

BREAKING GROUND



MEET THE
**2011 YOUTH
LEADERSHIP FORUM**
STUDENT DELEGATES!



[6] SHIFTING LANDSCAPES -
PART TWO



[12] TIMOTHY SHRIVER Q & A



[17] I AM INVISIBLE

CONTENTS

- 3 Meet the 2011 Youth Leadership Forum Student Delegates!
- 6 Shifting Landscapes—Remarks by Sharon Lewis Part Two
- 8 Poetry Book Review—*Unclipped Wings*
- 9 Discovering the Importance of Legislative Advocacy
- 10 Tennessee Partners in Policymaking Leadership Institute Graduates
Largest Class in Program's 18-Year History
- 12 Empowering for Change—A Q & A with Timothy Shriver
- 13 Poetry Book Review—*Candy Apple*
- 14 A New Vision for Employment
- 15 Book Review—*Gray Matters. Brain Injury: The Inside Perspective*
- 16 News from Pathfinder
- 17 I Am Invisible
- 18 Tennessee Spotlight
- 19 Partners in Policymaking 17th Annual Reunion Conference

ERRATA

In photo accompanying the article "Blind Man Driving" on page 5 of *Breaking Ground* Issue #60, are (left to right) Mark Riccobono, his wife Melissa Riccobono and Dr. Marc Maurer. The editors regret the omission of this information.

Larry Wilson took the photo of Elise McMillan on page 18 of *Breaking Ground* Issue #60. The editors regret the omission of this credit.

CONTACT INFORMATION



This free publication is produced six times a year by the Vanderbilt Kennedy Center for Research on Human Development and Kent Communications Group. Subscription requests, change of address, and submissions for possible publication should be directed to: *Breaking Ground*, Council on Developmental Disabilities, 404 James Robertson Parkway, Suite 130, Nashville, TN 37243. phone: 615-532-6615.

E-MAIL: breakingground@vanderbilt.edu.

Tennessee Council on Developmental Disabilities Grant Number 1-03999-1-0. Authorization Number 339371, July 2001. 5,600 copies. This public document was promulgated at a cost of \$.46 per copy.

MEET THE 2011 YOUTH LEADERSHIP FORUM STUDENT DELEGATES!



RANDY BINGHAM

Huntingdon, Carroll County

"My mother and grandmother have been positive influences. Grandmama would come over and help me with my homework and with my daily chores. She encouraged me to be in church and she got me started playing drums, and with the love of music. She helped me with my career in farming, and helped me buy my first two goats.

"My mother started me out with clothes and how to dress properly and how to be presentable out in the community. She has encouraged me to be better in school and in church, and to continue to go to church and to always help others."



CYNTHIA CACCIOLA

Paris, Henry County

"Since I was young, I have always thought I was so dumb, that I could not prove to myself and others that I could get the grades I wanted. I'm constantly trying to get the grades that I'll need to go to college, and to get accepted into the college of my dreams. [I am] hard working.

If I missed something that I knew I should have gotten right, I'll hound myself into making sure I will not get it wrong the next time; always trying to get better at everything I do.

"I hope this has a good impression on you...I didn't know I could do a thing like this until a few weeks ago, so thank you...I may not be the smartest or the tallest, but I try my hardest...Hopefully one day I could become a positive influence for someone else out there as well."



JOSHUA CARLTON

Chapel Hill, Marshall County

"Growing up with Dyslexia has been hard. I have been laughed at when trying to read out loud in class, which made me even more shy. Not wanting to even try, I just wanted to blend in and not be noticed. I had two teachers in my early years who refused to understand I had a disability. One told my mom all I needed was a belt taken to me and I would read. Then the other just talked down to me all the time. After my mom had me tested—because they refused to—those teachers said they would not learn a new program and new ways to help me for just one student. Those teachers said they would just pass me on to the next grade just to get me out of the way.

"A positive influence has been Mr. Smith. He is my Drama teacher. Mr. Smith helped me break out of my shyness. He put me in plays even though I struggled with reading the scripts. Mr. Smith believed in me and gave me a chance that I never thought I would have had growing up with a disability."



WILLIAM "HK" DERRYBERRY

Nashville, Davidson County

"I want to attend because I feel that I am a good leader. I am a good participant in my school classes and in my church youth group. I think I can make a difference in people's lives.

