual who has had sexual contact with a minor would be particularly appropriate where the minor has FASD, and, resultantly, is less able than others his or her age to resist sexual advances. Although the testimony of the victim with FASD is important, these victim-witnesses can compromise a case because they are both credulous and very eager to please.

A victim-witness with Fetal Alcohol Spectrum Disorder may believe that the correct response must be whatever answer the questioner may appear to want, whether or not the response is factually true. The victim-witness with FASD may respond with inaccuracies, not conscious falsehoods, but simply responses that are the proper answer. The police and prosecuting attorneys must carefully question such victims, taking pains not to lead them in a particular direction but, rather, to let them tell their stories.[3] This applies both in questioning possible crime victims and in preparing witnesses for trial.

> *"...we can envision few things more certainly beyond one's control than the drinking habits of a parent prior to one's birth." For the millions of individuals who already have Fetal Alcohol Syndrome/ Effects, it is too late to protect them from the harm that maternal alcohol caused their developing brains. But it is still possible to take effective measures to protect them from criminal abuse.*

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The Victimization of Individuals with Fetal Alcohol Syndrome/Fetal Alcohol Effects

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Courts, Recognizing that Crimes Committed with Awareness of the Vulnerability of the Victim, Impose Harsher Penalties on the Offenders

The resulting collection of behavioral disabilities render individuals with FASD, both as children and as adults, easy prey for criminal conduct. They are likely to accept criminal abuse, or to refrain from complaining to authorities, because they do not fully understand the inappropriateness of the treatment, or because they want to avoid displeasing the offender.

A child with Fetal Alcohol Spectrum Disorder might easily fail to grasp the importance of parental admonitions about sexual contacts with adults, and might fail to recognize the dangerousness of a situation. Some 72% of adolescents and adults with FAS/FAE have been physically or sexually abused.[4] Sexual abuse of children with FASD by adults in their own home is a particularly serious problem.

Where the criminal was aware that a crime victim was particularly vulnerable is, under both federal and state law, a well established reason to impose a more severe sentence.[5] A heavier sentence would be common, for example, for the mugging of a victim who uses a wheelchair or other mobility device. Some courts have recognized that harsher sentencing rules are entirely applicable to crimes against persons with Fetal Alcohol Spectrum Disorder.[6] More courts should impose a harsher sentencing rule, and more prosecutors should ask for it.

It is not sufficient to prosecute with particular vigor crimes against individuals with disabilities, including those with FASD. Those individuals are uniquely vulnerable to criminal abuse, and preventative measures should be taken to protect them from criminal acts. Because of their vulnerability to sexual abuse, special care should be taken in placing children with Fetal Alcohol Syndrome/Fetal Alcohol Effects in foster care, and in monitoring any children with FAS/FAE who are within the jurisdiction of government social welfare agencies.

Adults with FAS/FAE, if left to fend for themselves, will too often end up living on the streets or in other circumstances where they are likely to be particularly vulnerable to crime. The social services that many of these adults need, ranging from supported community living environments to job training, are as important to preventing victimization as they are to preventing poverty.

The Florida Supreme Court observed in its 1994 decision in *Dillbeck v. State*,[7] "we can envision few things more certainly beyond one's control than the drinking habits of a parent prior to one's birth." For the millions of individuals who already have FAS/FAE, it is too late to protect them from the harm that maternal alcohol caused their developing brains. But it is still possible to take effective measures to protect them from criminal abuse.

Recent Scientific Developments Make It Easier to Diagnose FASD

Although some criminals may quickly recognize the vulnerability of a victim with FASD, in the past formal diagnosis has often been difficult in adolescents and adults, except in the case of those with full-blown FAS facial features. Often there are no obvious facial features, drinking patterns are not definitive and frequently undocumented, and neuropsychological testing may be more effective in detecting the existence of cognitive problems than in explaining their origin.

