

TASH CONNECTIONS

Equity, Opportunity and Inclusion for People with Disabilities since 1975

Inside This Issue

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- **Using Person Centered Planning to Communicate End-of-Life Wishes**
- **Thoughts on Theresa Schindler Schiavo**
- **Guardianship is *Not* Self-Determination**
- **The Trust As An Alternative to Guardianship**

URGENT!
Dated Material Inside:
2005 TASH Board Election Ballot!

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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;



WHOM DO I CONTACT?



- **For issues of policy, chapter or committee support, or general concerns and suggestions, call:** Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail: nweiss@tash.org
- **For information on conferences, regional workshops, or technical assistance, call:** Denise Marshall, Director of Meetings and Information Resources, at (410) 828-TASH, Ext. 103, e-mail: dmarsh@tash.org
- **For questions about the TASH Annual Conference sessions and presenters, call:** Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail: knelson@tash.org
- **For questions about membership, conference registration or exhibiting, call:** Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholshey@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 TASH *Connections* submissions and advertising, conference sponsorship, or permission to reprint, call:** Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail: pnewton@tash.org
- **For information on Research and Practice for Persons with Severe Disabilities (a publication of TASH), call:** 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>

Payroll Deduction Plans in Support of TASH Mission

BY LYLE ROMER, Executive Director, Total Living Concept

As many of you already know, TASH has recently launched several fund raising efforts in support of its mission to make equality, justice and inclusion a reality for people with more significant disabilities. Contributions to TASH come in many forms: corporate sponsorships for our conference; planned giving; and personal donations, to name a few. Being a grassroots human rights organization since its inception, TASH also enjoys the support of many individuals around the U.S. and the world. Many of these people make small, but very significant financial contributions to TASH. In fact, when considering the income of people who donate small amounts, they are giving very generously from their limited funds: support that comes from their hearts as well as their checkbooks.

In order to not overlook the passion these individuals hold for the TASH mission, the agency I work for started a payroll deduction plan that allowed the staff of Total Living Concept, a supported living agency in Kent, Washington, to make direct financial support to TASH. While the plan is a simple one, its power lies in recognizing that though many people can't contribute \$500.00 or \$1000.00 to TASH, they are no less committed to the work of the organization, and their support is just as heart-felt as those with more financial resources. I wasn't prepared for the impact these contributions would have on me. I make it a point to not know who contributes or how much, but I am kept informed of the total amounts given. I also know that \$10.00 per pay check may not sound significant, but when someone makes \$10.00 an hour, and may not even work full-time, you have to take note of that person's selflessness. Our total contributions from this payroll deduction plan will come to about \$2000.00 for the year. The power of one is amazing; the power of the collective is awe inspiring.

I would encourage all of you who work in agencies to look into creating a payroll deduction plan for your employees. Every contribution has the potential for changing the life of someone with a disability. If our small agency with about 125 employees can raise \$2000.00, what would the impact of an agency with 1000 staff be? Do the math: \$16,000.00!

I would be happy to answer any questions you might have about how to start such a plan. Give me a call at (253) 854-7663, Ex. 111, or send me an e-mail, lyleromer@totallivingconcept.org.

Thank you!

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

**Char Brandl
Douglas Biklen
Tina Calabro
Shelly Counsell
Barbara Cutler
June Downing**

**Jo Montie
Joann Noll
Kathryn Peckham-Hardin
Lyle Romer
D. Lea Ryndak
Scott Shepard
Cynthia Sutton**

and welcome to our newest lifetime members

**Joanne Eichinger
East Greenwich, R.I.**

**Onondaga Community Living
Syracuse, N.Y.**

**S.L. Start & Associates
Spokane, WA**

TASH has a lifetime membership 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 or send an e-mail to rholsy@tash.org



THE 2005 EXECUTIVE BOARD ELECTION

One of the most important things members of any organization are asked to do is to participate in electing members of the Executive Board. Now is the time for you to decide who will help provide critical leadership toward accomplishing TASH's mission of equity, opportunity and inclusion 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 November TASH Conference in Milwaukee. The individuals who appear on this year's slate have made significant contributions in the lives of people with disabilities and have demonstrated leadership in the disabilities movement.

Your vote is critical. Please use the postage-paid, self-mailing ballot provided on page 11, or clearly write "ballot" on the envelope you use. Ballots must be received at the TASH office by **October 21, 2005**. 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:



**Jacki
Anderson**

Jacki Anderson's ongoing commitment to include individuals with

significant disabilities in all aspects of life has been readily evident throughout the three decades she has been in this field. As a classroom teacher, she spent 10 years working in the first integrated California public schools program for students with multiple disabilities, autism and other health impairments. These students, who had historically been served in institutions or segregated schools, taught her the power of teaching in natural environments, the importance of family partnerships in the educational process, and the tremendous need for both advocacy for effective services and educated support personnel.

These important lessons have been the foundation of her efforts as a trainer, researcher, and facilitator of systems change. She has over thirty years experience conducting inservice training activities around the country and has taught for twenty-four years in Special Education teacher training programs at the University of Wisconsin, San Francisco State University, and California State University Hayward, where she has served

as coordinator of the masters degree and credential programs in the area of moderate-to-severe disabilities since 1986.

Jacki's areas of specialization include personnel training, inclusion of individuals with significant disabilities, and positive behavior support. She has been awarded funds to pursue all of these interests via research, training, and model demonstration projects and has published the results in textbooks, chapters, and journal articles. She served as Coordinator of the California Research Institute on the Integration of Students with Severe Disabilities (CRI), Director of a series of personnel training projects addressing integration, community intensive instruction and inclusion, and as Training Coordinator for the Rehabilitation, Research and Training Center on positive Behavioral Support, a six University consortium dedicated to developing and disseminating practical technologies for supporting individuals with behavioral challenges in inclusive school, work and community environments. Over the course of this project, she coordinated the development of a comprehensive inservice training model to establish interagency state level training teams. She is currently Vice President of the Association for Positive Behavior Supports (APBS) and also serves on a variety of national, state, and local committees and advisory boards.

Jacki has been an active member of TASH since 1979 and of CAL-TASH since it was founded in 1982. She is past president of the CAL-TASH board, (board member since 1989), board member of TASH since 1998 and is currently serving as Executive Vice President. Jacki brings to the board an understanding of and commitment to the relationship between TASH and the chapters. She has a genuine interest in the organization's continued efforts in the areas of advocacy and the dissemination of information via the journal, newsletter and efforts to influence legislation and policy development that support the rights of individuals with significant disabilities to be active and respected members of our society.

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2005 EXECUTIVE BOARD ELECTION

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Diane Coleman

It's an incredible honor to be asked to run for the TASH Board. As a disability

rights activist, whose knowledge of TASH comes through policy work, I have long been impressed with TASH's clarity of purpose and vision, and willingness to take a stand on the cutting edge of key policy issues.

In my work with both ADAPT and Not Dead Yet, TASH has been a strong collaborator. TASH has joined in virtually every "friend-of-the-court" brief filed by Not Dead Yet, opposing the legalization of assisted suicide and euthanasia. We have worked especially closely on the guardianship policy issues surrounding the Terri Schiavo case, and I've had the pleasure of working with representatives from the Florida TASH chapter. Donna Gilles gave a powerful statement in behalf of TASH at our Schiavo press conference before the Florida Supreme Court hearings on Schiavo in summer 2004.

I hope that by joining the TASH Board, I can help both organizations and strengthen the relationship between TASH and Not Dead Yet. Society's devaluation of people with severe disabilities is perhaps nowhere more entrenched than in the health care system. As bioethicists look for ways to ration health care in an aging society, it appears that people with disabilities are everyone's best hope for the leadership needed to ensure that all people are valued equally.

I have used a motorized wheelchair since the age of eleven. My background



includes a law degree and a Masters degree in Business Administration from UCLA. I worked as an attorney for the State of California for seven years, and served as a member of the California Attorney General's Commission on Disability.

Relocating to Tennessee in 1989, I was Co-Director of the Technology Access Center of Middle Tennessee and served as Policy Analyst for the Tennessee Technology Access Project. Since 1996, I have been Executive Director of Progress Center for Independent Living in Forest Park, Illinois. I also serve as a member of the Illinois State Medicaid Advisory Committee, and a member of the Board of the Illinois Campaign for Better Health Care.

In April, 1996, I founded Not Dead Yet and continue to serve as its President. I have presented invited testimony before various subcommittees of the U.S. House of Representatives, and have appeared in various national media on topics related to Not Dead Yet, including *Nightline*, *ABC World News Tonight*, CNN, *CBS Evening News*, MSNBC, Fox News and National Public Radio. In 2003, I joined the adjunct faculty at the University of Illinois at Chicago to co-teach a series of graduate courses in disability and medical ethics.



Charles Dukes

I am really excited about the opportunity to potentially serve as a member of

the TASH Board. I have been a TASH member since 1999. I began my career in special education as a teacher in the Houston Independent School District, working at a facility for young adults awaiting adjudication. Our small team included 14 teachers, with only two of us specifically trained in Special Education. Our task was to insure the many students with labels of disabilities received timely and comprehensive services. This

experience helped me to better understand the importance of interagency cooperation and the need for direct links between families, agencies, and individuals in need of help.

After leaving the Houston area, I moved to the state of Florida where I currently reside. I began work for the School Board of Broward County, working in various schools. During my tenure in Broward County, the district was on the cusp of making inclusive education a reality on a large scale. Schools in general are not necessarily receptive to change, and this especially applied to high schools. One of my charges to this end was to provide district level training to teachers on financial ways that schools could better fund students' educational needs in inclusive settings. I was also involved with the goal of providing quality education in the least restrictive environment at my next destination which was in Dade County Public Schools.

While in the Dade County system, I taught at a high school and trained as part of the behavior team on effective ways to use functional behavioral assessment. After a few years with the system, an opportunity came for me to become part of the Center for Autism and Related Disabilities (CARD) network as a coordinator. Part of my duties as a coordinator for CARD was to assist families with understanding the behaviors of a loved one with autism, advocate for students with labels of autism with the school district, and provide support groups for adults with labels of autism and Asperger's.

I received my doctorate from Florida International University in Miami, Florida in the area of Special Education, with a concentration in curriculum and instruction. I am currently an Assistant Professor in the Department of Exceptional Student Education at Florida Atlantic University. I continue to run the support group for adults with autism and Asperger's. Some of the courses that I teach include classes in Applied Behavior Analysis, Classroom Management, and

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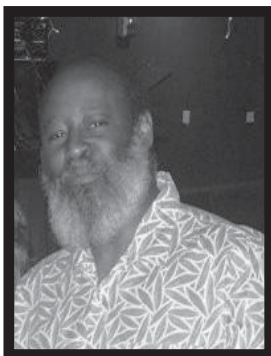
Inclusive Education for General Educators. In addition to my university requirements, I also work with a number of public schools in the South Florida area, assisting with positive behavioral interventions and effective instructional strategies.

I am committed to TASH and becoming a board member for several reasons. First, I am convinced that I can contribute to the work of the organization. The energy and hunger for change that I will bring to the Board can be put to use for the benefit of all. Second, I want to make an impact on the people and communities that TASH impacts. By working on the Board, I will be able to make a greater contribution to people and communities outside of my home state of Florida. As more and more individuals with labels of developmental disabilities grow older in age, it will take the collective efforts of many to ensure comprehensive, inclusive services are made available. Third, I want to add my voice to the conversation about the present and future of our society as we all work to make it fully inclusive. I want to bring this perspective to the Board and work in cooperation with current members to make change where it's needed and celebrate triumphs where they exist.

Ralph W. Edwards

It is an honor to be considered for membership on the TASH board, an organization that provides

creative and courageous leadership on disability issues. For several years, I've worked with TASH members Drs. Wanda Blanchett and Allen Crocker and Attorney



Barbara Ransom to coordinate the People of Color Strand at the TASH annual conference. We've explored issues of health, service delivery, access and funding, special education, family empowerment, and community building, particularly as it applies to the inclusion and well-being of the thousands of people of color with intellectual disabilities. The information and the networking from this Strand have transformative implications for disability policy and programs. We anticipate obtaining foundation funding to continue this important effort.

Professionally, my experiences as a manager in Massachusetts state human services agencies, Department of Public Health (DPH) and Department of Mental Retardation (DMR), provide a background and skills that can help TASH as it addresses community living, relationships, responsive health systems, individual and family empowerment. As a DPH manager, I've helped communities develop substance abuse programs, tackle AIDS prevention and education, and educate neighbors to accept and support residential programs in their neighborhood. In DMR, I work with self-advocates, families and other citizens to have input into Departmental policies and programs, striving to be valued partners with policy-makers and senior managers. The programs and activities include quality enhancement, community education, legislative advocacy, developing autism services, preventing abuse and mistreatment, and monitoring the quality of Department services.

