

Disability Issues

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Spring 2006

College Scholarships for Children of Parents with Disabilities

In recognition of the more than nine million parents with disabilities in the U.S. and their families, Through the Looking Glass (TLG) has announced the 2006 College Scholarship Fund specifically for graduating high school seniors who have parents with disabilities.

Scholarships funds are available to graduating high school students who:

1. Demonstrate academic and personal achievement;
2. Have grown up with at least one parent with a disability;
3. Will be a high school graduate or graduating senior by summer 2006.

Up to ten separate \$1,000 awards will be given out in summer 2006. These awards are one of several projects of Through the Looking Glass' National Resource Center for Parents with Disabilities. This National Center is funded by the National Institute on Disability Research and Rehabilitation (NIDRR), U.S. Department of Education.

More information and application forms are available on Through the Looking Glass' website: www.looking-glass.org. Forms may also be requested by calling 1-800-644-2666.

Founded in 1982, TLG is a nationally recognized center that has pioneered research, training, and services for families in which a child, parent or grandparent has a disability. Since 1998, TLG has been funded by NIDRR

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Transition Planning for Youth with Disabilities

by Linda Long-Bellil

Introduction

The transition from youth to adulthood is fraught with anticipation and anxiety for all children and their families. But, for children with disabilities there may be more than the typical amount of anxiety. The steps that might naturally follow for non-disabled children, e.g. following the path of one's parents into a particular college or trade, may or may not be the appropriate next steps for a child with a disability, or may require ongoing services and supports. Hard-won entitlements to children's services may evaporate as the child comes of age, and longstanding relationships with medical providers may be disrupted. Role models with disabilities may be few and far between. All of these factors combine to make it difficult for families and children to visualize what adulthood will look like and discern the steps forward to what can be a new and exciting stage of life.

Building Skills

Preparation for adulthood actually starts very early in a child's development as families come to understand their child's abilities, in addition to their disabilities, and work to help her build skills in areas that will serve her well later in life. In addition to academic skills, these may include things such as organizational skills, manual skills, self-advocacy skills and overall work habits.

Several programs exist to help young people build these skills. The Transition to Adulthood (TAP) program, funded by the Massachusetts Rehabilitation Commission (MRC), is offered through four independent living centers and provides services ranging from peer mentoring to advocacy for youth ages 14-22. Partners for Youth with Disabilities (PYD) offers its "Young Entrepreneurs" program, in which adult mentors work with youth to help them build job-related skills and plan for future careers. The Student Independent Living Experience (SILE) program based at the Massachusetts Hospital School works with children to enhance their independent living skills. Easter Seals of Massachusetts offers job training and assistive technology services. Contact information for all of the programs mentioned in this article is listed on page 4.

Managing their own medical care is one of the most important skills that children can learn to do step-by-step as they grow. Families and clinicians can facilitate this process over time by gradually, and to the extent feasible, increasing the level of responsibility given to children for tasks like making their own appointments or writing down a list of questions for their doctors. One resource in this area is PYD's "Making Healthy Connections" program

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which teaches young people how to manage their own care and navigate the health care system.

Clinicians can also be an important resource during the transition process. A useful guide for health care providers working with families on transition issues is the booklet *Transition Planning for Adolescents with Special Health Care Needs and Disabilities*. Both this manual and a similar guide for families can be downloaded, along with other helpful publications, from the Institute for Community Inclusion (ICI) web site.

Families can also contact the Department of Public Health (DPH). DPH has resource specialists who can refer families to care coordinators and other assistance. Also, starting in the Fall of 2006, additional training for care coordinators on transition issues is scheduled to be offered by the Massachusetts Consortium for Children with Special Health Care Needs, a policy and planning organization. Care coordinators interested in the training should contact New England SERVE. This training is supported by the "Moving Forward Together" grant funded by the federal Maternal and Child Health Bureau, which is also funding other activities such as Youth Advisory Councils for young adults ages 16-26, who will offer input on the training process.

Public Systems to Support Transition

During the teenage years, youth become eligible for transition-focused public services and supports. There are two formal transition processes. One is the school transition planning process required by the Individuals with Disabilities in Education Act (IDEA), which, as of 2004, requires schools to include goals, assessments and supports necessary for transition in the Individualized Educational Plan (IEP) "that will be in effect when a child turns 16." For many children this will mean that formal transition planning should begin at age 15.

