

Disability Issues

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Nancy Schock

Photo courtesy of University of Rhode Island

Tribute to Nancy Schock, 'Founding Mother' of Disability Issues

By Raymond E. Glazier

The disability community, indeed the world at large, lost a vibrant, compassionate, quietly powerful voice with the August 9th passing of Nancy Carpenter Schock. Nancy was the 'Founding Mother' of *Disability Issues*, and she was the dedicated mother of five children, two of whom had significant disabilities – a daughter with severe hearing loss and a son with Duchenne muscular dystrophy. Being a mom to these two children was the catalyst for Nancy to embark on an advocacy career, through which the lucky among us came to know her.

Nancy was teacher, author, administrator, dear friend, and mentor to many. In 1977 she founded the Boston-based **Information Center for Individuals with Disabilities**, which organized in a single location disparate pieces of

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Building Bridges to Employment Opportunity: The Working Partners Program

By Tim Sullivan

Barriers to employment for persons with disabilities are significant with current unemployment rates over 50% higher for those with a disability, according to the US Department of Labor. A new partnership between the Spaulding Rehabilitation Network (SRN) and Massachusetts Rehabilitation Commission (MRC) called **Working Partners**, is a first of its kind public-private partnership to create pathways for person's with disabilities to job placements. The program focuses on vocational rehabilitation to return patients and consumers to work while encouraging economic self-sufficiency and improving their quality of life.

"At Spaulding, we focus on preparing the person for life post-injury as well as how they can return to be contributors to our society," said Colleen Moran, Project Manager for Spaulding and the Working Partners Program. "By aligning our decades of experience in return to work with the resources of MRC we have truly created a model for person's with disabilities to receive the type of training to find the right job."



Colleen Moran, Project Manager for Spaulding Rehabilitation Network and the Working Partners Program. *Photo courtesy of Spaulding Rehabilitation Network*

The Working Partners program welcomes both local community members and patients from Spaulding. An MRC employment specialist works side by side with qualified



L-R: Dan Craven and Doug Palmer.

Photo courtesy of Spaulding Rehabilitation Network

candidates and potential managers in navigating state and local resources, with the ultimate goal of placement into vacant positions within Spaulding as well as other businesses. With the expected growth in healthcare jobs in the coming years, the chance to establish experience as a healthcare professional can create lifelong career opportunities.

One of the Program's first success stories is Doug Palmer, a unit service aide at Spaulding Hospital Cambridge. Several years ago, Doug suffered a traumatic brain injury in a skiing accident.

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Building Bridges to Employment Opportunity

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After two courses of rehab, he started working in hospital-ty, but it was not a good solution for the long term.

“At the end of the day we all want to feel we made a contribution that matters.”

— Colleen Moran

Doug. “Each day I get to contribute as part of the team. Just today I was able to help a patient who seemed down at first and when I left she had a smile on her face.”

Doug stocks supplies, assists patients with meals, delivers specimens to the lab, picks up blood products and is first responder to patient’s call bells. Doug brings to his role a deep capacity for compassion, based partly on his customer service background and his own experience

Through MRC and the Working Partners program, Doug learned about a new position opening up at Spaulding and applied. “Health care is a good fit for me,” says

as a patient, that helps patients and families deal with stressful events.

“Working Partners has given me purpose and hope for a better future,” Doug says. “At certain points in life you assess what you have done. This job helps with my need to make a contribution.”

Moran provided a succinct view of the program and the opportunities it creates. “At the end of the day we all want to feel we made a contribution that matters. It’s been so rewarding to work in this program not only to see the sense of pride we instill in our clients but to also see the employer who gains a valuable team member. It’s the classic win-win.”

For more information, including how you can become involved with the Working Partners Program contact:

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Tim Sullivan is Director of Communications, Partners Continuing Care & The Spaulding Rehabilitation Network

Tribute to Nancy Schock

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information on the many types of disabilities and every aspect of life with a disability, in a carefully crafted categorization system.