Personally, my family benefits from key aspects of TASH's work and influence. My son participated in special education programs. He lives in a supported apartment in a community consisting of caring relationships, not just a place. Employment is central to his life. We've experienced instances of abuse, both excellent and poor provider relationships, and challenges in accessing services. TASH information has been helpful in providing a context for these experiences, as well as effective strategies in response to them. It is also through my son's life experiences that I understand how

personally *unimportant* ethnicity is to him and his friends with disabilities. He has never described, nor have I observed, ethnic based incidents regarding others with disabilities. Unfortunately, research data indicates that this has not been the experience in interactions with disability providers, policy-makers, agencies and organizations. Much needs to be done to reduce disparities and to support inclusion. This is one of several areas where I hope to contribute to TASH.

I hold a Bachelors of Arts degree from Tulane University, a Masters in Public Health from the University of Texas School of Public Health, and a Master of Public Administration degree from Kennedy School of Government, Harvard University.

I am excited about the possibility of serving on the TASH board. I hope to work with my colleagues to define issues, form coalitions, influence policy, and build a joyous world for all of us. I appreciate your consideration.

Sue Rubin

My name is Susan Rubin. I am a 24-year-old woman with autism. I have been

motivated to run for the TASH Board due to the fact that I believe the people representing TASH should be those who not only advocate, but also live with a disability each and every day. I can offer insights that perhaps other candidates may not be accustomed to dealing with.

My main purpose for being a member of TASH is to help further educate those with misperceptions of what a person with a disability can achieve. As an advocate, I am dedicated to making a significant



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contribution to the lives, education, research, and welfare of those with disabilities and their families.

I am currently working towards my degree at Whittier College. I am a junior though I have been attending since 1997. This has been a long and tedious journey, yet it has shaped me into an individual with great pride in my accomplishments. I have participated in over fifty presentations to groups at conferences, colleges, and social service agencies, including five times as a keynote speaker since 1992. Just to name a few accomplishments I have been honored with thus far: Supported Life Institute Award; Wendy F. Miller Outstanding Individual with Autism Award from the Autism Society of America; and recipient of the CalTASH-Mary Falvey Outstanding Young Person Award. I was privileged to carry the Olympic Torch as a Community Hero in the 1996 Olympic games.

I am honored to be nominated for the TASH board and am confident that I will contribute a great deal of leadership and commitment to TASH's objectives, offer unique perspectives and be part of the future of TASH's dedication to individuals with disabilities."



Leslie Seid Margolis

I am honored to be considered for a TASH Board position. As an attorney at the Maryland Disability Law Center, Maryland's

protection and advocacy agency, for nearly 17 years, I have engaged in individual and systemic special education advocacy and in special education legal policy work at the

local, state, and federal levels. As the parent of an 11-year-old child with profound physical and cognitive disabilities who is fully included in a Baltimore City public school classroom, I also have a personal connection to disability issues.

As a longtime TASH member, I embrace the values that form the foundation of TASH, and work for the day when there will be sufficient supports and services available to ensure that all persons with disabilities are able to live in their home communities, attend neighborhood schools, and be employed competitively and productively without the need for extensive advocacy services.

Professionally, I have represented children with disabilities in individual special education cases and in juvenile court foster care proceedings for many years. Some of my most satisfying cases have involved moving children out of segregated settings into their neighborhood schools and communities.

I spent many years co-counseling a major systemic reform special education case against the Baltimore City public school system. I co-founded and continue to chair the Education Advocacy Coalition for Students with Disabilities, a group of approximately 25 individuals and organizations concerned about special education issues in Maryland. I have served, and continue to serve, on a number of state task forces and advisory committees related to special education, and on other disability-related boards and councils. I was a member of a state task force charged with the development of regulations regarding restraint and seclusion of students in schools. The task force was appointed in response to legislation I drafted in an effort to limit and regulate the use of restraint and seclusion in schools. Until then, Maryland has had no statewide law, regulations, or policies regarding the use of these highly aversive behavior controls.

At the national level, I have worked for many years to reform the federal special education monitoring process, and participated actively in a national workgroup that designed and promoted a system of

focused monitoring and active enforcement. I am an advisory board member of the National Center for Special Education Accountability Monitoring, a federally funded center whose mission is to assist states in improving the quality of their special education monitoring.

As a parent, I understand the reality of raising a child with severe disabilities. I understand that in some ways, the ability to pursue inclusive education for my daughter and to be a firm proponent of inclusion in all aspects of life is a luxury denied to many other families who do not have meaningful choices or options for their children.

Inclusion should not be a luxury, and it should not be something for which families have to fight. If re-elected to the Board, I would continue to have TASH use the expertise and experience of its members to develop a plan to increase the availability of supports, services, and resources so that more individuals with disabilities and more families will be able to choose inclusive living arrangements, schools, and jobs.

As a Board member, I would also continue to strive to cement the relationship between TASH and the protection and advocacy system and other disability organizations. At a time when disability protections are being narrowed by courts and are jeopardized from every direction, it is essential that we continue to find as much common ground as possible and work together to preserve the gains we have made and lay the groundwork for future progress."

Scott Shepherd



"I am truly honored and humbled to be selected as a nominee for the TASH Executive Board. I have been learning from people with severe reputations and their families for over 20

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years in the course of providing direct support services. Much of the work and research done by TASH members has shaped and guided me in the support I provide to people.

Some of the work I am involved with now includes coordinating state training in California on Positive Behavioral Support through the Rehabilitation, Research & Training Center on Positive Behavioral Support; currently serving as a Cal-TASH Board Member, serving on the Vendor Advisory Committee for North L.A. County Regional Center; and as a committee member for the Santa Clarita Mayor's Committee for Employment of Individuals with disabilities. I also teach part-time at C.S.U. Northridge (since 1991), where I teach courses on behavior assessment and positive behavior support, a class on issues related to transition for persons with disabilities, and I supervise teachers in their classrooms while they are completing their credentials.

My "real job", however, is directing a small non-profit agency which provides supported living and individualized day services for 19 persons about 1 hour north of Los Angeles. As a small agency, I have the opportunity to provide more than 20 hours of direct service a week, which ensures that I am still able to learn on the job. My most enlightening experiences have been transitioning a segregated 'behavior management day program' for individuals with autism to community based employment and career services and assisting people to move from large congregate facilities to homes of their own.

I believe that it is important to assist communities to build local strength and advocacy by identifying local family members, self advocates & professionals and providing them with training and resources that they can share with others while they build strength from within. Our TASH conferences have been trying to do this, and I think that we can improve our efforts in this area.

While I spend much of my time at the University focusing on inclusive services for children, I also believe that it is critically important to focus on quality services for adults. Budgets are tight for all services, but federal and state dollars seem to 'shrink' once people turn 22 years old. Post-22 services for adults seem to be relegated under the category of "careprovider" instead of teacher, job-coach, and support staff whose job it is to teach skills as well as to develop natural and typical supports in people's lives. We need to focus on live quality across the continuum, from birth to the sunset of life. Thank you again for this opportunity!"



Susan Yuan

I am honored to be nominated for the TASH Board, as this organization has inspired and sustained

me. At my first TASH conference in 1988, I discovered information I was eager to learn, solid values I could embrace, and dedicated, unique people who live those values.

Most important, I am the mother of 3 grown bicultural children. My youngest, Andreas, who has Angelman Syndrome, has shaped the way I see the world, determined my career and given me my closest friends. I work as the Associate Director and Coordinator of Family and Consumer Affairs for the Center on Disability and Community Inclusion at the University of Vermont. I'm currently President of the New England Chapter of TASH.

What are the issues I care about the most? The elimination of restrictive behavioral interventions, particularly in schools, is urgent. We don't have any of the worst practices in Vermont, so it has been difficult for many to realize that

seclusionary time out is still a problem. Restraint still happens, often without enough training and documentation. After more than a decade of effort, Vermont now has guidelines limiting restrictive behavioral interventions, and requires reporting from all schools. We continue to work with the VT Department of Education to get good data on any use of restraint or seclusion, and Vermont conducts training on positive behavioral support in schools.

I believe that good family support is the springboard for self-determination and self-advocacy. While self-advocates need their own voices to be heard, the more the two movements work together, the stronger our advocacy will be. Since 1993, I have offered the curriculum, Family Support, Self-Determination and Disability, in more than 20 states and territories. This training opportunity made it possible for me to come to know family and self-advocate leaders who have become an effective network of advocacy. These connections are even more important now as supports for families and people with disabilities are endangered by cuts to Medicaid and other programs.

Family support and opportunities for self-determination need to grow beyond the populations served now. People from diverse cultures should get support they need in ways that fit their own backgrounds. Parents with disabilities need rights and understanding support to raise their children successfully at home. If we raise our sons and daughters to have full lives and relationships, it follows that they should have the possibility of becoming parents themselves, if they choose.

Students with disabilities should grow up in their neighborhood schools, graduating into full lives in the community, with people who know and welcome them. I have done training in Vermont and around the country for teams of schools and families on effective participation of families in inclusive education. I firmly believe that inclusion, done well, is the best we can offer our children.

TASH 2005 Election of Five (5)

EXECUTIVE BOARD MEMBERS

Term of Office: 2002-2005

- 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 2005 TASH Conference to be held in November in Milwaukee, Wisconsin.

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.

- | | | |
|--|--|---|
| <input type="checkbox"/> Jacki Anderson | <input type="checkbox"/> Ralph Edwards | <input type="checkbox"/> Scott Shepard |
| <input type="checkbox"/> Diane Coleman | <input type="checkbox"/> Sue Rubin | <input type="checkbox"/> Susan Yuan |
| <input type="checkbox"/> Charles Dukes | <input type="checkbox"/> Leslie Seid
Margolis | |

For information about the candidates, please refer to pages 4-8 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 21, 2005.**

Mail your completed ballot to:

TASH, 29 W. Susquehanna Avenue, Suite 210
Baltimore, Maryland 21204
Attn: Ballot



**2005 TASH
Executive Board Election
BALLOT
Due in Baltimore on
October 21, 2005!**

FOLD BALLOT HERE



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End-of-Life Issues and Persons With Disabilities

A timely, responsible discussion of end-of-life issues and people with disabilities.

Guest editors: Timothy H. Lillie and James L. Werth, Jr.

This special issue of the Journal of Disability Policy Studies presents a balanced and scholarly cross section of perspectives regarding end-of-life issues and people with disabilities.

Journal of Disability Policy Studies



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Number 1
Summer
2005

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- Attitudes of Persons With Physical Disabilities Toward Physician-Assisted Death: An Exploratory Assessment of the Vulnerability Argument—*Karen Hwang*
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- Concerns About Decisions Related to Withholding/Withdrawing Life-Sustaining Treatment and Futility for Persons With Disabilities—*James L. Werth, Jr.*
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- Whose Choice Is It, Anyway? Disability and Suicide in Four Contemporary Films—*Merope Pavlides*
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TASH: Public Policy in Action

TASH AND NOT DEAD YET PLAN SUPREME COURT RALLY FOR DISABILITY RIGHTS

The Supreme Court has set October 5, 2005 as the date to hear oral arguments in two important cases of interest to members of the disability community:

Summary of the *Gonzales v Oregon* Case

The Oregon "Death With Dignity Act" has been challenged by the U.S. Department of Justice under the Controlled Substances Act, asserting that federal law prohibits physicians from prescribing controlled substances for assisted suicide on the grounds that it is not a "legitimate medical purpose" for their usage. The District and Circuit Courts have upheld the Oregon law, and the U.S. Supreme Court has agreed to hear the case. The legal issues pertain to the respective roles of federal and state government.

In a friend of the Court brief filed on behalf of Not Dead Yet, ADAPT, Center on Disability Studies, Law and Human Policy at Syracuse University, Center for Self-Determination, Hospice Patients Alliance, *Mouth* Magazine/Freedom Clearinghouse, National Council on Independent Living, National Spinal Cord Injury Association, Self-Advocates Becoming Empowered, Society for Disability

Studies, TASH and the World Institute on Disability, disability rights attorney Max Lapertosa wrote:

"Amici support the Attorney General's interpretive ruling that assisted suicide is not a 'legitimate medical practice' under the Controlled Substances Act, 21 U.S.C. §§ 801-971. ... If a state overtly excluded people with 'terminal' disabilities from suicide prevention laws and programs, it would undoubtedly violate federal civil rights laws such as the Americans with Disabilities Act. ... Yet, that is precisely the design and effect of the Oregon assisted-suicide law. A more devastating form of discrimination would be difficult to imagine. By assuming that it is irrational for a non-disabled person to end his or her life, but rational for a disabled person to do so, the law assumes that the non-disabled person's life is intrinsically more valuable and worthwhile than that of a disabled person.