Entitlement to services provided

as part of an IEP ends at the age of 22. For this reason, the second transition process, known as the Chapter 688 or "Turning 22" process, addresses how a child's daily living and other needs will be met as an adult. Chapter 688 requires school systems to refer a child who may need adult services to the appropriate agency at least two years before graduation or before the child turns 22, whichever comes first. That agency then determines eligibility for adult services and works with eligible youth and families to put together an "Individualized Transition Plan (ITP)." Because adult services, unlike children's services, are not an entitlement, i.e. they do not have to be provided to every eligible person, these services may have waiting lists. Therefore, parents should urge their school system to initiate the Chapter 688 process as soon as possible. The state Department of Education has a Bureau of Transitional Planning that oversees these activities and a very helpful web page describing how transition works, along with links to additional resources.

Each agency has its own system for addressing transition needs and staff who can help. For example, every Department of Mental Retardation (DMR) area office has a transitional coordinator who works with young

adults 18-22 and their families through the Turning 22 process to help them obtain appropriate adult DMR services. MRC staff can help youth access services such as assistive technology and the Supported Living program, which provides care coordination to facilitate independent living. The Massachusetts Commission for the Deaf and Hard of Hearing, the Massachusetts Commission for the Blind, and the Department of Mental Health can all provide similar assistance.

Families and youth can get help for navigating these state systems from organizations such as the Federation for Children with Special Needs. The Federation regularly conducts trainings on transition and has an upcoming training scheduled for early May. (See sidebar.) Federation staff can also help families with advocacy. Support is available from Massachusetts Families Organizing for Change, Family TIES, a program funded by DPH, and other groups as well. When necessary, referrals and assistance with legal issues and benefits information may be available through the Disability Law Center.

The Institute for Community Inclusion has several brochures

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Federation to Present Transition Planning Conference

The Federation for Children with Special Needs will present a conference titled "Planning a Life: Making the Most Out of High School" on May 5 and 6 in its offices at 1135 Tremont Street, Boston. The conference will offer transition planning information and resources for families and professionals who support students in special education ages 15-22.

High school is a time when all students need to be actively involved in planning for their future. At this critical juncture, students and families must be informed, proactive, involved and hopeful. The transition process can be overwhelming for families because resources and information on transition planning are often difficult to find. The conference will answer important questions for families about what they need to know about, when they need to ask about it and who they need to go to for answers.

Go to www.fcsn.org and click on "Planning a Life" to download the conference brochure. Space is limited to 35 participants.

LEGISLATIVE NEWS

Family Opportunity Act Passes

On February 8, the Family Opportunity Act was enacted as part of the final budget legislation that has been approved by the House and Senate. The Act would allow low- and middle-income families to access appropriate health care for their child with a disability through the Medicaid program. For the vast majority of these children, Medicaid is the only health insurance package that has the benefits they need.

In addition, states can establish a demonstration program for children with potentially severe disabilities. Medicaid services would be available under this program to children with disabilities that will become more severe unless the children receive appropriate services. Also, children who receive inpatient psychiatric services would be eligible for home and community-based waiver services. Newborns with significant disabilities would be presumed eligible for Medicaid and no longer have to wait for the first day of the next month for coverage. The legislation also establishes Family to Family Health Information Centers.

Families that can benefit from the Family Opportunity Act have incomes between approximately \$17,050 and \$60,000 for a family of four, have chil-

dren with disabilities that meet the Supplemental Security Income definition of disability, or have the potential to meet this definition if appropriate health care services are not provided, or have children receiving inpatient psychiatric services.

Families will benefit in the following ways:

- Children with significant disabilities can receive the health care services they need to reach their potential.
- Parents can accept raises, promotions or new jobs that increase family income above the poverty line.
- Parents who have remained single to keep family income under the poverty line can get married.
- Parents no longer have to choose between paying for the health care for their child or other necessary family expenses, such as food, clothing and shelter.
- Parents no longer have to place their child out of the home in order to access appropriate health services.
- Parents will no longer have to forgo custody of their child in order to access appropriate health services.

Adapted from information provided by Easter Seals via www.easterseals.com

Money Follows the Person Act Passes

In February Congress passed the Money Follows the Person Act. This is part of recent federal legislation that will help people who want to move out of nursing homes and other institutions and instead receive services in the community.