The Information Center was an analog ‘disability Internet’ long before the Internet or personal computers to search it even existed. Voluminous folders of hard copy documents were housed in metal file cabinets, along with summarizing information briefs on cross-disability topics ranging from the practical ‘How to get a Handicap or Disabled Veteran license plate’ to fun things like ‘How to get discount live theater tickets’. Under Nancy’s capable management, and with funding from the Mass. Rehab Commission, the Information Center staff of employees and volunteers, most of whom had disabilities themselves, fielded hundreds of toll-free telephone calls each week from persons new to disability life, as well as their concerned family members and friends.

The Information Center staff often functioned as peer counselors, helping callers refine or expand upon their original inquiry. Nancy trained the

staff to read between the lines and listen for the real concern of each caller. In fact, one of the Information Center’s unique roles was as incubator for the aspirations and ambitions of young staff members with disabilities. For many staff members, their Center employment was an introduction or a re-entry into the world of work. Nancy nurtured each volunteer, each employee. One such person was the late, very talented Paul Kahn, under whose editorship the Information Center’s irregularly published *Together* newsletter evolved into the *Disability Issues* quarterly newsletter. Those of us who met Nancy Schock in

**We’ll always love you, Nancy,
just as you loved us.**

those days knew her as a gentle but strong advocate for all persons with disabilities - determined, fearless, and kind. Most of us never knew her as the young war widow and solo parent in the late 1940s, who went to Columbia Teachers College for a Master’s degree that led to teaching positions at the Universities of Cincinnati, Kentucky, and Rhode Island. The University of Rhode Island was her alma mater,

and it was there, as head of the University’s Women’s Physical Education Department, that Nancy met her husband of over 60 years, Charlie Schock, who survives her, along with her five children, nine grandchildren, and seven great grandchildren.

Nor did we know Nancy as the star athlete who earned six varsity letters in field hockey and basketball as an undergraduate, all the while maintaining academic honors and campus leadership positions. In recognition of her standout career, Nancy was inducted into the University of Rhode Island’s Athletic Hall of Fame in 1991. In 2002, Nancy Schock received an Honorary Doctor of Humane Letters from the University of Rhode Island in recognition of the services she provided to persons with disabilities and to the University. We’ll always love you, Nancy, just as you loved us.

Raymond E. Glazier, Ph.D., formerly of Abt Associates Inc. in Cambridge, is an SSDI beneficiary who returned to full-time employment in order to support himself and his family; now semi-retired, he is founder and Principal of disAbility Research Associates, LLC of Belmont, MA.

Disability Issues is a publication of Spaulding Rehabilitation Network, a member of Partners HealthCare. The Spaulding Rehabilitation Network includes Spaulding Rehabilitation Hospital. Its main campus located in Boston, as well as Spaulding Rehabilitation Hospital Cape Cod, two long term care facilities Spaulding Hospital Cambridge and Spaulding Hospital North Shore and two skilled nursing facilities, as well as twenty three outpatient sites throughout Eastern Massachusetts. Spaulding is a teaching hospital of Harvard Medical School and the official rehabilitation hospital of the New England Patriots. Spaulding is the only rehabilitation hospital in New England continually ranked since 1995 by *U.S. News and World Report* in its Best Hospitals survey with a #5 ranking in 2011. For more information, visit www.spauldingnetwork.org.

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From the Editor

Dear Readers,

With the upcoming election, the country is buzzing with an endless stream of news reports and commercials. In this issue, we bring you provocative articles, informative resources, and live events focusing on some of the ballot initiative questions. Along with voting for our national President, State Senator and other local officials, these ballot questions will have direct impact on the lives of Massachusetts's residents.

As U.S. citizens, we have the privilege to cast our vote and choose our elected officials. With this privilege, also comes the responsibility to go beyond the sound bites we hear in commercials, and learn about the policies and programs that the candidates support. According to the U.S. Department of Labor, 54 million adults in the U.S. report having a disability, which represents 20% of the U.S. population. We are a huge demographic! If we all go to the polls, we would be a key demographic that the candidates would be compelled to pay attention to and support more actively. Your voice matters! Let it be heard on November 6th.