Assisted suicide also raises serious ethical concerns regarding the medical profession's treatment of the disabled. It requires doctors to make difficult, if not impossible, determinations of a person's competency and life expectancy, the consequences of which are both ultimate and irreversible. The availability of assisted suicide also distracts from the determination whether a person's desire to die might be lifted with improved treatment, community-based health care or other measures that improve a person's independence and dignity. ...

But the Court of Appeals avoided this analysis by holding that the Attorney General's directive on prescriptions for assisted suicide 'interferes with Oregon's authority to regulate medical care within its borders. ... If any federal restriction on the practice of medicine infringed upon a "fundamental" state function, it would call into question Congress' entire regulatory scheme for prescription medication, which has been in effect for three decades and has been repeatedly upheld and enforced. ... The Court of Appeal's holding is of significant concern to our organizations beyond its implica-

tions for assisted suicide. Congress and federal agencies often regulate 'medical care' to prevent abuse of or discrimination against people with disabilities. ... For example, in *Olmstead*, this Court held that the unnecessary institutionalization of people with disabilities by states was discrimination under Title II of the Americans with Disabilities Act (ADA). Although Title II's definition of discrimination did not explicitly identify unnecessary institutionalization, the Court relied in part upon the Attorney General's regulations and interpretations of the Act in discerning Congress' intent. ... Although this interfered with a 'medical' decision approved under state law (and carried out by the State itself), it was nevertheless understood as appropriate federal action."

What Does Disability Have to Do With Assisted Suicide?

Many people who favor legalization of assisted suicide object to the involvement of disability rights organizations in the public debate. After all, they say, assisted suicide is about terminal illness, not disability.

The disability experience is that people who are labeled "terminal" based on a medical prediction that they will die within six months, are — or almost inevitably will become — disabled. Furthermore, virtually all "end-of-life care" issues — access to competent health care, adequate pain relief, in-home personal care and flexible, consumer-responsive supports, peer counseling, family support — have been disability rights issues for decades. It should be noted that suicide, as a solitary act, is not illegal in any state. Disability concerns are focused on the systemic implications of adding assisted suicide to the list of "medical treatment options" available to seriously ill and disabled people.

What's Wrong With The Oregon Law?

The Oregon Law grants civil and criminal immunity to physicians providing lethal prescriptions based on a stated claim of

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TASH and Not Dead Yet Plan Rally at the Supreme Court in Support of Disability Rights

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“good faith” belief that the person was terminal, acting voluntarily, and that other statutory criteria were met. This is the lowest culpability standard possible, even below that of “negligence,” which is the minimum standard governing other physician duties.

As the Oregon Reports on physician-assisted suicide make clear, the state has not been able to assess the extent of non-reporting or noncompliance with the law’s purported safeguards. There are no enforcement provisions in the law, and the reports themselves demonstrate that non-terminal people are receiving lethal prescriptions.

More disturbingly, the reasons doctors actually report for issuing lethal prescriptions are the patient’s “loss of autonomy” (87%), “loss of dignity” (80%), and “feelings of being a burden” (36%). People with disabilities are concerned that these psycho-social factors are being widely accepted as sufficient justification for assisted suicide, with most physicians not even asking for a psychological consultation (5% in 2004, 16% overall) or the intervention of a social worker familiar with home and community based services that might alleviate these feelings. The societal message is “so what?” or “who cares?” Recent government reports rank Oregon highest in the nation in elder suicide.

The Oregon law is not about individual choice but rather physician judgments. Studies consistently demonstrate that physicians and other health care providers rate the quality of life of people with significant disabilities and illnesses significantly below the individual’s rating of their own quality of life. The Oregon law gives physicians the power to judge whether a particular suicide is “rational” or not based on his or her prejudicial devaluation of the individual’s quality of life, and then to

actively assist certain suicides based on that judgment.

This should be viewed as a violation of the Americans with Disabilities Act, which prohibits discrimination based on disability. That is the core of the disability argument in the *Gonzales v. Oregon* case.

Summary of the *Schaffer v. Weast* Case

This case will examine who bears the burden of proof – parents or schools district – in special education due process hearings under the Individuals with Disabilities Education Act. The circuit courts have split on this issue: five have assigned the burden of proof to the parents and five have assigned it to the school system. TASH and allies were dismayed when the Department of Justice recently switched its views on the case and filed an amicus brief supporting putting the burden of proof on the parents rather than the school system.

On August 9, 2005, the National Council on Disability (NCD) issued a Position Statement explaining that the burden of proof should always be on the school district. This is a comprehensive article that explains the history of this case and the Court’s history in resolving similar cases where the federal statute does not assign the burden of proof to one party or the other. Pete Wright was the author of the NCD article.

TASH members can download and read Pete’s excellent article at:
<http://www.ncd.gov/newsroom/publications/2005/pdf/burdenofproof.pdf>



Not Dead Yet and TASH are going to be working with other allies to organize a rally at the court. With both issues on the docket, we are hoping to hold a large event. For more information and to volunteer to help with the rally, Contact Diane Coleman at NDYCOLEMAN@aol.com

Our thanks to Diane Coleman for the Gonzales case summary.



NATIONAL CENTER FOR SPECIAL EDUCATION RESEARCH OPENS

The National Center for Special Education Research (NCSE) officially opened July 2005, marking the transfer of special education research activities from the Office of Special Education and Rehabilitative Services (OSERS) to the Institute of Education Sciences (IES). The Institute for Education Sciences supports a comprehensive research program to promote the highest quality and rigor in research on special education and related services, and to address the full range of issues facing children with disabilities, parents of children with disabilities, school personnel, and others.

For more information about IES activities visit: <http://www.ed.gov/about/offices/list/ies/ncser/index.html>.

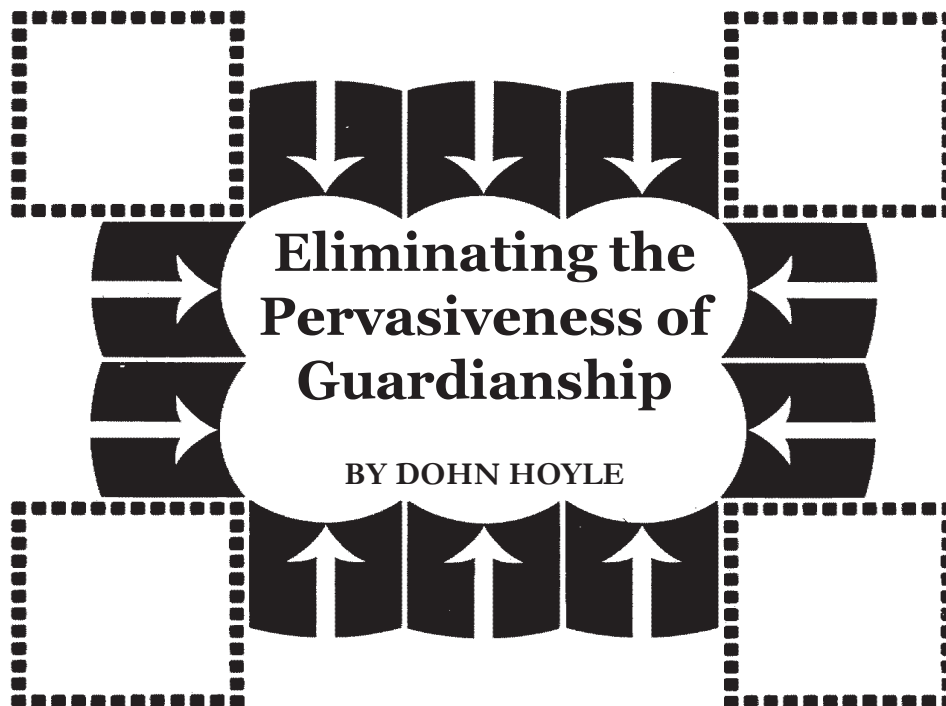
For information about this and other TASH Public Policy activities, contact Jamie Ruppmann, Director of Governmental Relations, at [jrppmann@tash.org](mailto:jruppmann@tash.org)



Consider joining TASHUpdate and keep abreast of current trends in disability research, policy and practice!

TASHUpdate is an internet discussion group that covers all aspects of progressive disability policy, practice and thought. It is a vehicle for seeing what others are doing, getting ideas and information, and bouncing your thoughts off of others who share your values and concerns.

To participate in TASHUpdate, send an email to TASHUpdate-subscribe@yahoo.com and follow the directions to subscribe.



Eliminating the Pervasiveness of Guardianship

BY DOHN HOYLE

The timing is right to change the current pervasiveness of guardianship. We have moved away from parents and professionals making decisions about placements for people with disabilities in homes, facilities, and day programs. The principles and practices of person-centered planning and self-determination give us the tools to support individuals with disabilities to have the lives they want in the community. This change bodes well for rethinking our reliance and benign attitude towards guardianship.¹ There is clearly a dichotomy between guardianship and self-determination or person-centered planning. As Kathy Harris points out in her article, *Making Guardianship Unnecessary*, "The imposition of guardianship is the total antithesis of self-determination principles."

Any close look at this topic leaves one convinced that a culture of guardianship currently exists. We have all heard people with disabilities who find it necessary to assert, "I'm my own guardian." Only people with disabilities, especially those with developmental disabilities, find it necessary to do so. Guardianship

permeates our field to such an extent that professionals, parents and people with disabilities assume everyone with a disability has a guardian -- some just happen to be their own guardian, unlike others who have a 3rd party as their guardian.

Reasons to be optimistic about changes in this regard include changes in our language and our practice. As we make these changes, the current overemphasis on guardianship cannot go unchanged. Supporting and accommodating individuals, rather than caring for them, changes how we view and deal with people with disabilities. Accommodating an individual's disability and assuring the supports they want and need to live, learn, work, play and participate in their community projects a different image -- an image incompatible with guardianship.

Congregating people and segregating them established a view and mentality, emphasizing differences and deficits. The power of including people with disabilities, based on the accommodations and supports they need as an individual, instead emphasizes the traits and qualities we all share, as well as the strengths and capacities of each person. As people with disabilities are

supported to live in their own places, contribute or enter the workforce through customized employment and truly participate in their own communities, guardianship will be seen as increasingly incongruent.

Running contrary to an optimistic view of the timing of this issue of TASH *Connections* are some very discordant items. The first of these has to do with the wholesale trampling of the due process rights of people with disabilities (as well as those who gain disabilities with age) when they are the subject of guardianship proceedings. Many persons are not even present in court as their rights are removed. It is near automatic in many places for the subjects of guardianship proceedings to be excluded from their own hearings.

Representation for those who are the subjects of guardianship petitions is weak, if present at all. If the court appoints an attorney, he or she typically has no background in disability, and does not wish to upset the court or take up much of the court's time. This is especially true if they would like subsequent appointments by the court. Judges and attorneys blur the role of guardian ad-litem and act in a very paternalistic manner. The brevity of hearings, usually only a few minutes, speaks volumes about the lack of due process and care with which guardians are appointed. Lady Justice, blindfolded and evenhandedly weighing evidence and individual rights, is clearly absent from most courtrooms during guardianship proceedings.

Some would argue that this problem should be addressed through legislative or legal action. I disagree. Many states have near model statutes on guardianship. Each calls for due process, most for limited or partial guardianship and some call for guardianship to be determined necessary. At least one goes so far as to require the finding of necessity on the record.

Despite good statutes and language, rights are ignored when it comes to practice in many courts. Due process apparently would take too much time and to what end.

¹Here, I make the assumption that we do not mean "guardian-centered planning" or "guardian-determination."

Eliminating the Pervasiveness of Guardianship

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The person would still have a disability. Sadly, necessity is seldom viewed in light of available, viable alternatives. Therefore, the overwhelming majority of petitions filed for guardianship result in the appointment of a third party as guardian for the individual with a disability (or the person who is aging).

One solution to the problem might be to slow down or stop entirely petitions to the courts. While this sounds simplistic on its face, it is anything but simple. It will require an education campaign -- a campaign aimed first at parents and family members and, subsequently, at professionals and others in the field. I am resigned to the fact that this will be a long term project. What makes it important, of course, are the lives of people with disabilities, most of whom will live well past their parents' lifetimes.

My experience is that, in most instances, parents' first instincts are correct. Upon first hearing about the subject of guardianship, parents are likely to ask "why?" or "why would I do that?" What follows, in an atmosphere of guardianship being the norm, is a barrage of information, including considerable misinformation. Well intentioned, if not particularly well informed, professionals begin pronouncements of mantras which they have heard, usually ending in a chorus of "you must do it," "you need to do it," and a list of horrible things which could occur "if you don't do it." The "it," of course, is seeking and obtaining guardianship for their adult or soon to be adult son or daughter.

What is most amazing about this relates to a question I was asked by another contributor to this publication, Joel Welber. His question was, "Don't parents realize they are permanently altering their relationship with their son or daughter? They are changing a two-party relationship to a three-party relationship, with the third party being the court." In effect, they are

inviting the government into their relationship with their child.