All too often people with disabilities of all ages wind up having to go to a nursing home or other institution, because they either do not hear about community based support services or the waiting lists are far too long. Lack of funding for community-based services is one of the main reasons for this problem. But now, by listening to people with disabilities, the government has figured out how these services can be provided without additional costs. The money that pays for the person's services in the nursing home or other institution can be used instead to pay for their services in the community, hence the name Money Follows the Person. In fact, the cost of community-based services is, on average, a third less than the cost of equivalent institutional services.

In 2007, under the federal Money Follows the Person law, states can apply to CMS (the federal Medicaid agency) for this initiative. Using Money Follows the Person, for the first year a person moves out onto community services the federal government will cover a higher percent of the cost of his or her services, and states will pay a smaller portion. After that first year the match rate will return to the regular rate, but even this can save the state money.

Across the nation, 287,098 or 20.5% of all people in nursing homes have said they would rather live in the community. Now they are more likely to get their wish.

Excerpted from an ADAPT news release.

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available on its web site to guide families through the transition process. ICI also has an innovative new web site called "ThinkCollege.net" (www.thinkcollege.net) with information for youth, families and professionals on colleges, financial aid and other resources for individuals with cognitive disabilities and other non-traditional students who, in the past, may never have considered going to college.

Conclusion

The transition process is a good example of how "it takes a village to raise a child." Despite all the obstacles, more opportunities are available to youth with disabilities than ever before. With the help of their families, clinicians, school systems and other service providers, many young people with disabilities have the potential to live happy, healthy and productive adult lives in the community.

TRANSITION PLANNING RESOURCES

Community Programs

Federation for Children
with Special Needs
Contact: 1-800-331-0688 (in MA)
Web site: www.fcsn.org

Institute for Community Inclusion (ICI)
Contact: 617-287-4300 (Voice)
or 617-287-4350 (TTY).
Web site: [www.communityinclusion.org/
publications/indexb.html](http://www.communityinclusion.org/publications/indexb.html).

Partners for Youth with Disabilities (PYD)
Contact: (617-556-4075 (Voice),
617-314-2989 (TTY)
Web site: www.pyd.org

The Transition to Adulthood
(TAP) program
Massachusetts Rehabilitation Commission
(MRC)

Contact: Jim Durant, Turning 22 Program
617-204-3626 (Voice), 617-204-3815 (TTY).
Web site: www.state.ma.us/mrc

Student Independent Living Experience
(SILE) program
Contact: Bryan Drake at 508-856-7604 or
bryan.drake@umassmed.edu

Easter Seals of Massachusetts
Contact: 1-800-922-8290,
1-800-564-9700 (TTY)
Web site: www.eastersealsma.org

Massachusetts Families
Organizing for Change
Contact: 1-800-406-3632
Web site: www.mfofc.org

New England Serve
Contact: 617-574-9493.
Web site: www.neserve.org

Disability Law Center
Contact: 1-800-872-9992 (Voice),
1-800-381-0577 (TTY)
Web site: www.dlc-ma.org

State Agencies

Bureau of Transitional Planning
Department of Education (DOE)
Contact: 617-727-7600 (Voice),
617-727-0014 (TTY)
Web site: [www.doe.mass.edu/sped/
links/transition.html](http://www.doe.mass.edu/sped/links/transition.html)

Department of Public Health (DPH)
Bureau of Family and Community Health
Contact: 800-882-1435 (Voice),
617-624-6001 (TTY)

Family TIES of Massachusetts
Department of Public Health (DPH)
Contact: 1-800-905-8437
Web Site: www.massfamilyties.org
Massachusetts Commission

for the Blind (MCB)
Contact: (1-800-392-6450 (voice) (MA
Only), 1-800-6556 (TTY) (MA Only)
Web site: www.state.ma.us/mcb

Massachusetts Commission for the Deaf
and Hard of Hearing (MCDHH)
Contact: (617-740-1600 (Voice),
617-740-1600 (TTY)
Web site: www.state.ma.us/mcdhh

Department of Mental Health (DMH)
Contact: (617-626-8000 (voice),
617-727-9842 (TTY)
Web site: www.state.ma.us/dmh