According to a study recently published by a team of researchers at the University of Washington, it is possible to differentiate FASD-diagnosed brains from "normal" brains with 80% accuracy using magnetic resonance (MR) brain images.[8] Abnormalities of the corpus callosum, a cluster of transverse nerve fibers connecting the two hemispheres of the brain, underlie the measure permitting this discrimination. The same measurements can be applied to brain images of other adolescents and adults, such as those of victims in a forensic context, when the images are produced using the same protocol as those that were used in the original study. This sharp new quantitative tool, based on new scientific methods, is available to both prosecuting and defense attorneys.

Kay Kelly is the Project Director of the FAS/FAE Legal Issues Resource Center at the University of Washington. For further information about FAS/FAE or the FAS/FAE Legal Issues Resource Center, visit the Center's web site at http://depts.washington.edu/fadu/legalissues/

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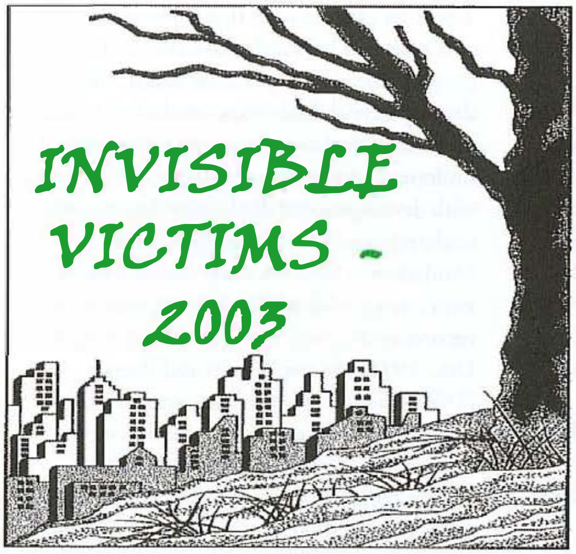

INVISIBLE VICTIMS - 2003

BY DANIEL D. SORENSEN

Crime against people with significant disabilities is a problem similar to violence against women, elder abuse, and child abuse. Yet, crime against this population remains largely invisible and unaddressed. Studies consistently show that the level of violent and other major crimes against children and adults with significant disabilities is from four to ten times higher than crimes against people without disabilities. These studies also show that such crimes are reported and prosecuted at a lower rate, and have lower rates of conviction.

People with disabilities represent approximately 20% of the population of our country. Over half of all families have loved ones or close friends with significant disabilities. The number of people with disabilities appears to be growing for a variety of reasons, not the least of which is the aging of our population.

Who are people with these disabilities? They include people with developmental disabilities (such as an intellectual disability or mental retardation, autism, cerebral palsy, epilepsy), traumatic brain injury, severe physical disabilities, major mental disorders, degenerative brain diseases (such as Alzheimer's, Parkinson's, Huntington's), permanent damage from a stroke, organic brain damage and other significant disabilities. People with such disabilities are among those most at risk of violent and other serious crime.

THE RATE OF VICTIMIZATION

Research consistently finds that people with substantial disabilities suffer from violent and other major crimes at rates many times higher than that of the general population. Dick Sobsey, in a review of the research literature, concluded that the conservative estimate is that this population is over 4 times as likely to be victims of crime than are people without disabilities (Sobsey, 1996a). Sobsey also believes that the more accurate figure is between 5 to 10 times higher (Sobsey, 1996b).

Joan Petersillia (1998) estimates that roughly 5 million crimes are committed against people with developmental disabilities in the United States each year. She compares this with 8,000 hate crimes, 1 million elder abuse victims and 1 million spousal assault victims each year. The National Committee to Prevent Child Abuse survey indicated that over 1 million cases of child abuse are reported each year. The number of crimes against people with all types of disabilities would be four to five times greater than the number against people with developmental disabilities alone. This means that crime against all people with substantial disabilities may be higher than elder abuse, child abuse and domestic violence combined.

There are numerous studies that support these conclusions.