The question I think needs to be asked is, "who has the most power in that relationship?" Clearly, it is not the now powerless person with a disability. Nor is it the parent as guardian. That leaves the court, to whom the parent must report and must satisfy, and who has the authority, albeit infrequently exercised, to replace a parent with someone else as guardian of that parent's son or daughter.

Professionals wield amazing power to be able to convince parents to do such a thing. Clearly, one reason they are able to do so is a lack of information about or planning for the future. Prior to making a recommendation for such a drastic step, once which holds tremendous long term implications, one would hope professionals would help parents understand the consequences of such a step and carefully weigh their options in light of same. The short term involvement of professionals, when viewed in light of the lifetime commitment of parents, mitigates against true long term planning. It also means a lack of awareness of how current recommendations/actions will affect persons with disabilities and all aspects of their lives far into the future.

School professionals, for example, typically have little understanding of life for people with disabilities, and even less contact with them as they live some thirty to thirty five years beyond their parents' lifetimes. Yet, professionals blithely make the recommendation to seek guardianship without such understanding and without knowledge of the myriad of alternatives to guardianship which don't remove a person's rights. Making a recommendation for guardianship without either is inexcusable.

IDEA '04 (IDEA) mandates that a student learn of his/her rights and responsibilities one year before reaching the age of majority. One can expect that this will provide an opportunity for the relevant school personnel to recommend petitioning the courts for guardianship. Parents will be told and frightened into believing they will lose the ability to control their child's educational program and even to receive

information regarding their child unless they become their son or daughter's guardian.

This time could, and I believe should, be spent instead with the school and parents working collaboratively with the student towards such outcomes as self-determination, employment options, transitioning to post-secondary education alternatives, and the like. And, if necessary, preparing the alternatives to guardianship for the student for when he/she does reach the age of majority.

This is a change that will require specific education for both parents and the professionals who work with their son or daughter. Information on the various alternatives to guardianship and which are appropriate, if any, for a particular student, need to be provided to both audiences. Examples of the methodologies, instances of and experiences with each are especially useful. It is also important that parents and professionals see current possibilities and the outcomes we should now expect. Then it is possible to align the alternatives with a desirable future. This also makes it clear why unintended consequences of guardianship in the future are unacceptable.

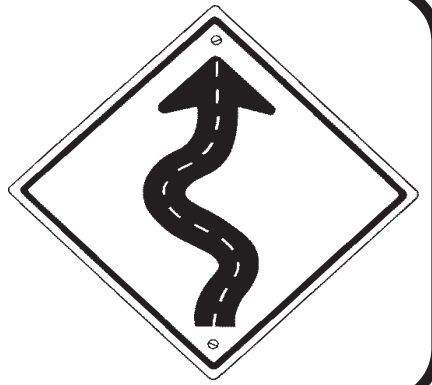
This challenge/opportunity is one which is about to be realized. Should we be able to mobilize in time, we will be able to prevent many needless petitions which will otherwise lead to many needless and possibly detrimental guardianships. We have no time to waste.

Guardianship is seldom, if ever, necessary. It is incongruent with what people with disabilities, regardless of severity, want and needlessly impinges upon individual rights as well as our obligation to honor a person's preferences. It represents an outmoded, outdated methodology and, in keeping with TASH's position on the subject, is contrary to TASH, and I would hope, your values.

Insert Dohn Hoyle's contact information

Guardianship and the Disability Rights Movement

BY DIANE COLEMAN and TOM NERNEY



Introduction

The disability rights movement has never been monolithic, but it has experienced an increasing consensus about the importance of limiting the legal authority granted to guardians, especially in life and death health care decision-making. Twenty-six national disability rights groups asked the courts not to allow Terri Schiavo's guardian to bring on her death. But the arguments advanced by the disability rights perspective were long dismissed by a burgeoning and now fully developed movement.

The self-determination movement is far ahead of courts, legislatures, media and society at large when it comes to the theory, importance and practical aspects of determining the preferences of people with significant intellectual disabilities. While many states have added due process protections to guardianship laws, and many have adopted reforms favoring guardianships limited to specific types of decisions rather than all decisions affecting a person's life, implementation of these reforms has been woefully inadequate.

Bioethics – The Single Greatest Threat

It can be argued that the convergence of the fields of ethics, medicine and law into a powerful field of bioethics represents the single greatest threat to the welfare of those with significant disabilities in this country. Under the rubric of utilitarian ethics and the language of rights, discrimination against people with disabilities has become enshrined in law and popular imagination. And this new right to die is

relentlessly moving to the duty to die. What was once hidden medical practice has moved to publication in prestigious journals and, finally and very quickly, into contemporary case law. Some milestones in this recent history are compelling.

In 1973 two doctors (Duff and Campbell, 1973) published an article in the *New England Journal of Medicine* advocating for the withdrawal of treatment from newborn infants with disabilities.¹ They argued that this was, in fact, now accepted practice and prevented a life of "suffering." There was some outrage expressed and even a congressional hearing but, by 1983, when the starvation death of the Indiana "Baby Doe" case reached the public, the issue had largely been settled within the medical community.

Both the Indiana case and the 1983 Oklahoma Children's Memorial Hospital case, where infants with spina bifida went untreated, produced extensive media coverage and, for the first time, introduced public discussions of the cost of life-long treatment for these children. The Oklahoma medical protocol (Gross, Cox, Tatyrek, Pollay & Barnes, 1983) specifically factored in the relative poverty of parents in the selection process for what was called a treatment protocol.² For the first time non-treatment became a form of treatment. Starvation and dehydration were soon to become painless, and persistent vegetative state as a medical description would soon enter the vocabulary as a way to depersonalize the individuals with disabilities.

In 1984, doctors at the Brown University Medical School (Walker, Feldman, Vohr & Oh, 1984) argued in *Pediatrics*, the journal of the American Academy of Pediatrics, that even though only 16% of premature babies born at very low birth weights in a study they conducted had significant life-long disabilities, all of the low birth weight children should not be treated.³

There were still some debates going on within this field of bioethics. Daniel Callahan, a pioneer in the field and once a voice for reason and compassion wrote in the Hastings Report in 1983 that the feeding of hungry or disabled individuals was "...the perfect symbol of the fact that human life is inescapably social and communal." (Callahan, 1983)⁴ Less than four years later, Callahan changed his mind under pressure and, in a review of his book, the American philosopher Sidney Hook took him to task for not going far enough. (Hook, 1988).⁵ Callahan had also proposed at this time that we consider certain aging individuals with disabilities as "biologically tenuous" in order to further advance the rationing of medical care.⁶

Is there now, given the severe fiscal constraints that all states are experiencing, especially in their Medicaid programs, an emerging "duty to die?" In the 1997 edition of the *Hastings Report*, John Hardwig wrote that that time had come. (Hardwig, 1997)⁷ In that article, he defended the former governor of Colorado, Richard Lamm, (who acerbically asked elderly people with disabilities to step aside and make way for the young) and explicitly called for our personal obligation to die should we become unable to care for ourselves. How close are we to witnessing this new duty to die by surrogate means? How many guardians would dutifully embrace their new responsibility?

Case History from Quinlan to Schiavo

Prior to the 1970's, the right to refuse treatment was not a major source of social concern. Unwanted medical treatment was not a big issue. After all, the federal government did not enter the health

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insurance field until 1965. There were court disputes over the right of an individual to refuse life-sustaining treatment, but these tended to focus on situations in which the individual had an additional basis for refusing treatment beyond that of privacy, such as religious convictions against certain types of medical intervention.

Beginning in the 1970's, several high profile court cases defined and expanded the right to refuse treatment. Five of the leading cases involved the right of a substitute decision maker to refuse life-sustaining treatment for a person deemed "incompetent."

The first of these involved Karen Quinlan, a New Jersey woman stated to be in a coma or persistent vegetative state. Ms. Quinlan's family sought to remove her ventilator. When the state Supreme Court granted them that right in 1973,⁸ it turned out that she could breathe without the ventilator. The family did not propose to remove her food and fluids, and she lived ten more years. To the best of the authors' knowledge, no segment of the disability community expressed opinions about this case through articles or friend-of-the-court (amicus) briefs.

Throughout the 1980's, courts found an individual's right to refuse treatment in several cases involving male quadriplegic ventilator users who demanded liberty from nursing homes or, in the alternative, death through "pulling the plug." Again and again, courts reviewed the legally relevant state interests – preserving life, preventing suicide, protecting third parties, and protecting the "integrity of the medical profession" – and found them insufficient to overcome the individual's so-called "right to die".⁹ Society was more ready to grant death than liberty from a nursing home. At this point, the disability rights group, ADAPT, began filing amicus briefs in these cases, finding that a choice

between a nursing home and death is no choice at all.

Against this backdrop, in the late 1980's, the Michael Martin case arose, in which a mother disputed a wife's decision to remove a feeding tube from a brain-injured man. The Michigan courts refused to substitute the mother as guardian, but would not allow the wife to withhold Mr. Martin's food and water.¹⁰ There was no unified disability community response to this case, but it was a subject in articles and conference presentations in the physical disability community.

In 1990, the U.S. Supreme Court issued its first and still only ruling on the substantive power of guardians to withhold life-sustaining treatment in the *Cruzan* case. The developmental disability community, notably The Arc, filed an amicus brief in the case, but the physical disability community did not. In this pivotal case, the highest court in the land found that providing food and fluids by tube is medical treatment, that "competent" individuals have a right to refuse treatment, that this right survives "incompetence" and may be exercised by a substitute decision-maker, and that a state may require "clear and convincing evidence" of an individual's wishes before allowing a guardian to withhold life-sustaining treatment.¹¹ The Court pointed out that a high evidentiary standard was appropriate because even a well meaning guardian may have conflicts of interest or other competing motives. The Court did not rule on whether a lower standard could be allowed if adopted by a state. While many states have, in fact, adopted lower standards, this crucial issue has not yet been revisited by the U.S. Supreme Court.

Several years later, the problem of non-voluntary and involuntary withdrawal of food and water moved onto the broader disability community's radar screen. Before Terri Schiavo, there was Robert Wendland in California. Both his wife and mother agreed that Mr. Wendland was not in a persistent vegetative state, and that he had not left clear and convincing evidence of his wishes. Nevertheless, his wife argued that she should be able to remove his tube

feeding anyway. A state statute, based on a national model health care decisions code, gave her the right to starve and dehydrate him, and forty-three bioethicists filed a friend of the court brief in agreement. Ten disability rights organizations filed against the general presumption that no one would want to live with his disabilities, being used to justify lowering constitutional protections of his life.¹² Ultimately, the California Supreme Court agreed with disability groups that his life could not be taken without clear and convincing evidence of his wishes.¹³

By the time the Schiavo case reached major national attention in 2003, twenty-six national disability organizations had taken a position that Terri Schiavo should receive food and water, due to the highly conflicting evidence of her wishes and the fact that she had not chosen her own guardian.¹⁴ Disability organizations were deeply disturbed to see court after court uphold questionable lower court rulings. This time, 55 bioethicists supported the removal of food and water. Disturbing, too, was that the court allowed most of Terri Schiavo's rehabilitation funds to be spent on her husband's lawyers, that she was denied a properly fitted wheelchair, a swallowing test, swallowing therapy, the potential for oral feeding, speech therapy, and the freedom to leave the hospice with her parents, even temporarily. Disability advocates were concerned that adult protective services did not intervene, and the state protection and advocacy agency tried, but proved powerless. It would appear that the prevalent prejudice that no one would want to live like Terri Schiavo translated into her guardian's unfettered right to treat her at best as a prisoner, at worst as though she was already dead.

It only takes common sense to recognize the potential for conflicts of interest in a guardian, even conflicts of which they may be unaware. A recent Alzheimer's study confirmed previous studies that caregivers have a lower opinion of their relative's quality of life with Alzheimer's than the individuals themselves have, and found an explanation for the discrepancy. It seems

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that the caregivers project their own feelings of the burden of care-giving onto the people for whom they provide care.¹⁵ And what of state guardians? In an ominous ruling, the Kentucky Supreme Court declared in 2004 that a public guardian may deprive life sustaining treatment from a man labeled “mentally retarded,” despite the financial conflict of interest for a state guardian of a ward on Medicaid.¹⁶

The growing disability consensus

While it is clear that most people, in and out of the disability movement, want to have the right to refuse unwanted medical treatment, the alliance of developmental and physical disability groups and their consensus around the *Wendland* and *Schiavo* cases demonstrates a growing concern about non-voluntary and outright involuntary medical killing through withholding of treatment, even food and water. People with disabilities and allies are feeling the pressures toward death from several directions.