Department of Mental Retardation (DMR)
Contact: 617-727-5608 (Voice),
617-624-7783 (TTY)
Web site: www.state.ma.us/dmr

Massachusetts Rehabilitation Commission
Contact: 1-800-245-6543 (Voice/TTY)
Web site: www.state.ma.us/mrc



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as the National Resource Center for Parents with Disabilities. The overall goal of this national center is to increase knowledge regarding parenting with a disability and support more accessible and disability-appropriate resources for diverse parents with disabilities and their children. The Center's services and activities include: national toll-free information and referral; technical assistance and consultations; professional trainings, workshops and presentations; national library and resources clearinghouse; publications and training modules; a national parent-to-parent network of parents with disabilities; international newsletter; website and bulletin boards; and regional and statewide systems development.

For more information contact: Through the Looking Glass, 2198 Sixth Street, Suite 100, Berkeley, CA 94710.
(510) 848-1112 or (800) 644-2666.

Recent Changes to the Federal Special Education Law

By Matthew Engel

Part 2

Editor's note: On December 3, 2004, President Bush signed into law amendments to the federal special education law known as The Individuals with Disabilities Education Improvement Act of 2004 (IDEA 2004). Most provisions of the law took effect on July 1, 2005. In Part 1 of his article Mr. Engel, an attorney at the Disability Law Center, described the changes in the law that affect discipline of students. In this section he details the changes in due process.

Due Process

Changes to the due process or hearings and appeals section of the law appear to be designed to formalize procedures and make them more comparable to court litigation rules, while at the same time encouraging parties to resolve their differences short of a hearing.

Once a hearing request has been filed by either the parent or the school district, the other party must now respond within 10 days in a manner that specifically addresses the issues in the complaint. If the non-complaining party feels the notice is insufficient, it may notify the hearing officer within 15 days of receipt of the complaint. The hearing officer then has 5 days to rule on the sufficiency. In some circumstances, the party will be allowed to amend the complaint, but a hearing officer can also dismiss a complaint, if it is deemed insufficient. Parties may not raise issues at hearing that were not addressed in the hearing request, absent an agreement to do so.

The above rules create added difficulties for parents who attempt to navigate the due process system without benefit of legal advice or representation. As a general rule, it is clearly inadvisable for parents to proceed in a hearing without legal assistance. Therefore, consideration should be given to requesting a mediation session where legal representation is not so critically important. IDEA 2004 establishes that mediation may be utilized for any matter, even when a due process complaint has not been filed. Previously, a complaint had to be filed first. The Amendments also make mediation agreements legally binding and enforceable in state or federal court.

IDEA 2004 adds what is termed a "Resolution Session" after a parent has filed a hearing request. Unless both parties agree in writing to waive the meeting, the school district must convene a meeting with the parents and relevant members of the IEP Team who have specific knowledge of the facts identified in the hearing request. The district must convene the meeting within 15 days of receiving notice of the hearing request. At the meeting, the

parents discuss the complaint and the facts that form the basis of the complaint. The district has 30 days from receiving notice to resolve the issues to the satisfaction of the parents. Otherwise, the case may proceed to a due process hearing. If an agreement is reached, the parties must execute a legally binding agreement that is signed by both parties and is enforceable in state or federal court. There is a "cooling off" period where either party may void the agreement within 3 business days of the execution. Finally, the district may not bring an attorney to the meeting unless the parents are accompanied by an attorney.

In establishing the Resolution Session, Congress expressed a clear intent that, whenever possible, a dispute about special education services should be resolved short of a hearing. While advocates agree that a negotiated settlement is preferable to proceeding to a hearing, there is concern that these meetings may be unproductive and allow the district to pressure parents into agreeing to less than favorable settlement terms. The law allows the parties to use mediation as an alternative to the Resolution meeting, and that may be a preferable option, since a good mediator will help ensure that any agreement is fair.

Parents who retain an attorney and prevail in a due process hearing are still entitled to have the school district pay for their attorney's fees. For the first time, however, IDEA 2004 adds provisions about when the parents or the parents' attorney may be responsible for paying the district's legal fees. These provisions only apply when the parents' or their attorney's claim is frivolous or is being used to harass school district personnel. While this a very high standard to meet, districts may threaten to bring an action for fees against parents who are not knowledgeable about this provision.