Along with our election season, October is **National Disability Employment Awareness Month**. We bring you an article about the Working Partners program, which is a model for this year's theme, "**A Strong Workforce is an Inclusive Workforce: What Can YOU Do?**" The program's partnership between MRC and Spaulding show what's possible when a public-private partnership is created with mutual commitment to developing employees with disabilities as a contributing, valuable, and integral part of the workforce.

It's with great sadness that we share the news that Nancy Schock, our "Founding Mother" of *Disability Issues* passed away in August. I never had the pleasure of meeting this remarkable woman so I, along with many of our readers, am learning about Nancy as mother, advocate, friend, teacher and mentor to the disability community through this beautiful and heartfelt tribute.

Marianne DiBlasi, Editor

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Call (617) 349-5718/voice or
send an email to cmmoran@partners.org

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www.workwithoutlimits.org/DisabilityIssues

Having “Second Thoughts” about Assisted Suicide

By John B. Kelly



John B. Kelly
Photo courtesy of
Mark Ostow

Question 2, which would legalize assisted suicide in Massachusetts, may sound good at first, what with all the proponents' talk about "autonomy" and "independence." After all, these are powerful words in the disability community, which has fought for over a generation for independent community living. But a closer look at this bill shows plenty of danger. We take the name of our disability rights group, Second Thoughts, from the fact that

the more people hear about this flawed bill, the more likely they are to have "second thoughts."

The so-called "Death with Dignity Act" is modeled on laws in the two states - Oregon and Washington - that have legalized assisted suicide. The law would authorize doctors to write prescriptions for a lethal dose of barbiturates for people medically judged to be "terminally ill," defined as having less than six months to live. But as disabled people know, terminal diagnoses are famously inaccurate: people outlive their terminal diagnoses by years or even decades. Second Thoughts member, John Norton, testified at the Statehouse in March that if assisted suicide had been legal when he received a terminal diagnosis at age 19, he would have used it. Now John works to save people from the fate he avoided 55 years ago.

Misdiagnosis, forever an impediment to effective medicine, would likewise cause unnecessary deaths. Last October, Oregonian Jeanette Hall's letter to the Boston Globe detailed her vote for legalization and request for assisted suicide after her own terminal diagnosis. "I didn't want to suffer," she wrote. But her doctor persuaded her to try more treatment, and now - 11 years later! - she urges us to avoid her mistake.

In 2011, exactly 1 out of 71 Oregonians seeking assisted suicide were referred for psychiatric evaluation. With the total 14-year referral rate below 7%, people are not being adequately evaluated. Michael Freeland, who had a 43-year history of depression and suicide attempts, easily got a lethal prescription, and it was only because he mistakenly called an opposition group that he was spared suicide. He also outlived his terminal diagnosis.

Disabled people constantly hear how expensive we are, how money could be better spent elsewhere. In Oregon, Barbara Wagner and Randy Stroup received letters from Oregon Medicaid denying them chemotherapy for their cancer. The letters did inform them, however, that the state would cover the \$100 cost of assisted suicide. Because assisted

suicide will always be the cheapest treatment, its availability will inevitably affect medical decision-making. In a system constantly under pressure to cut costs, choice will be constrained.

Kate had originally requested the option of suicide "in case she was in bad pain or if the indignities of losing control of her bodily functions became unbearable." One day, after her colostomy bag leaked, she decided to die on the spot, but then changed her mind. Finally, the afternoon she returned after being sent to a nursing home for a week, she suggested she take the pills. Her family facilitated her suicide immediately. Perhaps with the underlying social factors addressed - adequate home care, a less burdened family, and the social acceptance of incontinence, Kate would have made a different decision.

Amazingly, the Massachusetts initiative allows one of the two required witnesses at a request to be an heir. Financial advantage has always been a strong motivator for foul play, and because the law requires no witnesses at the time of death, there is no way to know whether or not suicides are voluntary. Death certificates must list the cause of death as the underlying disease rather than suicide.