First, increasingly throughout the last decade or more (since the fiscal incentives of managed care overtook the health care system), people with disabilities and medical treatment consumers in general experience the need to be knowledgeable advocates to ensure proper health care is provided. Second, while the Patient Self-Determination Act of 1991 purported to help people effectuate their right to make their own health care decisions, whenever people with disabilities are admitted to a facility, the boilerplate forms they are given are not balanced and objective, but exclusively oriented toward refusal of treatment. The community is full of anecdotes of people with disabilities pressured by social workers to sign do-not-resuscitate orders.

One of the leaders of the end-of-life care movement, Dr. Ira Byock, was interviewed

by *Ragged Edge Magazine*, a leading disability rights publication.¹⁷ He stated that Partnership for Caring and Last Acts, national leaders in the movement until they disappeared under a cloud late last year, had excluded the disability perspective, and that this exclusion was “deliberate and irresponsible.” What’s especially disturbing is that they had fifteen years and hundreds of millions of dollars in funding from prominent foundations, and set up surrogate decision-making protocols to end the lives of people with intellectual disabilities, without seeking the input of such individuals and the established organizations that address issues of self-determination for people who have less typical ways of receiving, processing and communicating information.

Barriers to consensus

A commonly stated reason within the disability community for hesitation or refusal to join the campaign to save Terri Schiavo was the problem of association with religious, pro-life and right-wing advocates. While disability advocates were covered in over 100 national and local television news broadcasts and talk shows on Schiavo, that was a mere drop in the proverbial bucket of Schiavo coverage overall.

When we analyze why the pro-life and religious advocates received such disproportionate attention, one factor is that disability advocates did not have the financial or personnel resources to carry out a large, prolonged vigil in Florida. But long before the last few weeks of Terri Schiavo’s life, the disability perspective was ignored. For the last three decades, certain bioethicists have told the press and the public that euthanasia is about compassionate progressives versus the religious right. Concerned disability groups don’t fit the long-settled script and so disability advocates have been marginalized or ignored entirely.

It is a long-term fight for disability advocates to be heard through the barrier of the established script. The organizations that supported Terri Schiavo’s right to food and water held their position as one consistent

with disability rights, and not necessarily identified with either the right or the left. In fact, advocates worked to hold policy-makers from both sides of the political aisle accountable. But so many reporters were suspicious that disability groups were secretly puppets of the right wing, that Not Dead Yet often added the following statement to Schiavo interviews: “The far right wants to kill us slowly and painfully by cutting the things we need to live, health care, public housing and transportation, etc. The far left wants to kill us quickly and call it compassion.”

Apart from the right-left tension, also known as “strange bedfellows,” there are some individuals with disabilities who substantively disagree with the positions taken by national disability advocacy organizations. Some view these positions as paternalistic and over-protective, contrary to the principles of self-determination. Some individuals with disabilities favor legalization of assisted suicide. Some object to identifying Terri Schiavo as a person with a disability.¹⁸ The disability rights movement is not sufficiently strong-spoken and recognized in the mainstream community to escape the neutralizing effect that a few individual dissenters can have on the message of groups representing millions.

In hindsight, the facts in the Schiavo case also suggest that an *Olmstead* challenge could have been raised. Using self-determination oriented, person-centered planning approaches, the claim could have been made that Terri Schiavo’s *Olmstead* rights were violated by her guardian when he incarcerated her in a hospice facility, rather than allowing her to receive long term care services at home with her mother and family. Her ability to live at home and her preference to be with her mother could have been tried in federal court under the Americans With Disabilities Act, using experts from the disability rights and self-determination movements.

Futility is proof that more unity is needed

Unfortunately, the anecdotal evidence suggests that Terri Schiavo’s case may be

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Guardianship and the Disability Rights Movement

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the tip of a very large and almost fully submerged iceberg. It appears that bioethics has pretty much dominated end-of-life care movement work in policy-making, imposing a "lifeboat" approach, deciding who gets thrown out.

In fact, if neither the patient nor guardian are willing to refuse life-sustaining treatment that the physician does not want to provide, futility policies have been developed through which doctors simply over-rule the patient or guardian. This is involuntary euthanasia. The AMA recommends procedurally based futility policies, which take the family through a series of steps, including ethics committee reviews, to persuade them that the doctor's decision not to treat is best.¹⁹ Increasingly, the only "good" decision is a "death" decision.

Conclusion

As we watch state Medicaid programs cut people and services, knowing that many disabled and non-disabled will die as a result, the importance of unity within the disability community has never been more clear. If we know that we are not better off dead, and we know that society is not better off without us, we had better say so very strongly. We must not only build our alliances within the movement, but reach out to other health care advocates and help them understand that our lives are not a waste of society's resources.

For these reasons the authors believe that it is long past time to create an emergency summit on these issues, raise dollars to advance a disability rights agenda and create several parallel strategies within academia, the media and our social and cultural organizations. There is no longer time to wait on the sidelines.

Diane Coleman is President of Not Dead Yet, a national grassroots disability rights organization opposing the legalization of assisted suicide and euthanasia.

Tom Nerney is Director of the Center for Self-Determination.

*Comments about this article may be sent to Ms. Coleman at
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Keynote Presenters



Peter Yarrow

Based on his passionate belief that music can be a particularly powerful organizing tool as well as a source of

inspiration for children, Peter has incorporated the music of Peter, Paul and Mary that inspired generations of activism since the 1960s, as well as a new song called, “Don’t Laugh at Me,” penned by Steve Seskin and Allen Shamblin, in his new venture. This song, with its arresting lyrics “Don’t laugh at me, don’t call me names; don’t get your pleasure from my pain,” could serve as an anthem for the growing movement to build safer and more respectful school environments for children.

Over the years, many issues have moved Peter to commit his time and talent, and his creative and organizational achievements have given Peter the wisdom and experience to address what he considers to



be perhaps his most meaningful undertaking to date: “Operation Respect: Don’t Laugh at Me.”

Kenny Miller

Life has not always been easy for Kenny, as is the case for many people



with disabilities. Kenny, who has the label of autism, has experienced verbal, physical, and mental abuse that most of us can’t even imagine. Despite those negative experiences, Kenny is the first to acknowledge that there have been many changes for the better over the years, due in a large part to others like Kenny who have spoken up and said “I’m a person, too.”

Now Kenny’s mission is to raise awareness that we all have abilities and disabilities. “The truth is people with disabilities would rather have you focus on their abilities rather than their disabilities.” Kenny has concentrated on his strengths as a speaker and a teacher to form his own consulting and training business. Kenny adds, “Sometimes people can’t see my abilities because they don’t have the ability to look over my disability. My job as a speaker is to give them that talent.” Kenny will share views and lessons on abilities, careers, and how to be successful in life.

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Keynote Presenters

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Mary Falvey

Mary will share her beliefs regarding "The evolution of inclusive education -- where we have been, where we are, and the critical actions that are needed to keep the momentum."

Mary bases this perspective upon her experiences and passion as an educator, advocate, parent and community activist. She is a long-time TASH member, Editorial Board Member of *Research and Practice for Persons with Severe Disabilities* (RPSD); Cal-TASH Chapter Officer, and a past International Board member of TASH.

Mary is the Director of Student Services in the Charter College of Education at California State University, Los Angeles (CSULA) where she is responsible for admission into credential programs, student teaching, and credential recommendations to the California Commission on Teacher Credentialing (CCTC). She coordinated the credential and masters programs in moderate/severe disabilities, as well as the masters program in Inclusion Facilitation at CSULA for 25 years. Mary has written, edited, and contributed chapters to over 14 books and has written four books of her own.

Her most recent effort, *Believe in My Child with Special Needs*, was published by Paul Brookes Publishing Co. in 2005.

One of the hallmarks of the TASH Conference is the incredible array of presenters from all around the world. Sessions are truly share shops, led by many of the leading TASH authors, researchers, family members, and individuals who are leading inclusive and self-directed lives. We have received close to 300 proposals that are in the final stages of review and scheduling. Watch the website for more information on sessions and speakers.

Breakout topics focus on issues across the lifespan and feature cutting-edge, practical information that you can put to use in your community.

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- ❖ Quality Education in Urban Settings
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- ❖ Alternate Assessment
- ❖ Empowerment through Assistive Technology
- ❖ Assisting Individuals to Develop Responsive, Functional Communication Systems
- ❖ IEPs that Foster Quality Inclusive Education
- ❖ Accessing the General Education Instruction
- ❖ Increasing Literacy Skills
- ❖ Peer Interactions and Developing Meaningful Friendships
- ❖ Positive Approaches to Behavior Change
- ❖ Inclusive Community Recreation & Leisure
- ❖ Related Service Provision in General Education Environments
- ❖ Roots of Inclusive Instruction for Individuals Labeled with Significant Disabilities
- ❖ The Tools of Self-Determination and Re-Affirmation of Community
- ❖ Supporting Individuals with Special Health Care Needs in Inclusive Settings
- ❖ Effective Practices in Personnel Preparation
- ❖ System Change Towards Whole School Reform and Access to the General Ed Curriculum for All
- ❖ Aging, End of Life Wishes, and the Grief Process
- ❖ Progressive Supports for Inclusive Community Living
- ❖ Eliminating Aversives, Restraints and Seclusion

- ❖ Post Secondary Education and Other Inclusive Options for Students in Transition
- ❖ Competitive Employment and Effective Workplace Supports
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- ❖ Community Wait List Initiatives
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As part of our 30th anniversary celebration, TASH is holding a

Silent AUCTION EVENT

WHEN: Friday, November 11
(auction items will be available for preview and bidding beginning Thursday, November 10)

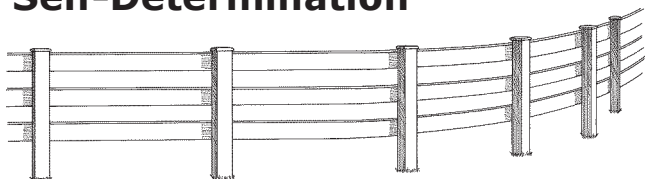
WHERE: Exhibition Hall, 2005 Annual TASH Conference

We had so much fun hosting our first ever silent auction in honor of our 25th anniversary, we've decided to hold another! We are collecting unique, one-of-a-kind gift items, sports memorabilia, artwork, apparel, jewelry, books, services, edibles, and lots more to auction off to the highest bidder! Proceeds from this event will support the TASH Conference Scholarship Fund, which assists parents and self-advocates to attend future TASH conferences.

Interested in donating an item for the Silent Auction? Please contact Priscilla Newton, Director of Marketing, at 410-828-8274, ext. 102 or send an e-mail to pnewton@tash.org



Guardianship is *Not* Self-Determination



by Kathy Harris

Guardianship is created so that one person can take over the decisions of another -- another who has been determined to be incapable of making decisions for him/her self. This imposition is the total antithesis of self-determination principles. Although some still see guardianship as having a benevolent purpose, we must:

[r]ecognize guardianship for what it really is: the most intrusive, non-interest serving, impersonal legal device known and available to us and, as such, one which minimizes personal autonomy and respect for the individual, has a high potential for doing harm and raises at best a questionable benefit/burden ratio. As such, it is a device to be studiously avoided.¹

Claude Pepper, U.S. Representative from Florida in the 70's, and a champion of the rights of older people, made the following statement in a study of guardianship conducted by the Pepper Commission:

"The typical ward has fewer rights than the typical convicted felon. They no longer receive money or pay their bills. They cannot marry or divorce ... It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception ... of the death penalty.²

Guardianship frequently removes constitutional rights of individuals. Over thirty states have statutes that deny the right to people under guardianship to marry or vote. The simplest of decisions that we all take for granted can be taken away from the individual and given to another under guardianship. This includes the right to decide where we want to live, what kind of work we may wish to pursue, where we'd

like to travel, how we'd like to spend our money, even who we want to spend our time with.

Some providers of services for individuals with labels of developmental disabilities have requested that families or friends seek court-

appointed guardianship because the providers believe it is a legal necessity. In fact, there is generally no legal requirement that if a person needs assistance with decision-making, that the person who acts as a surrogate decision-maker must be a legal guardian. Providers are often not familiar with alternatives, and thus do not promote the use of support circles, family consent policies, powers of attorneys, trusts, and other alternative surrogate decision-making devices.

Support circles which function through a person-centered process are an important key to avoiding guardianship. We all have friends, family and others who we call upon when we need help or advice when making life decisions. When we need to make decisions about health care, finances, or where to live, we ask knowledgeable people who make up our "support circle" to help us make these decisions. These people we call upon for help do not file to become our guardians, even though we may be incapable of making good decisions without their help.

Individuals with developmental disabilities need the same kind of support circles to help make decisions. This decision making process is essential to living the self-determined life we all enjoy. When called upon to write a "plan" for someone's life, we first must determine what the individuals themselves desire for their own lives. If individuals aren't able to communicate their desires for any reason, their family, friends, and others close to them can help to determine their wishes. They do this by using their knowledge about the individual and how they communicate. This includes their observations about the individual's behavior including facial expressions, gestures, and sounds that indicate their

preferences. In this way, the support circle can arrange medical treatment, help at the school IEP, or gain supports from community programs that will help the individual with a disability find a place to live or get a job.