Conclusion

The complexity of IDEA 2004 adds to the difficulty parents may have in navigating their way through its maze of rules and regulations. The Disability Law Center is available to help children with special needs obtain the full benefit of their rights. If you are interested in getting a more comprehensive analysis of IDEA 2004, you can contact me by telephone (413) 584-6337, 1-800-222-5619, or by e-mail mengel@dlc-ma.org.

Mr. Engel is grateful to Diane Smith of the Maine Disability Rights Center for granting permission to use her written materials on IDEA 2004.

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Northeastern University to Present ASL Festival

Northeastern University has announced that it will present the 9th Annual George W. Veditz ASL Festival and the Marie Jean Philip ASL Poetry, Storytelling, and Deaf Art Competition on April 7-8. Ayisha Knight-Shaw will be the Master of Ceremonies. Performers will include Mark Morales, Adrian Blue, Sound Off Theatre from Connecticut, Boston's local Deaf Blind Acting Troup, and students from the Learning Center for Deaf Children. Registration flyers are available at <http://www.asl.neu.edu/festival/nowfestival.htm>.

Center for International Rehabilitation Seeks Artwork

In August the United Nations (UN) is expected to conclude negotiations on a treaty called "A Convention on the Rights of Persons with Disabilities." The adoption of this historic treaty will be a crucial step towards guaranteeing universal recognition of the human rights of all persons and will focus international attention and concern specifically on the rights of people with disabilities.

To celebrate the anticipated signing of this historic Convention, the Center for International Rehabilitation is creating an online arts exhibition called the Expressions Gallery. The Expressions Gallery may be found at ConventionYES! (<http://www.conventionyes.org>), a website and campaign designed to support the UN Convention process.

The Expressions Gallery is designed to showcase the work of all artists and to provide a space for members of the disability community, their friends, families and supporters to reveal the personal side of their experience with disability. The Expressions Gallery includes works by the general public as well as

by professional featured artists.

To submit your work to the Gallery, you must first register at the ConventionYES! website. Registration is free and simple. Then visit the Gallery, click on the link to "contributing your work," and complete the submission form. Submissions will be reviewed to ensure that the content is appropriate. Then they will be posted within one week.

For additional information, contact project administrator Laura Frankel by e-mail at frankel@cirnetwork.org, or by phone at 312-229-1359 x250.

Emergency Information Organizer Now Available

The "LIFE FILE" KIT is a comprehensive, convenient way of organizing emergency information for yourself and your loved ones, including your pets. It includes multiple pages for health information, weatherproof labels, a large transparent plastic envelope for your home, office or briefcase, a smaller transparent envelope for your car, easy-to-follow guidance, advocate information, and more. The Kit can enable first responders and emergency rooms to act in a more effective and timely manner. To purchase a "LIFE FILE" KIT send \$12.95 check or money order (this includes shipping and handling within the US) to: Debra Lipsky, P. O. Box 90, Sharon, MA 02067

Special pricing is available for large orders.

IBM Releases Tools for Accessible Design

IBM is offering free assistive software downloads as part of its continuing efforts to promote products aimed at aging baby boomers and people with disabilities. Its new alphaWorks accessibility site (<http://www.alphaworks.ibm.com/aw.nsf/techindex?SearchView&Query=Accessibility&q=Accessibility>

<http://www.alphaworks.ibm.com/aw.nsf/techindex?SearchView&Query=Accessibility&q=Accessibility&s=aw&SearchOrder=&SearchFuzzy=False&Start=1&Count=10>) features assistive technology products, including Home Page Reader 3.04, a Web browser that talks. The site offers links to information about adaptive Web technology, hardware (including a keyboard optimizer and head tracking camera), and software. It also features the aDesigner, a disability simulator that helps Web designers ensure their pages are accessible. A Reflexive Interface Builder will help software developers create applications with graphic interfaces that people with disabilities can use.

IBM announced that the technology it has aimed at people with disabilities will be available for free to anyone. The company states that its efforts to promote technology to all people regardless of ability began as a philanthropic endeavor but is evolving into a business transformation.