"In 2007, former Nashville Mayor Bill Purcell invited me to be the honorary Mayor of Nashville for one afternoon. He allowed me to sit at his desk and feel some of the contracts that he was working on. He gave me a Key to the City of Nashville. He made me feel very important.

"I would like to attend college if possible. I know college will be a challenge for me, but being blind and having [cerebral palsy] is also

CONTINUED ON PAGE 4 →

challenging. I like school and enjoy learning. My goal is to become a motivational speaker someday."



KELSEY HERZOG
Germantown, Shelby County

"I want to be a part of your program because I want to understand what opportunities there are for kids like [me] after I finish high school. I think I will be a good candidate for this program because I love to learn new things.

"My disability has made it harder to understand new things, and also understanding the world around me.

"Ms. Baker, my counselor, has been a positive influence. I can go to her whenever I am feeling all alone, and whenever someone is being mean to me or to anyone else, and she kinda helps me. I remember last year...she would come in and talk to the class to find out specific problems we were having at school, or maybe at home. She is able to help us think through our problems."



TAYLOR JACKSON
Germantown, Shelby County

"I feel I am qualified to be a delegate to this Forum because I am a seventeen-year-old who has overcome many obstacles associated with being autistic. These obstacles include personal challenges relating to communication,

and interpersonal and building relationships skills. To manage these challenges, I have focused on self-development through training, participating in group sessions, and using various tools and learning techniques.

"To help myself, I have found it beneficial to participate in volunteer and community activities that permit me to be an advocate for others with similar or other disabilities. This has allowed me to grow as an individual and lead others.

"Throughout my life, I have encountered people who have helped me to overcome my challenges. Going forward I would like to be a person who can give back and help others to be successful."



RONALD "JOSH" KEENER
Knoxville, Knox County

"When I was 10 years old, I went to the Tennessee School for the Blind. It was scary at first because I had to ride the bus from Knoxville to Nashville and Nashville

to Knoxville every weekend and holiday. The campus was unfamiliar to me and at first I stayed to myself. After a while, I decided I was there to experience something new. I started talking to people. I made lots of friends and found that I liked listening to music. Although I was scared at first, I pushed through it and I learned a lot.

"I am interested in meeting new people from across the State of Tennessee to see if we can start new groups to support people with disabilities in schools, churches and other social gatherings.

"I want to work a job and study the Bible during the evening. I also want to keep my life open for any other unexpected possibilities."

CHRISTINA LYNN
Big Sandy, Benton County

"I feel that my abilities to work with others who may or may not have a disability by using good communication skills, creative thinking and leadership skills to overcome any obstacle that may be a challenge in life, is something that I have learned to achieve in my life.

"Ms. Treva has taught me how to speak up for myself and show others who don't believe that people with disabilities can have a normal life just like anyone else, as long as you put your mind to it. Showing the world that I can finish high school and go on to college is something I know can be done.

"My future plan after high school is to attend college to get my Bachelor's degree in Criminal Justice...After college I plan on pursuing my dreams of one day owning my own business, and working with others who achieve their goals of succeeding in life."



KIRA MCCALL
Nashville, Davidson County

"If I had to pick two people who have positively influenced me, I would pick my mom and my elementary school vision teacher, Ms. Fee. They helped me with three important things: independence, tenacity and openness. These three things helped me become who I am today.

"When I was in the 8th grade, I won the award for math student of the year. I hadn't been anticipating winning any awards other than the honor roll, and when I heard my name called, I was glad. I had worked very hard that year...of course, I didn't do all that work just to win an award, but it felt good to be recognized for all that work I had done.

"As I was standing on the National Mall, listening to [President] Obama's inaugural address, it was affirmed: If America can elect an African-American president, then anyone—as long as they meet the requirements—can be president, even if they have a disability."



MICHAELLA

MICHAELLA MICHAEL
Tullahoma, Coffee County

"I want to take part in the Tennessee Youth Leadership Forum to develop leadership skills to help other people who also have disabilities. I want to work on my self-advocating skills.

"My parents have a very close friend who I refer to as my uncle. He looks past my disabilities and always has a kind word or solid advice for me. My mom is always

giving me advice on the right choices to do in life; an example of that is the kind of classes that are best for me to take. My parents give me good support, which helps me face each day head on.

"I have had many surgeries and I have had to become a patient person. My teacher, Ms. Neal, who holds my folder, has pushed me to do more and more to advocate for myself, and make me a better person."