- Murry reported that a 1990 study of 150 people with a wide range of disabilities found that they had a 2 to 10 times greater risk of criminal abuse than people without disabilities.
- Wilson and Brewer (1992) completed a study in Australia in which they took a sample of 174 adults with intellectual disabilities and compared their rates of criminal victimization to a sample of people without disabilities in that same community. They found that people with intellectual disabilities had a victimization rate for sexual assault 10.7 times higher than that for the non-disabled comparison group and 12.8 times higher for robbery.

In a survey of health providers who cared for victims of sexual assault with disabilities (Mullan & Cole, 1991), people with both an intellectual (mental retardation) and a physical disability were identified as most vulnerable to sexual assault, with people with mental illness a close second.

In addition to these extremely high rates of sexual assault, there is evidence that people with substantial disabilities are often sexually assaulted repeatedly. Sobsey and Doe (1991) found that 80% of a sample of 162 people with developmental and other substantial disabilities who had been sexually assaulted had been sexually assaulted more than once, while 49.6% had experienced 10 or more sexual assaults.

It is not just people with developmental disabilities who are experiencing these very high rates. People with some form of mental illness experience the highest rates of crime and violence. A study of psychiatric inpatients found that 81% had been physically or sexually assaulted (Jacobson & Richardson, 1987). An important study of 278 randomly selected people with psychiatric disabilities from 30 large Los Angeles board-and-care homes found that 33% had been victims of crime over the previous 12 months (Lehman and Linn, 1984). The comparable rate for the general population in Los Angeles County at that time was 3.5%. This is a crime rate 9.5 times higher for this population.

Linda Teplin, in what may be the most powerful study on crime against people with disabilities in this country, has completed a study on 1000 randomly selected people with mental illness in the greater Chicago area (in publication). She used the National Crime Victimization Survey instrument. She found that the rate of violent crime against this group was 9.4 times higher that against the general population. This is consistent with the 1984 study by Lehman and Linn, as well as other research.

Other studies are consistent with these findings. The California Department of Mental Health has surveyed over 15,000 of its clients with severe and persistent mental illness and 337 of its clients with a dual

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mental health and substance abuse diagnosis (Performance Outcomes Update, 2000). This survey found that the rate of violent crime was 18.7 times higher for adults with severe and persistent mental illness than the rate for the general population based on the National Crime Victimization Survey. It also found a stunning rate of violent crime 62 times higher for those clients with a dual diagnosis. These higher rates were also found when looking at property crimes. The survey reports that property crime rates for adults with severe and persistent mental illness is nearly seven times higher and that property crime rates for adults with a dual diagnosis are 18 times higher.

In another study of the lives of women with disabilities, a women with disabilities action group conducted research on the subject of crime and found that 70% of women with cognitive or physical disabilities had been victims of violence (Stimson and Best, 1991). There is research that crime rates are even higher in institutions, group homes and other segregated facilities. The Roeher Institute in a 1993 publication found that, "...people with disabilities may be at particular risk of victimization in these "safe" arrangements." Sobsey and Mansell (1990) concluded that the risk of being sexually abused was two to four times higher in an institutional setting than in the community.

Children with disabilities also suffer higher rates of criminal abuse than children without disabilities. A recent and methodologically sound study of over 50,000 children in Omaha schools during 1995 to 1996 found that children with disabilities suffered a rate of reported abuse 3.44 times greater than children without disabilities (Sullivan and Knutson, 1997). Children with intellectual disabilities (mental retardation) experienced rates of physical abuse 3.8 times higher and sexual abuse 4 times higher than children without disabilities.

There is a large body of research on criminal abuse against children with disabilities, and it appears that as individuals grow older, the chance that they will be victims of violent crime increases relative to the general population. This increase may be attributed to the differences in vulnerability as children grow older. Children with more substantial disabilities and children without disabilities, at infancy, have very similar degrees of vulnerability. This continues for toddlers but begins to diverge soon thereafter. By adolescence, the gap has grown much wider, and by adulthood, has grown to the large differences reflected in the different rates discussed above.