There are cases in which individuals do not have family or friends in their lives to act as a support circle. This calls for creative development of ways to bring community members into these individuals' lives so that over time a support circle will develop, thus negating the need for guardianship.

When such a support system is in place, there is no need for a legal guardian to make decisions for the individual. In fact, imposing guardians on individuals could interfere with the support circle process. If there is a court-ordered guardian, there is a danger that one person may be allowed to impose their decisions on the individual without the benefit of knowing what the person desires, either directly or through the observations of the support circle.

Courts around the country have begun to recognize that outside supports for an individual may negate the need for guardianship. In Iowa, the Supreme Court there has stated, "In making a determination as to whether a guardianship should be established ... the court must consider the availability of third party assistance to meet a ... proposed ward's need for such necessities."³

The Pennsylvania Supreme Court stated, "Persons cannot be deemed incapacitated if their impairments are counter-balanced by friends, family or other support."⁴

And Tom Nerney, Executive Director of the Center for Self-Determination, has stated, "We have to reject the very idea of incompetence. We need to replace it with the idea of 'assisted competence.' This will include a range of supports that will enable individuals with cognitive disabilities to receive assistance in decision-making that will preserve their rights."⁵

Through self-determination, with the use of a person-centered planning process,

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Guardianship is *Not* Self-Determination

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guardianship can be avoided. This would be to the advantage of the individual, who retains his/her decision-making rights, and to the community that reaps the benefit of total inclusion of all of its citizens.

Those who followed the Terry Schiavo case in Florida this past year have found good reason for alarm about the direction of our society for people with intellectual disabilities. Most states now recognize that individuals have a "right" to determine their wishes through living wills and patient advocate forms, and can give directions about removing life-sustaining procedures.

What about people who have been determined "incompetent" by a court of law, thus unable to make such decisions for themselves? Such decision-making ability is given to guardians, who are charged with making decisions in the person's "best interests." Given that people who have been adjudicated "incompetent" have historically faced a loss of status, rights, and value, it has become acceptable to determine that death is preferable to living with a disability.

A change is needed to raise awareness of the value of people with disabilities as equal to those without disabilities. It is essential that the idea of making decisions in the "best interest" of individuals be replaced by families, friends, and those close to people with intellectual disabilities willing to go through the work of ascertaining the individual's preferences and dreams. Only in this way will people with disabilities attain true equality and overcome the enormous prejudice against them.

Other alternative methods to handle decision-making also may be useful. Most states have family consent statutes, or their health care providers have family consent policies. These statutes and policies allow family members or others who are close to the individual to make medical decisions in the event individuals cannot make the

decision for themselves. Providers of other kinds of services and supports also have such policies and recognize that there is no reason to have legal guardianship imposed as long as a family member or other close person is involved in the person's life and can arrange needed services. If your state does not have a family consent statute, or if providers are not aware that they may implement such policies, they need to be informed of this simple and effective alternative to guardianship. More often, the statutes or policies exist, but are not used.

Another device that may prove useful is the use of durable powers of attorney. These are documents that can be used by an individual to designate another person to discuss and make decisions about medical decisions, living situations, confidentiality issues and other areas of concern. In this way, family members or others who have always assisted the individual in making such decisions can continue to do so without filing a petition to become guardian. The power of attorney allows the individual to give that power to someone, and they can also take away that power if they become unhappy with the decisions being made.

When money is involved, there are other alternatives. If an individual is the recipient of public benefits and is unable to handle the funds, a representative payee can be appointed. This is someone who receives and disburses the money for the individual. If a parent wants to provide for their son or daughter with a disability after the parents' death, or if a substantial amount of money comes into an individual's life, amenities trusts, also known as special needs trusts, can be devised. These kinds of trusts appoint a trustee to handle the funds without interfering with the individual's Medicaid benefits. Additionally, such trusts can specify that someone visit the individual to assure they are satisfied with his/her living situation and support systems. This is more than the imposition of a guardian or conservator can do for an individual, and gives more peace of mind to parents who worry about what will happen to their son or daughter when they are gone. A

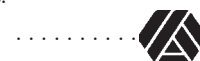
knowledgeable attorney should be consulted about these trust documents.

Educational programs about these kinds of alternatives need to be implemented for families, professionals and advocates. Putting an end to the systematic removal of rights and concomitant removal of protections for people with disabilities needs to be a priority. This means a different way of doing business. Those who care about an individual with a disability and those who make their living because of individuals with disabilities, have an obligation to discover what people like and don't like, what their desires and preferences are. We should employ the many alternatives which currently allow people to avoid guardianship altogether. Ultimately, we can use the framework of person-centered planning and self-determination to obtain the optimum choice making. We can assure individuals with disabilities, including those with cognitive disabilities and those who communicate using alternative methods, access to life, liberty and the pursuit of happiness. In so doing, we will have eliminated an unnecessary barrier to individuals' opportunity to seek their piece of the American dream.



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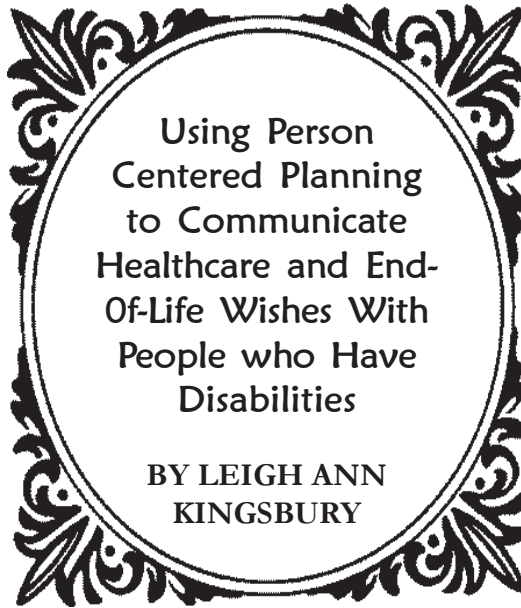


As more and more people with labels of developmental disabilities are welcomed into their communities and are living in communities of their choosing; as more and more people with disabilities are experiencing self-determination (or, at least attempts from the system to support the principles); and as more and more people with developmental disabilities are living to old age, the need to think about advance care planning, including wishes about extraordinary treatment, advance directives and health care powers of attorney increases.

Disability or no, Americans are not generally well-prepared to address end-of-life issues. It is a subject we avoid until a crisis hits. Nationally, it is estimated that at least 50% of people have not made their wishes known to someone else (personal communication, Ellen Cameron, MSW, Lower Cape Fear Hospice, April 2002). For people with labels of developmental disability (such as mental retardation), the assumption is that that figure is even higher.

This issue is not just about becoming critically or terminally ill, nor having a disability that compromises one's health. This is about being self-determined and planning for one's life ... from beginning to end. Self-determination should not start and stop at some mythical age. It does not stop when one gets old or when one is diagnosed with a potentially terminal illness. Self-determination ought to be about one's entire life.

"Person-centered planning has become the norm" (personal communication. Michael Smull, July, 2001). In many states, person-centered planning is legislated. If done well, we include in an individuals' person-centered plans their friends, families, paid and non-paid supporters, their hopes, dreams, fears, clinical concerns, support needs, and more. End-of-life wishes and plans ought to be an integral part of an individual's person-centered plan, too, especially if that person is very ill, aging or aged. Having a developmental disability is not a prerequisite. Good person-centered planning is equally effective with people



who have dementia or other acquired disabilities.

To be clear, this article is not about passive or active euthanasia. This is specifically about helping people communicate their wishes (advance care planning) should they be unable to do so at some point in their lives. Although we spend much of our lives figuring out "how to live," we rarely figure out what we want the end of our life to look like (assuming we have some measure of control over that at all).

In the field of developmental disabilities, we have championed person-centered planning as a means for people to convey what is important in their lives, the way they choose to live their lives and the supports needed to do so. We know that the core values of person-centered planning include autonomy for the person, attempting to honor his or her wishes while balancing health and safety, and supporting interdependence, companionship and relationships. In using person-centered planning to help someone communicate end-of-life wishes, those values do not change.

One of the many questions to be addressed, and certainly not to be answered entirely here, is "how do we remain ethical and mindful as we use person-centered planning to help someone communicate

end-of-life wishes, especially someone who is dying?" Botsford and Force (2000) have addressed this question to a certain degree: "Despite the fact that we each may have unique views about end-of-life, we need a core set of values to guide our decisions and actions in supporting people with intellectual disabilities ... (There are) four principles that are applied in bioethical dilemmas ... 1) respect for the autonomy of the person; 2) do no harm; 3) do what is good and; 4) justice."

As those who embrace the values and goals of person-centered planning, we should expect to apply those same principles if we were helping someone document and communicate his/her end-of-life wishes and/or if we were helping to support someone who was dying. Knowing this, and knowing that many people receiving supports and services already have a planning process in place in their lives, it makes sense to use person-centered planning to help people identify their healthcare or end-of-life wishes.

For example, whom the person would trust to make healthcare decisions for him/her if he/she were unable to do, whom the person would like to have present if he/she was dying, what kinds of treatment/intervention he/she wishes to have or not have, what type of religious or spiritual support he/she wants, etc. A word of caution: many people receiving supports and services do not have good, skilled or even adequate planning taking place. Adding a potentially tumultuous topic such as end-of-life to an already poor planning process is a bad idea.

When I first began this work I thought we really ought to be having these conversations with almost everyone. I have since learned and now believe that we need to be very, very careful—not just about the people we plan with, but equally with the systems that support those people.

For people who do not use words to communicate (people with the label "non-

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Using Person-Centered Planning to Communicate End-of-Life Wishes

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verbal”) and for people who use augmented communication devices, writing this information down ahead of time is crucial. Not using words to talk is not the same as not communicating or having nothing to say. Most of us know many people who communicate quite clearly with behavior and body language. Planning ahead and establishing an on-going conversation with the people in the person’s life who may be called upon to make an end-of-life decision should the person be unable, is a critical step. It may never be words from which we learn the information needed; but knowing someone well over time, how they communicate with their behavior and having that information up-to-date and written down may be exactly the information that decision makers will need.

I recently had the opportunity to be involved in planning with a woman who has significant intellectual disabilities and who is dying of incurable cancer. She has a legal guardian, and in the state she lives in that person will ultimately make her healthcare decisions. There have been a number of on-going conversations between her guardian and residential and vocational staff about how to support her best as she dies. In these conversations, policy issues within her service agency and cultural issues within her family have surfaced. Had these issues not been addressed ahead of time, they could have lead to a great deal of turmoil for her family and her agency at her death. Dealing with these issues ahead of time has allowed for clarification and planning. As one administrator person noted “we have had other people die in our program, but we have never communicated so well about it and talked about these issues before it happened. We feel much more prepared this time around.”

It is imperative that the person who is dying has his/her physician as an ally, in addition to other clinicians, family members and friends. Anyone who has had the

experience of trying to make end-of-life decisions at the eleventh hour knows that planning ahead of time is a much better alternative. Surrogate decision making may be challenging enough without the burden of not knowing someone’s clear wishes and having a means to support those wishes. Again, this article is not intended to answer all these questions, but rather open a dialogue for thinking about ways to address them.

Clearly, one of the issues that must be addressed on an individual basis is that of decision making and informed consent. One of the reasons to have the person’s physician or clinicians informed of and/or involved in future healthcare and end-of-life conversations is the issue of capacity and competency. Competency, as most of us know, is a legal term and judgment made by a court of law.

Often confused with competency however, is the issue of capacity. Capacity is a clinical term, based on criteria used to help determine if the person has the ability to make certain decisions. While we do not have the time nor space here to sort through that specific issue at length, it bears mentioning as we learn more about how people with disabilities wish to participate in advance care planning. The Gunderson Lutheran Respecting Choices Program on Advance Care Planning suggests there are four components to capacity.

1. The ability to understand that one has authority—that there is a choice to be made.
2. The ability to understand information (elements of informed consent).
3. The ability to communicate a decision and the reason for it.
4. The ability to make a decision which is consistent with one’s values and goals and which remains consistent over time.

Though not developed specifically for people with developmental or intellectual disabilities, the components may be one reasonable set of standards with which to

Self-determination applies to one’s whole life—and advance care planning, which can be accomplished as part of trusting and mindful person-centered planning, must be a part of the process.

begin the discussion. Furthermore, there is much additional literature on evaluating the capacity of individuals without mental retardation which can be used as a guideline for assessing “capability” for those with intellectual disabilities (Kingsbury, Reynolds and Wheeler, 2005). Overlaying that knowledge with the issues of advance care planning is one next logical step in this discussion. One of the challenges for people with intellectual disabilities is that medical professionals will question one’s capacity if it has not been clearly demonstrated ahead of time; and that questioning can lead to delayed decision making or decisions being made that are in conflict with the person’s wishes.