Finally, that word "dignity" in the act title signals that assisted suicide is not about preventing pain and suffering during the actual dying process, but about escaping the perceived quality-of-life beforehand. People's concerns listed by prescribing doctors are almost exclusively social: people seek assisted suicide because of limitations on activities, incontinence, feeling like a burden, and perceived loss of dignity.

We disabled people know that our dignity does not depend on performing our own self-care or being continent every hour of every day. We know that there are social supports such as home care and PCAs that can remove any family burden, and we understand that our dignity is just fine thank you, without having to die to get it.

John Kelly is a long time Boston-based disability rights activist and writer. He is the Director of Second Thoughts: People with Disabilities Opposing the Legalization of Assisted Suicide, a ballot committee organized to oppose Ballot Question 2. His work on end-of-life issues has been featured in the Boston Globe, local TV and CNN International. He is past chair of the Boston Commission for Persons with Disabilities. In recognition of his years of advocacy regarding streetscape access, Mayor Thomas M. Menino proclaimed July 26, 2012, the 22nd anniversary of the signing of the Americans with Disabilities Act, to be "John B. Kelly Day" in the city of Boston.

Dignity 2012: In Support of Question 2

By Paul A. Spiers, Ph.D.

I just received the *Voter Information* pamphlet from the Massachusetts Secretary of State in the mail, which contained the ballot questions for this November. I refer you to that pamphlet or www.dignity2012.org for the wording of Question 2, also known as the *Death with Dignity Act*.

Question 2 will allow terminally ill adults with six months or less to live, the ability to request a prescription for life-ending medication from their doctor. The law has 16 different safeguards, including approvals from two doctors and waiting periods. Doctor participation is voluntary and no doctor would ever be forced to prescribe against their will. The principal at issue here is not health insurance coverage or better access to medical care for persons with disabilities, both valid and important concerns. The principal at issue here is choice, and it is the same principal from which we all benefit because it is the foundation of the Americans With Disabilities Act.

When I awoke in a hospital after ten days in coma and weeks of confusion to discover I had sustained a spinal cord injury (T6-7), I immediately thought of ending my life. That was before I learned I could still have purpose, friends, and a career even though I had to use a wheelchair to get around. I also learned how important it was to have a law - the ADA, which mandates that I be provided with the same choices and access as those who use legs to get around.

Had I taken my life then, at a time when I was depressed and despairing, that would have been an impulsive, self-destructive act; that would have been a suicide. However, after Question 2 has passed, the sole fact of having suffered a spinal cord injury

and become a person with a disability, would not allow me access to the law. In fact, it would protect me from those who, in a moment of sympathetic understanding, might have thought it best to help me die because I had acquired a physical disability.

The law is clear and provides more safeguards than many think is necessary. It protects persons with disabilities. We have to be terminally ill, we have to want it, we have to request a prescription, and we have to decide if or when to take that prescription. It might not be your choice. I can respect that, but please respect that it might be my choice.

This is a decision for terminally ill patients alone, not politicians, government, religious leaders, or anyone else. We all deserve the right to make this decision for ourselves if we are faced with the final stages of a terminal illness. This is the most personal of decisions and it should not be denied to a terminally ill patient who might find comfort in it. A "YES" vote on Question 2 is a vote for individual rights and personal freedom.



Paul A. Spiers, Ph.D.

Paul A. Spiers, Ph.D. is a Forensic Neuropsychologist, who served as Chairman of the Board of Directors for the Hemlock Society / End-of-Life

Choices, and Caring Friends in 2003-2004. Paul helped to oversee organizational restructuring during his term on the board, and was instrumental in bringing about the reunification of Choices with Compassion in Dying.

Get out and Vote!

Tuesday November 6, 2012

Information for Voters:

2012 Ballot Questions

<http://www.sec.state.ma.us>

Printed copies of the ballot questions may be obtained at city and town halls, some libraries or by calling 1-800-462-VOTE (8683).