REPORTING OF CRIMES

In addition to these high rates of victimization, there is evidence that crimes against people with substantial disabilities are often not reported (failed to result in a crime report). The components of the criminal justice system cannot take necessary action when they are not informed of crimes. Every police department, sheriff's office and district attorney that we have consulted in California reported that they have very few cases involving victims with substantial disabilities, dramatically less than the relative rate of violent and other major crime would predict. This is a practical and concrete indication that major crimes against people with substantial disabilities are being reported at a much lower rate than for the general population.

It is estimated that less than 4.5% of serious crimes committed against people with disabilities in California have been reported, compared to 49% for the general population. This is based on an analysis of California's Adult Protective System data compared to National Crime Victimization Survey data.

> The disproportionate rate of crimes against people with disabilities is first, and most importantly, a civil rights issue. People with disabilities have a fundamental right to equal protection and equal justice. The advocacy and service provider systems have failed to insist on these fundamental rights and to educate their members about this problem and have, therefore, participated in this pattern of discrimination.

There are other studies that support this conclusion. The Seattle Rape Relief Project program for victims of sexual assault with developmental disabilities concluded, based on their clinical experience, that there is underreporting of sexual assaults of victims with developmental disabilities that exceeds underreporting with other populations (Anderson, 1985). A study of 162 people with a range of disabilities found infrequent reporting of crimes to authorities (Sobsey & Doe, 1991). In the Wilson and Brewer (1992) study, 71% of crimes against people with more severe mental retardation went unreported. This compares with 56% of violent crimes that go unreported for the general population (National Crime Victimization Survey, 1999).

Similarly, several studies suggest 80-85% of criminal abuse of residents of institutions never reach the proper authorities (Powers, Mooney & Nunno, 1990). A University of Alberta study suggests one reason for this. It found that 40% of those criminally abused and 40% of non-abusing staff of care facilities studied are reluctant to come forward with criminal abuse issues for fear of reprisals or retribution from administrators (Helm, 1990). Administrators may find themselves in a situation that to report a violent crime can lead to negative publicity which may involve questions about their competence, damage their career, or even lead to losing their jobs. Minimizing the severity of the reported abuse or deciding that it was unlikely that a crime occurred avoids such risks.

Reporting to "proper authorities" often includes reports to non-law enforcement agencies that result in administrative actions such as licensing sanctions or the firing of or resignation of the suspect. State law frequently mandates reporting of serious crimes, but administrators often determine were to send such reports by their interpretation of what actually occurred. Reports of incidents diverted from the criminal justice system are not part of the crime reporting data and represent an unequal remedy when compared to arrest, prosecution and incarceration.

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James found a much higher rate of non-reporting in a study of people with developmental disabilities, a finding that is consistent with the idea that people with more severe disabilities are more vulnerable and less likely to report a sexual assault. This study found that only 3% of cases of sexual assault involving people with developmental disabilities are ever reported to authorities (James, 1988 as reported in Tharinger, Horton & Millea, 1990). This compares with a reporting rate of sexual assaults of from 16% (Kilpatrick, Edmunds & Seymore, 1992) to 28.3% (National Crime Victimization Survey, 1999) for the general population.

There is a widespread perception among people with developmental and other more significant disabilities and their advocates that reporting crimes may often be useless (Sobsey and Doe, 1991).

POLICE FOLLOW UP AND PROSECUTION

There is expert opinion and empirical evidence that, when reported, there are lower rates of police follow up, prosecution and convictions of crimes against people with disabilities.

A range of possible explanations offers themselves. These cases are inherently difficult to investigate, prosecute and bring to trial. Criminal justice personnel often lack the special skills and special training required for these cases. The cognitive and communication difficulties for some of these victims present special challenges, including the unfounded assumption that such victims almost always make incompetent witnesses.

Negative stereotypes and prejudices can interfere with fair consideration by the criminal justice system. A 1999 study of 234 adult victims of a traumatic crime who had a label of mental disability (Marley & Buila, 1999) found that nearly half of the crimes reported to police resulted in unsatisfactory responses from the police. In 11.7% of these reports, the victims found the police disbelieving, 6.6% angry, 18.3% rude/sarcastic, and 11.7% no help provided.