Additionally, holding conversations about end-of-life wishes with legal guardians is critical. For the many people who receive supports and services away from their family’s or guardian’s home, and especially people who have little or no family involvement in their lives, paid direct support professionals are likely to be providing the day-in and day-out support. Those professionals usually care deeply about the individual with disabilities. They may even describe their relationship as “we’re like family.” They may also have a very clear idea of what they believe the person’s wishes would be because they know the person well, or because they have actually engaged in that conversation with the person. If however, the legal guardian’s wishes differ from the person’s (assuming the person’s wishes are known), and if the guardian chooses to act on his/her wishes, direct care staff and others who know and love the person may be deeply saddened, angry and confused over the choices that are made.

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Using Person-Centered Planning to Communicate End-of-Life Wishes

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Several years ago I had the experience of providing support to a group of direct support professionals when someone they cared deeply for had died. Unbeknownst to them, the guardian made the decision to end nutrition and hydration. When the staff, who at that point were visiting the man in a nursing home, showed up and discovered this situation, they were flabbergasted. Some agreed with the decision; some did not. However, that was not the issue. They clearly had no decision making authority. Their only role at that point was to visit and provide companionship; but having supported the gentleman for many years, they loved him dearly and they just did not understand. They had no information. It is unfair to the person receiving supports and services and the people who support and love the person to not have end-of-life wishes conversations well before the time comes to act upon those wishes. Even if everyone intimately involved in the care and support of the person is not on the same page or does not hold the same beliefs, it is helpful for everyone to have a clear understanding of what to expect when the time comes.

This is not to imply by engaging in advance care planning that “when the time comes,” everything will go smoothly or that it will be “easy.” A dear friend died of brain cancer several years ago; it was a slow and devastating process in his and his family’s life. When he died, a little more than 3 years after his diagnosis, his wife said “no matter what I thought about ‘how ready’ we were ... we were not. I was absolutely not ready to lose my spouse ... and no amount of planning (which we did a lot of) would have made me any more ‘ready.’”

Advance care planning and communication of end-of-life wishes involves numerous parties: the person, the spouse, the family, the guardian, the provider, caregivers, friends, and medical professionals. We need to understand that end-of-life decision-making, like good person-centered

planning, is not an event but an on-going process, and there must be a series of conversations, ultimately leading to decisions, based on the person’s, family’s, guardian’s experiences, values and beliefs. Trying to have these conversations, and make decisions and plans when people are under extreme stress, when they are sad and frightened makes no sense. One of the keys to ensuring that this already-stressful-time is not made even tougher is good, on-going communication. One means of ensuring that communication is to recognize the person’s and family’s (or guardian’s) wishes in the individual’s person-centered plan.

In Washington D.C. this year, with generous support from the Quality Trust for Individuals with Disabilities, we have begun the Life Choice Planners Project (LCP). LCP was developed because of the need to address the aging and/or end-of-life issues that are facing a growing number of people with developmental and intellectual disabilities who currently receive services in the District. The project will use the core skills and tools of person-centered planning and coaching as established by the The Learning Community for Essential Lifestyle Planning as the foundation for planning. The project, will then layer over that foundation information about end-of-life issues.

In year one, we will develop a small cadre of facilitators who will receive hands-on support and mentoring to become skilled coaches around aging and/or end-of-life issues, including such topics as:

- how to balance what is important to a person, while also ensuring that what is important to plan for is addressed;
- the importance of daily, cultural, and spiritual, rituals;
- how to address issues of grief and bereavement;
- supporting people who have dementia, etc.

In addition, we have produced a how-to guide to help planners facilitate conversations with people about healthcare and end-of-life decisions. This manual will be available shortly for public use.

Because each end-of-life scenario is unique to the dying person, the coaches’ skills will be around good planning and access to resources, not specifics about diseases and terminal illness (though some of that learning will naturally occur). One of the issues that seems to matter a lot to agencies and staff is “what do we do once we know someone is dying”? We hope that through LCP we will develop a network of people who feel somewhat more at ease with this question and have a toolbox of skills and resources to coach the people who are actively supporting the individual who is dying.

Why should we help people who have developmental disabilities communicate end-of-life wishes? They have a right to be active participants in their healthcare, just as people without disability labels. People with disabilities, their spouses, loved ones, friends, family members, guardians, provider staff, and others need to know and understand what the options are. Physicians and other medical care providers need to have a greater understanding of the abilities of people with developmental disabilities and their right to be an active part of this planning process. Advance care planning should be a part of everyone’s life, whether or not one has a disability label.

Without communicating one’s wishes, loved ones are left to make decisions of which they are often unsure and which could be in conflict with what the individual would desire. Use of a person-centered planning process should not, and in many places cannot preclude the use of a specific form or process for one’s advance directives and the naming of one’s health care agent (durable power of attorney, healthcare proxy), but a thoughtfully considered person-centered plan can be the foundation for developing more formal directives.

The use of person-centered planning ought to support conversations around what is important to and important for the person; what matters in everyday life; what the person’s values are; what their hopes, dreams and fears are; what supports are

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If you haven't read Diane Coleman and Tom Nerney's article in this issue of *TASH Connections* (beginning on page 16), please make sure you do. It provides a factual context for this article. I struggled with putting these thoughts about Terri Schiavo and others in her situation, on paper. Some readers will be upset at me, but my intention is to get us to stop and think about our potential complicity in the promotion of a negative image of people with disabilities. And by "we" I mean me, too.

These questions I pose come from questioning my own motives for being a good advocate, and from recognizing the hypocrisy with which I practice. I think it is wise to declare my political tendency as a moderate-to-liberal Democrat, because many of the points I make in this article have been attributed to conservative Republicans. One thing I have learned as an advocate is that people of differing political beliefs share the same passion and vision regarding the rights of people with disabilities. This is not an article about partisan politics, nor should any of the issues I discuss be identified as such.

Over the span of three years I chaired a series of breakouts at TASH conferences that created discussion about our personal biases and how they can affect our credibility as advocates for people with disabilities. I use the term "advocates" broadly to include all who work towards upholding the civil rights of people with disabilities — people with disabilities themselves, family members, professionals, friends.

The first part of the discussion was about our presumptuous behavior of defining a quality of life for anyone other than ourselves. The image of what constitutes a "quality of life" differs for each of us, and often differs from what we project as a quality of life for a person with a disability. Our bias can become evident when we participate in planning (person centered or otherwise) for individuals who cannot speak for themselves. The professional vision of "quality of life," a terminology that has become part of our professional language as it pertains to consumers of services, may look very different from what



The Good Advocate: Thoughts on Theresa Schindler Schiavo

BY DONNA GILLES

we have for ourselves. It is a quality of life that we, as the good advocates prescribe, sign on to, support that becomes reality. And it may be that the reality we have helped to create is the same one we reject when making end-of-life decisions for ourselves and our loved ones. So, my question is, "What are we, the good advocates, really doing to support people with disabilities, who are vulnerable to the biased decisions of others, in creating lives that we would not reject for ourselves?"

Extending the idea of how our biases can affect our actions, my co-presenters and I generated discussion over the effect our language has on our actions as the good advocates. For years we have been on the soap box about using people-first language, language that doesn't demean, but shows respect for the person. But despite our use of people-first language and making every effort to use the "right" terminology to describe someone's state of being, we still show how we really feel about disability when speaking about our own choices in life -- and recently our choices in death.

I have heard the good advocate, a professional, say in front of a person with a disability that if she were to be pregnant with a child with that same condition, she would choose to abort. I have heard the good advocate, a self-advocate, proclaim that he would not want to live "like that" when talking about being in a "persistent

vegetative state." I have heard the good advocate, a parent, claim how it was for the best when a child with a disability died from health complications stemming from that disability.

With this kind of language and the painful message it sends to people with disabilities, we have a long way to go beyond the people-first issue. So my question is, "Why do we, the good advocates, spend a lot of time on ensuring that our family, friends, colleagues, and students use respectful language, only to turn around and send a message that life as a person with a significant disability is not acceptable?"

For years -- since our profession and our advocacy started in the early '70s -- we have denounced the imposition of medical professionals and the use of the medical model in educating students with disabilities and in supporting adults with disabilities in community settings. We have accused the medical professionals of over medicating, over emphasizing institutionalization, denying people with disabilities access to quality medical care because of an understanding that "if you can't fix it, quit." So my question is "How can we, the good advocates, after years of fighting the medical community, readily decide that medical ethicists and physicians are to be revered when making determinations on the kindest, most ethical way to cause a person with a significant disability to die?"

For years we have waited for an all-out Congressional debate and discussion over the civil rights of people with disabilities -- to have disability-related issues front and center. So why were we outraged when members of the Senate and the House of Representatives fought for Terri Schiavo's life? And why, knowing how to read between the lines as well as we do, did we not understand that if Congress truly cared about the life of a person with a disability and not just about pleasing a political faction, that they would have started the discussion a year earlier? Think about it. Is it out of the realm of possibility that our legislators waited until the final hour so that no legal action could have saved Terri

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Schiavo? Certainly supporters of both sides of the issue were appeased, one openly, the other subliminally.

Most of you know the legal aspects of the case: that there was an absence of an advance directive, that the judge weighed the testimony of witnesses on both sides, and decided that Terri would want to die. But living in Florida and listening to the issues surrounding Terri Schiavo's life and death, has been an education about where people with disabilities lie on the continuum of respect. The language was abominable. Terri had a few pet names adopted by the press, "Comatose Terri Schiavo," "brain-damaged woman," as well as others.

I attended a debate over the issue of whether Terri Schiavo's feeding tube should be removed. Yes, a debate – about whether a woman should live or die. It was a group of medical ethicists versus advocates from a variety of perspectives. One ethicist crudely described the condition of Terri's brain as if she already were the subject of an autopsy. He also said that removing her feeding tube was not the same as starving her to death. Obviously, he felt compelled to soften his statements to address the issue that we aren't allowed to starve our pets, and that in our country, people are not supposed to starve to death. (Note: this appeasement was also heard during the release of the autopsy report when the physician seemed satisfied that Terri died from dehydration and not starvation, as if dehydrating while you are starving is a bargain).

Terri's family was in the audience, some in tears. He then declared in a raised voice to the audience of several hundred people that they should not let the disability community make decisions for them. Several people with disabilities sitting in the front were shocked. One audience member finally asked, "How much does keeping her alive cost?", as if Terri had an

insidious type of bounty on her head. But I had heard these arguments before related to other people. What shocked me was the response of a State Senator's staff member to my couching of the issues as disability focused. Her response was, "But, ma'am, Terri Schiavo is not disabled, she is at the end of her life." In my naiveté, I was unprepared for that answer. I informed her that by ADA standards, she most certainly was disabled; and if her feeding tube is removed, she most certainly would be at the end of her life. So my question is, "What fuels the fear about having a disability as severe as Terri Schiavo's that has us believing that it is a fate worse than death?"

When I started my career as a teacher and TASH was in its infancy, the message was to always work under the assumption that all children can learn. In the early '90s, I was fortunate to attend a seminar by a prominent attorney who had written about and litigated extensively around the IDEA and its precursors. He described a case that he had just won about a child who was technologically dependent to stay alive (i.e., a breathing tube, etc.) and was in what we called a low biobehavioral state, and yet was ordered to be educated in a general education fourth grade (I believe) class, demonstrating that legally, the language that supports inclusion means "all."