New Guide for All People Seeking Rx Drug Coverage

The Massachusetts Medicaid Policy Institute and the Center for Health Policy and Research at UMASS Medical School have created a new supplement to their recent *Pathways to Public Health Insurance Coverage*. The 4-page Prescription Drug Coverage Supplement is designed for everyone seeking coverage, not just Medicare beneficiaries, and includes an easy-to-follow "decision tree" chart. For a link to the guide go to <http://www.compartners.org/news/2006/02/13/new-guide-for-all-people-seeking-rx-drug-coverage/>.

New National Mentoring Center Announces Conference

Partners for Youth with Disabilities (PYD) recently announced the opening of the PYD National Center. The

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Center's first conference, "Aspire, Achieve, Empower: The First Conference on Mentoring for Youth with Disabilities," will be held in Boston on September 13-15. For information about the conference and its Call for Papers visit <http://www.pyd.org/national-center/conference.htm>.

Emergency Cell Phone Program Extended to Boston



"Project Independence," a new program designed to provide persons with disabilities with emergency use cell phones, has been extended to the City of Boston. After such tragedies as Hurricane Katrina, the City of Boston is reaching out to vulnerable and underserved populations to ensure their safety in the event of an emergency. Many disabled persons may not be able to afford a cell phone and would be isolated in an emergency situation. The cell phones are reconditioned with new batteries and chargers by a firm that is owned and operated by disabled persons. The City of Boston has implemented the program with the Boston Police Department and the Mayor's Department of Homeland Security. The program already operates in Brookline and Newton.

"Project Independence" was created by Donna Suskawicz, a Brighton resident and employee of the Massachusetts Rehabilitation Commission. Ms. Suskawicz was recently honored for her community work by being named a Massachusetts Unsung Heroine of 2006 at a reception at the State House. The event was produced by the Commonwealth of Massachusetts Commission on the Status of Women.

Report Released from Mini-Conference on Disability and Aging

Disability is one of the leading issues in aging. The likelihood of developing a chronic disabling condition only increases with age. In response to this, the White House Conference on Aging (WHCoA) sanctioned the Mini-Conference on Disability and Aging, inviting key stakeholders from the aging and disability community to help formulate specific recommendations to the Policy Committee of the WHCoA.

The National Institute on Disability and Rehabilitation Research (NIDRR) has made available the final report and recommendations from this Mini-Conference. The report is titled Seeking Solutions to Improve Health, Productivity and Community Living. It summarizes the deliberations of the event and presents high-priority, agreed-upon recommendations across five policy areas: social engagement and productivity; healthy long-term living; economic security; assistive technology and universal design; and positive messaging. These recommendations will be considered for inclusion in the final WHCoA Policy Committee recommendations that will be advanced to the president and Congress.

For a copy of the report, go to http://www.whcoa.gov/about/policy/meetings/mini_conf/FINAL%20REPORT_07_21_05.pdf.

Assistive Technology Conference to Be Held in May

"AT 'Round the Clock: at Work, School & Play!" will be the theme of Yesodot's Y-TECH Assistive Technology Day to be held on Sunday, May 21 at the Carroll Center Assistive Technology Center, 770 Centre Street, Newton. This will be an informative and interactive conference showcasing state of the art assistive technology software, hardware,

and "low tech" adaptive products for recreation and daily living for children and adults with physical or developmental disabilities, learning disabilities, autism, and for individuals who are deaf or blind.

Yesodot is a program of Jewish Vocational Services (an agency of the Combined Jewish Philanthropies), which maximizes potential and builds community foundations for Jewish children and young adults with disabilities by strengthening their families. The Carl and Ruth Shapiro Family Foundation has provided generous support for the conference, which is also being held in partnership with the Adapted Activities Library, a program of Massachusetts Department of Mental Retardation.

For more information contact: Alissa Kinney at akinney@jvs-boston.org; (617) 399-3231; or (617) 399-3299.

New SCI Exercise Blog

The RRTC on Spinal Cord Injury (SCI): Promoting Health and Preventing Complications through Exercise has announced a new blog about spinal cord injury and exercise. Pam Mackie, the blog author, will share her personal experiences and insights about SCI secondary conditions, exercise, and general health through personal stories, sharing of facts and practices, interviews, and other means. You can also go to the blog and share your struggles and successes in maintaining fitness while living with a SCI. The blog can be reached through the following websites:

<http://rrtc-sci.livejournal.com>

<http://www.sci-health.org>

<http://www.ilru.org/html/projects/SCI/index.htm>

Disability Issues

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