Register to Vote

The deadline to register for the November 6th election is October 17th. Contact your city or town hall, and complete an affidavit of registration. To obtain a mail-in application, or call 1-800-462-VOTE (8663) or download a form at www.sec.state.ma.us/ele

Voting by Absentee Ballot

Apply for an absentee ballot from your city or town clerk or election commission no later than noon on Monday November 5th. All applications must be made in writing.

2

Ballot Question 2:

Prescribing Medication to End Life

A YES VOTE would enact the proposed law allowing a physician licensed in Mass. to prescribe medication, at the request of a terminally-ill patient meeting certain conditions, to end that person's life.

A NO VOTE would make no changes in existing laws.

Resources In Favor: Compassion and Choices - www.compassionandchoices.org

Dignity 2012 - www.dignity2012.org

Resources Against:

Committee Against Physician Assisted Suicide - www.stopassistedsuicide.org

Second Thoughts -

www.second-thoughts.org

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Choices at the End of Life

Choices at the End of Life" is a week-long series of programs held October 21-28 at First Parish in Lexington MA. This series was stimulated by the placement of the Question 2 ballot initiative, "Prescribing Medication to End Life" ballot initiative, also often referred to as the "Death with Dignity Act".

The lead event on October 21 will be a panel discussion, "The Pros and Cons of the 'Death with Dignity' Initiative," moderated by Richard Knox of NPR. John B. Kelly, Executive Director of Second Thoughts (and author of an article in this issue) will be a panel member. During the week, workshops and presentations will deal with Hospice, Legal Issues at the End of Life, The Five Wishes, and Helping children and Adolescents Cope with Death. The final event on October 28 will be a moderated panel of Lexington

clergy of varying faiths examining death and dying from their own religious perspectives.

All events are open to the public and free of charge. Advance registration is requested. Visit www.fplex.org or call 781-862-8200.

Choices at the End of Life

The "Death with Dignity" Initiative: A week-long exploration of ethical, personal, and practical issues

October 21-28, 2012 | FIRST PARISH IN LEXINGTON

Events are open to the public and free of charge. Registration is requested for all events; visit www.fplex.org or call 781-862-8200.



Toys for Kids with Special Needs

As the holidays come closer, are you frustrated by the fact that toys for kids with special needs can be hard to find? Do you want to give someone something awesome that they can really have play with on their own? If you are, here are some good places to get your gift shopping started.



A good place to begin is with the Toys 'R' Us Guide for Differently Abled Kids. It is available in stores and online, and features a wide variety of toys that will appeal to all ages and abilities. Visit www.toysrus.com and click on Category/ Learning & Educational Toys/Differently-Abled Toy Guide. It's not super easy to find, but it's there!

Another awesome website is www.ableplay.org, which features reviews and ratings of hundreds of toys, which you can search for under a variety of categories.

Enabling Devices is a company that makes a very wide selection of switch toys (and more) for children with motor difficulties, and they also carry a wonderful little device called a battery interrupter, which can turn basically any battery-operated toy into a switch toy. It is not nearly as expensive as a regular switch toy (prices start at about \$14) and allows children to use their own switch. You can request a catalog or browse their web site at www.enablingdevices.com.



SpecialNeedsToys is another wonderful company with everything from supportive swing sets and trampolines to switch toys and Braille playing cards. Adults as well as kids will enjoy the products here. Have you ever

wanted to turn a wheelchair into a rocking chair? In addition, they offer a price match guarantee for all products. They have both a physical catalog and a website, www.specialneedstoys.com.

So go on, and give your favorite kid something that Santa's elves could never make.



Information Briefs



October is National Disability Employment Awareness Month

Held each October, National Disability Employment Awareness Month (NDEAM) is a national campaign that raises awareness about disability employment issues and celebrates the many and varied contributions of America's workers with disabilities. This year's theme is "A Strong Workforce is an Inclusive Workforce: What Can YOU Do?"