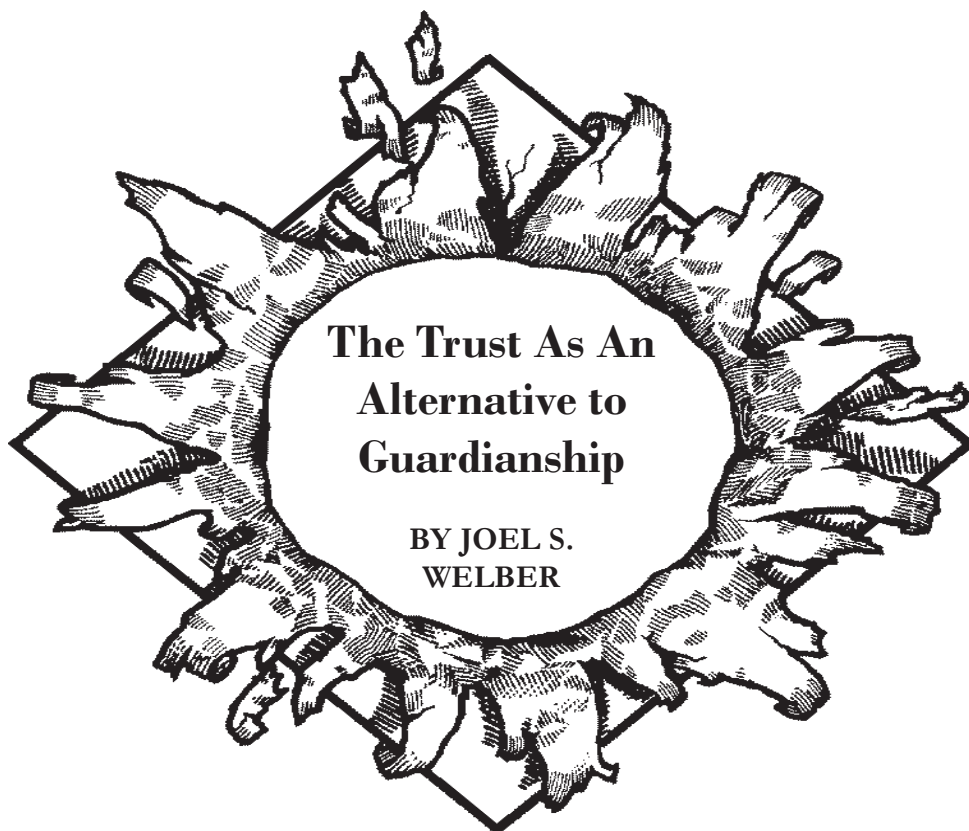
Prominent researchers in our field were studying how to make an educational impact on children who were in low biobehavioral states, funded by the US Department of Education. Technology that supports access to communication, academic instruction, and environmental control had already become more advanced than any of us believed could exist, and more advanced than many of us knew how to operate. We taught children and young adults who were fed and hydrated through tubes, and children and young adults who were cortically blind (the autopsy indicated that Terri was cortically blind). We would have taught Terri Schiavo had she been school age.

Today, there is research that indicates that "persistent vegetative state" may be misdiagnosed in some individuals, and that

there is a new category of "minimal conscious state" that better characterizes the condition in some people. It has been reported that doctors don't necessarily agree when diagnosing the same patient, and that one MRI is not enough. Today, we know a lot more about how to optimize what an individual with cortical blindness processes. We had the knowledge and the technology to help Terri Schiavo when she first had the stroke, and we certainly had it when she died. So, my final question is "At what point does our zeal for 'all means all,' 'all can learn,' 'equity, opportunity, and inclusion for people with disabilities' end, and the preservation of our personal visions of quality of life prevail at the expense of the very people we profess to value?"

I have not answered these questions of myself to my satisfaction, and neither will you. But if we as the good advocates – people with disabilities, families, professionals, friends — could go back to the basics and begin to think about the messages we send through our actions and our words, certainly it would be start.





The Trust As An Alternative to Guardianship

BY JOEL S. WELBER

General discussions of alternatives to guardianship do not usually focus on the trust as an important alternative. Trusts are properly seen as estate planning devices for parents who have children with disabilities. Trusts also are commonly used as a device to shelter assets that are otherwise disqualifying for Medicaid if owned by the person with a disability. The following information expands upon these ideas and illustrates why trusts can also be seen as an alternative to guardianship for people with disabilities.

Introduction to Trusts

Many members of the community of people with disabilities are familiar with trusts. Over the past three decades, trusts have emerged as a common, widely accepted estate-planning device for families that have children with disabilities. Trusts enable parents, for example, to leave money for children who are Medicaid eligible. The "third party trust" (parent for child) can provide a source for the purchase of amenities without affecting the children's ongoing eligibility for either SSI or Medicaid. Medicaid does not consider the trust as a countable asset, and properly

structured distributions from the trust are not countable income.¹

In some cases, trusts are created to conform to the provisions of OBRA93 (Omnibus Budget Reconciliation Act).² These trusts are designed to move otherwise countable assets belonging to a person with a disability under federal law, into a trust that is not countable as a current asset and to permit distributions for amenities that are also not countable as unearned income. The OBRA 93 trust is used to shelter the Medicaid recipient's own assets, not as an estate-planning device for his or her parents. Such trusts are often necessary to protect ongoing eligibility, for example when an otherwise eligible individual receives an inheritance or personal injury settlement that results in a lump sum distribution of countable assets that are disqualifying for Medicaid.

Most OBRA 93 trusts are what is known as Exception A trusts, and contain a provision that upon the death of the Medicaid recipient (beneficiary), any remaining trust assets will "pay back" any state that has provided medical assistance (Medicaid) to that person during his or her lifetime. The

trade off is that the Medicaid recipient enjoys the use of the assets and income that those assets generate during his or her lifetime, and the state receives the remainder interest of the trust following death in order to get paid back for the benefits received.

Introduction to Guardianship

Generally, the purpose for the creation of a guardianship is to identify and empower a person to make decisions on behalf of another person. The guardian is a surrogate decision-maker, acting on behalf of a ward. In Michigan, if the person for whom a guardian is appointed is a person with developmental disabilities, the guardianship is created by a Probate Court under the authority of the Mental Health Code.

Guardians can be invested with the broadest of powers that can include medical decision making, authority to decide residence, complete control over finances, and virtually any other decision that a person without a guardian can make on his or her own. Courts can also limit a guardian's powers and can reserve certain decision-making authority to the person with a disability in a partial guardianship.

Schools, mental-health bureaucracies, some hospitals, and other institutional providers are comfortable working with guardians; often moreso than in working directly with the individual. The existence of a guardian's Letters of Authority is a license to speak with the guardian about the person with a disability, and allows the institution to by-pass the person with a disability in the decision making process. While the institution may see this process as more "efficient" and substantive than one that requires a decision or consent from a person with disabilities, advocates clearly understand that guardianships are not tools created for the convenience of institutions.

The history of the use of guardianships for people with disabilities suggests that substantial numbers of guardianships have been created without a demonstration of

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the need for surrogate decision making and certainly without the exploration of suitable alternatives to guardianship. Many parents approach probate courts and request guardianships for their child merely as a function of the child attaining the age of majority. Often these parents are completely unaware of the existence of alternatives to this course of action. Those parents who are made aware of alternatives often pursue alternatives instead of creating guardianships.

The Trust as an Alternative to Guardianship

A trust requires three parties: the Grantor or Settlor who creates the trust, the Trustee who manages the assets held in trust and the Beneficiary, who receives the beneficial use of the trust assets. In an estate plan, the parents are the Grantors and Trustees during their lifetimes. Most of the time, they are also the beneficiaries while either of them is living.

Following the death of the parents, a Successor Trustee who is named in the trust instrument takes over the management of the trust assets. At this time, a separate share or sub-trust is funded for the benefit of the person with disabilities who becomes the beneficiary of that trust. In other words, if a child has disabilities, the parents' estate plan provides that the child's inheritance is put into the hands of a trustee, rather than delivered to the child outright and free of trust.

The role of the trustee is to manage the assets entrusted to it and to make expenditures for the beneficiary consistent with the terms of the trust. Such expenditures are generally in the form of amenities to enhance the quality of the beneficiary's life, rather than to provide basic support such as food and shelter. There is ample literature on what types of expenditures are permissible from a trust created by a beneficiary's parents. This trust is called a "third party trust" in Medicaid parlance.

The trust serves as an alternative to guardianship for at least three reasons.

1. Ownership of the assets in trust alleviates any need for a Guardianship of the Estate of a person with developmental disabilities.

The trust provides a built-in benefit of placing the management of assets into the hands of a trustee and removing the assets from the estate of beneficiary. Because the beneficiary does not have to manage trust assets, there is no need for any type of judicial intervention to create a guardianship of the estate with respect to these assets.

In cases where no trust is created in the estate plan of the parents (usually as a result of serious oversight), the child with disabilities receives an outright distribution as a devisee (i.e. a person who receives a gift of real property under a will) under a Last Will and Testament. In these cases, one "solution" to the almost certain Medicaid disqualification that results from the inheritance is to create an OBRA 93 trust, with Medicaid payback provisions. Such a trust will create Medicaid eligibility but only upon the beneficiary's death. States' will receive "pay back" for Medicaid payments issued to the deceased beneficiary during his/her lifetime.

Where no OBRA trust is created, there is a loss of Medicaid. Sometimes, this loss may be tolerable if the inheritance is large. However, under even these particular circumstances, there will almost always be a strong inclination on the part of other family members to seek some "protection" of the assets through judicial intervention.

This means that family members or somebody in the community that provides support is likely to seek the appointment of a conservator for a person deemed "legally incapacitated" or a guardian for a person with developmental disabilities. Under either circumstance, whether there is an OBRA 93, Exception A trust or whether there is a guardianship of the estate approved by the Probate Court, the parents failure to properly plan the inheritance produces a result that is less than optimal.

2. The income that the trust assets generate is managed by the trustee, and is only distributed in conformance with the instructions contained in the trust document.

Once the trustee holds assets, the law requires that they be invested under a standard of prudence. The invested assets should produce income, and the income is expended for the benefit of the beneficiary. The trustee is given discretion as to the specific types of expenditures that the trust will make. As noted, these expenditures will ideally improve the quality of life of the beneficiary. The beneficiary is permitted, to the extent possible, to participate in decisions about expenditures. Trust beneficiaries can request distributions; they may not be able to demand distributions under "third party or OBRA 93 trusts," but they can make their requests to the trustee.

In general, these distributions are made without prior court approval and without subsequent court accountings. The relationship between the trustee and beneficiary is private, subject only to periodic possible review by the State Medicaid Agency in the administration of the Medicaid program. Assuming that the trust qualifies as a third party trust or an OBRA 93 trust, and assuming that the expenditures are consistent with the instructions in the trust, this review merely confirms that the beneficiary's eligibility is not affected by the trust or expenditures from it.

The on-going relationship between the trustee and the beneficiary affords each the opportunity to get to know and appreciate the other. Whether the trustee is a bank, a financial services company, or a relative, the trustee can and should solicit input from the beneficiary concerning expenditures. The trust will insulate the assets from third party exploitation and will, at the same time, permit the beneficiary to express his or her own wants and needs in the requests for distribution. There is no part of this relationship that requires judicial involvement.

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3. Often the trust is the only investment that the beneficiary has access to, albeit at the discretion of the trustee. In addition, the only other income that most beneficiaries have is from Social Security. This income is used to pay for food and shelter and is often handled by a Representative Payee. Again, no guardianship is required to handle any portion of the estate of the beneficiary of the trust.

One thing that many people with disabilities have in common is that they live at or below the poverty level. During the adult lifetime, a person with a disability who is eligible for Medicaid will not own non-exempt assets that exceed \$2,000 in value.³ Also, the individual's income is very limited; in many cases he/she receives SSI or SSDI and perhaps some small wages. This income is almost always consumed monthly on ordinary living expenses.

As a result of these factors, there usually is no "estate" that the person with disability has that would require the protection of a guardianship. It is a somewhat moot point with respect to the protection of assets. The inheritance in trust does not change this picture at all. Certainly, the trust can and should be used to raise the standard of living and enhance the overall quality of life of the beneficiary, but because the trust will necessarily involve a trustee, there is no need to seek court supervision over the management of the assets.

In effect, the trust serves as a suitable and private alternative to guardianship once it is funded and providing enhancements to the beneficiary. To expand upon this point further, a well-drafted trust will contain provisions that instruct or even require the trustee to monitor the well being of the beneficiary, and to periodically assess his or her needs. The trustee may choose to do the assessment personally, or may hire a third party such as a social worker to visit with the beneficiary and to report to the trustee concerning the beneficiary's "condition" and needs.

Some attorneys recommend that parents name siblings or other close relatives to serve as advisors to the trustee. The advisor provides monitoring services to the trustee and advocacy for the beneficiary. Many parents want to assure that siblings can participate in the decision making processes attendant to the person with a disability that will occur following the parents' deaths.

However, parents are sometimes leery about entrusting siblings with the management of the beneficiary's inheritance. As a general rule, trust estates should be professionally managed unless the entire estate is so small that the trustee advises that professional management does not make financial sense for either party. Most trust officers have the integrity required to make such an observation. At that point, siblings may be the only or best alternative to a corporate fiduciary.

Whether or not an advisor is named in the trust document, the trustee will need to monitor the beneficiary's needs and will employ such persons as are required to do so. Again, the point is that no guardianship is required to permit this to happen; it occurs naturally as a function of the relationship between a trustee and beneficiary.

Insert Joel Welber's contact information

¹ Program Eligibility Manual (PEM) 401

² 42 USC 1396p(d)(4)(A)

³ PEM 400, at 4



Using Person-Centered Planning to Communicate End-of-Life Wishes

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needed for the person to have a meaningful and quality life on their terms; and how all of those elements can be supported and honored as the person ages, acquires a disability and/or is dying. Self-determination applies to one's whole life -- and advance care planning, which can be accomplished as part of trusting and mindful person-centered planning, must be a part of the process.

Leigh Ann Kingsbury, MPA, is a Gerontologist with InLeadS (Innovations in Leadership and Support) in Wilmington, N.C.

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