Sobsey (1994) reviewed a number of research studies on this topic and reported that they all agreed that convictions of offenders were rare in spite of the chronic and severe nature of the criminal abuse. A survey of 119 cases of sexual assault against people with intellectual disabilities in Britain was consistent with these findings. It found that no action was taken in almost half the cases, and prosecution or disciplinary action took place in only 18.5% of the cases (Brown & Turk, 1994). Another study (Sobsey and Varnhaggen, 1991) looked at sexual assaults of people with disabilities. It reported that 65% of cases reported to the police were not prosecuted because the police declined to press charges usually citing the victim as an incompetent witness. In another 18% of these cases, the prosecutor refused to pursue charges. In another 18%, the offendet was never found. Many of the victims were dissatisfied with the legal action taken or denied.

In another study of known sexual assaults of people with intellectual disabilities in Britain, police investigated only 21% and only 9% were referred by police for prosecution. Just two of these (less than one per cent) proceeded to court, and only one resulted in a conviction (Brown and Stein, 1997). This is consistent with a Boston Globe (6-10-2001) survey in Massachusetts that found that only 5% of serious crimes against people with disabilities were prosecuted compared to 70% for similar crimes against people without disabilities. Sobsey (1996b) stated that overall there is not good prosecution of these cases but that it varies greatly across different criminal justice systems.

The worst danger is that predators may also believe they are unlikely to be successfully prosecuted. A clinician at Atascadero State Hospital, a forensic facility in California, reported that he overheard two sex offenders talking. One said to the other, "Get a job in the D.D. (developmental disabilities) system when you get out, it's easy pickings." Unfortunately, such people probably also hold that perception about the mental health system and other systems providing care for people with significant disabilities.

CONCLUSION

The personal experience of people with significant disabilities and their families, as well as empirical research, paints a picture of very high rates of violent and other major crime directed against citizens with disabilities. People with significant disabilities represent a sizable portion of our population, suffer violent crime at substantially higher rates than most citizens and are less protected by the criminal justice system than other persons because of lower reporting rates for violent crime and lower prosecution and conviction rates.

This is first and most importantly a civil rights issue. People with disabilities have a fundamental right to equal protection and equal justice. The advocacy and service provider systems have failed to insist on these fundamental rights and to educate their members about this problem and have, therefore, participated in this pattern of discrimination.

This is also a major public health problem. Violent crime can have a profound destructive impact on its victims. People with disabilities, their families and service providers must take action to reduce this epidemic of violence and crime.

Each of us must find the time to address this problem in our lives and in our work.

Dan Sorensen is a long-time parent advocate and currently heads California's initiative to combat crimes against people with developmental disabilities.

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Violence Against Women with Disabilities

BY MARC DUBIN

Violence against women with disabilities is a subject that needs to be discussed within the disability movement and within groups addressing violence against women. Furthermore, there is a need for collaborative efforts between disability advocates and members of the criminal justice community. This article will primarily address crime victims with labels of mental retardation and other developmental disabilities. It should be noted, however, that crime victims with other disabilities are also entitled to a better response by service providers and law enforcement, including the provision of sign language interpreters, removal of architectural barriers, and policy modifications such as allowing an individual with a service animal into areas with a designated "no pets" policy.

For far too long, crime victims with disabilities have been denied services and suffered the consequences of victimization. In a recent survey conducted by Oregon Health & Science University, 30% of women with disabilities said abuse was a barrier to employment, 64% said abuse kept them from taking care of their health and 61% reported that abuse prevented them from living independently ("Abuse of People With Disabilities." Document Number 2868 at www.cavnet.org).

For far too long, disability advocates have remained silent. We need to educate survivors, service providers, the disability community, and the criminal justice community. Communities Against Violence Network (CAVNET) provides a way to do this.