Although led by the Office of Disability Employment Policy (ODEP), NDEAM's true spirit lies in the many observances held at the grassroots level across the nation every year. Employers, schools and organizations of all sizes and in all communities are encouraged to participate in NDEAM, and ODEP offers several resources to help them do so. Activities range from simple, such as putting up a poster, to comprehensive, such as implementing a disability education program. Regardless, all play an important part in fostering a more inclusive America, one where every person is recognized for his or her abilities — every day of every month. Resources are available online at www.dol.gov/odep/topics/ndeam/resources.htm

Accessibility Exhibit at Architecture Boston Expo

The Boston Society of Architects (BSA) sponsors the Architecture Boston Expo, one of the largest events for the design and construction industry in the country. It will be held this year from November 14-16 at the Boston Convention and Exhibition Center, 415 Summer Street, Boston, MA 02210. Through October 31, you can register to visit the Exhibit Hall (only) for FREE by going online to www.abexpo.com.



This year, the BSA will have their own interactive exhibit in the exhibition hall, revealing some of the details involved in making spaces accessible. They plan to have two ramps, toilet rooms, kitchenettes, and more meant to look identical to one another. One will be universally designed and easy to use, while the other will have common design errors making it difficult or impossible to use. Expo attendees are encouraged to navigate through the space with a wheelchair, scooter, crutches, or blindfold. They may be assisted by people with real disabilities who will both ensure that the attendees are safe, and can explain the design distinctions that make one side much more user friendly than the other.

Check this universal design exhibit out and add your voice about what works and why. The BSA is building this educational exhibit for the Expo, but they are designing it to be reused again and again in the future to educate others about accessibility. Some of the other exhibitors at the Expo will be addressing universal design as well.

The Purple Shoes Challenge



The Purple Shoes Challenge invites people with physical and/or sensory limitations to improve their fitness, conditioning and athletic skills. Participants set performance goals to determine their personal best. How far

can you run, walk or wheel in 60 minutes? Purple Shoes athletes are encouraged to maintain a year round fitness program and to keep a log of their workouts. Athletes must be at least 6 years of age to participate.

The event will be held on Saturday, November 3, 2012 at the newly refurbished Wayland High School in Wayland, Massachusetts. The Purple Shoes Challenge is hosted by The Katie Lynch Foundation, a non-profit organization developed to fund programs that promote opportunities and respect for people with disabilities.

For more information, visit www.katiesraces.com or call 617-947-3803.



Get Out and Vote! - Continued from page 5

3 Ballot Question 3: Medical Use of Marijuana

A YES VOTE would enact the proposed law eliminating state criminal and civil penalties related to the medical use of marijuana, allowing patients meeting certain conditions to obtain marijuana produced and distributed by new state-regulated centers or, in specific hardship cases, to grow marijuana for their own use.

A NO VOTE would make no change in existing laws.

Resources In Favor:
**Committee for
Compassionate Medicine**
www.compassionforpatients.com

Resources Against:
Vote No on Question 3
www.votenoquestion3.org

Information Briefs - Continued from page 7

Disability Film Series



The cable station, Turner Classic Movies, will dedicate the month of October to exploring the ways people with disabilities have been portrayed in film.

The Projected Image: A History of Disability in Film features more than 20 films ranging from the 1920s to the 1980s. Each night's collection will explore particular aspects, themes, or types of disability, such as blindness, deafness and psychiatric or intellectual disabilities. In addition, one evening of programming will focus on newly disabled veterans returning home from war.

The Projected Image: A History of Disability in Film will air 4 films each Tuesday in October, beginning on October 2 at 8pm. In a first for TCM, all films will be presented with both closed captioning and audio description (via secondary audio) for audience members with auditory and visual disabilities. See the schedule at: www.tcm.com/2012/projectedImage/

Each year since 2006, TCM has dedicated one month toward examining how different cultural and ethnic groups have been portrayed in the movies. If you appreciate this type of programming, visit their website and let them know!