The Nature and Scope Of The Problem

Women with labels of mental retardation and other developmental disabilities are vulnerable to abuse by caretakers, family members, and strangers. Alarmingly, the few studies that have examined this group have found rates of criminal victimization that are far higher than those of other women. One study found that 70% of women with developmental disabilities had been sexually assaulted, and that nearly 50% of women with mental retardation had been sexually assaulted 10 or more times. (Sobsey and Doe, 1991). This represents a 50% higher rate of victimization than the rest of the population. Children with disabilities are also at greater risk. One study of children with disabilities found that they were many times as likely to be victims of physical abuse as children without disabilities. (Crosse, et al. 1993). Despite such high rates of victimization, few of these cases come to the attention of law enforcement or service providers. We need to ask why, and we need to do something about it. Fortunately, resources do exist, as do collaborative models.

The Report

Police officers are not always the first responders to crime victims with disabilities. When an individual is in an institution or group home setting, staff are often the first to observe the effects of abuse. It is important to train staff that suspicions of abuse must be reported -- and the report should be in writing with as much specificity as possible. The date, time, and place of the incident must be noted, as well as the names of any witnesses. All staff and residents should be confident that such reports are taken seriously, and all reports should be forwarded to law enforcement for review. Photographs of injuries should be taken and enclosed with the abuse report. If the victim is nonverbal, or has a cognitive disability, the report should note this, and should indicate how staff communicates with the individual.

Efforts should be made to develop a relationship with local law enforcement in advance of any reports -- the police should have a 24-hour contact number for the facility, and the facility should designate a contact person who regularly attends community meetings concerning crime victim issues. In this way, collaborative relationships can be fostered, and law enforcement can be confident that they will be able to appropriately address the needs of a crime victim with a disability.

The Investigation

Too often, law enforcement declines to make an arrest citing an inability to interview the victim adequately, or citing a lack of confidence that the local prosecutor will go forward with the prosecution. This failure results in a reduction in reporting, as victims eventually come to believe that their complaints will not be taken seriously. What can be done to overcome this?

First, disability advocates can develop cooperative working relationships with their local law enforcement community. Meet with the local police department; meet with the local prosecutor. Let them know what service you provide, and how willing you are to assist them. Identify the group homes and institutions in your community, and share this information with police.

When an officer gets a call to respond to an address that houses individuals with developmental disabilities, the response needs to be different than a traditional call. Compound questions such as "Who were you with and what happened?" may tend to confuse an individual with a mild or moderate cognitive disability. It is also important that leading questions, which may be easily answered in the affirmative, should not be used. Questions need to be broken down into simple terms, and the officer needs to change the language of the question until he/she is understood.

Some persons with cognitive disabilities choose to intentionally hide their disability; officers need to be trained to recognize this. In addition, the perpetrator may be a staff member, and the responding officers need to be prepared for this. If the victim has a communication or cognitive disorder, the disability advocate should be prepared to assist the officer in understanding how the victim best communicates. These discussions are best done in advance, so that officers will know who to call for assistance.

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Violence Against Women with Disabilities

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The Prosecution

It is essential that disability advocates work with local prosecutors as well. Most prosecutors' offices have a victim/witness unit, staffed by sensitive advocates assisting crime victims. Work with them to let them know what resources you have available, and try to integrate yourselves into community meetings so that this issues is raised as often as possible.

Resources

A number of helpful materials exist. For example, ARC of the United States has developed a curriculum for law enforcement that is available by calling 800-433-5355. In addition, the National Sheriff's Association has developed an excellent handbook for law enforcement entitled "*First Response to Victims of Crime Who Have a Disability,*" available on the CAVNET site (www.cavnet.org - document number 2791). The Justice Department also has published an excellent resource called "*Working With Crime Victims With Disabilities,*" available at the CAVNET sire as well (document number 757).

CAVNET has hundreds of documents on this subject available. In addition, CAVNET has recently developed an easy to use program that allows you to add any of these documents directly to your site -- the CAVNET DataBase Builder. Visit www.cavner.org for more information.

Marc Dubin, Esq. is a Trial Attorney in the Disability Rights Section, Civil Rights Division, U.S. Department of Justice.

Look for additional resources on the Communities Against Violence Network web site, <www.cavnet.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.

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Priscilla Newton, *Editor*

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