CHRIS

CHRIS PETULA
Chattanooga, Hamilton County

"I like to learn...I go to school in Smyrna. They have training jobs. I do car detailing and oil changes. After I graduate college, I have to find a real job. I need to get organized for a real job.

"Ms. Biddle helps me do my school work. She helps me do a speech in her church and she wants me to read to little kids about "You Are Special". She also helps me do some magic at Siskin

Hospital. My title is "Chris Petula, Dr. of Laughter".



KENDYL

KENDYL SCHWINDT
Hendersonville, Sumner County

"I feel like I am qualified to be a delegate because I am responsible. I am respectful to people around me and I like to help people. Last semester, my friends in [the] CHOICES [program] elected me to be house manager. As house manager I am responsible for making sure our class runs smoothly. I remind my friends to do their chores...I lead morning meeting.

"Some people have a hard time understanding me when I talk. My disability keeps me from driving a car, because I have trouble focusing sometimes.

"After I leave the CHOICES program I plan to go to TRC (Tennessee Rehabilitation Center) in Smyrna and learn new skills. After I attend TRC, I want to get a job. I would like to be a veterinarian."



PRESTON

PRESTON VIENNEAU
Nashville, Davidson County

"Two positive influences in my life would be my mother and Bono from U2. Every time I see my mother work hard on some projects, it motivates me to do great things. She has taught me a lot of life lessons that I had to learn the hard way. I want to be a good example to my kids, like my mom.

"Bono is such a great person, and he's an activist. He saved the children of Darfur. I think I would want to be an activist, go on mission trips and save lives.

"I have Asperger's syndrome. It is sometimes hard for me to make eye contact and I am somewhat reserved. Also, sometimes I have stammering problems, it's hard for [me] to get the words out. I talk really fast before actually thinking about my thoughts. Dr. Kelly has taught me techniques to control those urges of getting the words out."



NAQUISHA

NAQUISHA WILLIAMS
Nashville, Davidson County

I believe I am qualified because I am determined and willing to better myself and help others. I am able to advocate for myself and I believe I can advocate for others. I am a team player and passionate about finding my role as a leader in my community.

"My experience with my disability in a school IEP (Individualized Education Plan) meeting is important. I used to become agitated, impulsive, sometimes argumentative and not in agreement with my meeting and team members. Now, with learning to advocate for myself, I'm trying my best to understand. With my experience in advocating for myself, I feel that in uncomfortable settings I have learned to understand my diagnosis and symptoms in order to better respond and resolve my issues. I am able to speak with the youth group about my journey."

SHIFTING LANDSCAPES

Current Challenges and Opportunities in Developmental Disabilities Policy

REMARKS BY SHARON LEWIS — PART TWO

Sharon Lewis was appointed Commissioner of the Administration on Developmental Disabilities (ADD) in March 2010. ADD is the federal organization responsible for implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. She has over 10 years of experience as a disability policy advocate, including work on major disability-related federal legislation. She served as the Senior Disability Policy Advisor to the U.S. House Committee on Education & Labor and its Chairman George Miller on legislative strategy and disability-related policy in education, employment and health care. She is the parent of three daughters, including one with a disability. These are excerpts from her presentation at the Vanderbilt Kennedy Center as its 2011 Martin Luther King Jr. Commemorative Lecturer.

ECONOMIC EMPOWERMENT. Employment is but one component of economic empowerment. [Last] July, ADD held a half-day conversation on economic self-sufficiency with leading staff of disability organizations and federal agencies. I was astounded by the lack of knowledge regarding one simple premise: It is possible to be a person with a significant disability who participates fully in education, goes to college, works in a real job making more than sub-minimum wage, saves money, buys a house, and still can access supports and services such as health care and personal attendant services through public programs. The complexity of systems makes this difficult, but understanding that is important to change the dynamic.

A key problem related to savings and financial security for beneficiaries of Social Security Disability Insurance (SSDI) is the confusion about how disability programs treat income and resources for purposes of program eligibility. For example, saving has never been a problem for SSDI beneficiaries because these benefits are not based on economic need and there is no restriction on savings, investment or asset accumulation. A common misconception in the disability community is that SSDI is means tested. It is not uncommon to find SSDI beneficiaries disposing of their resources out of fear that retaining them will cause loss or reduction of benefits.

Supplemental Security Income (SSI) beneficiaries do have significant barriers to asset accumulation. Strict resource limits have not been increased since the program's inception in 1974. Congress would need to make a statutory change that carries a high cost, so the politics of passage is difficult. In order to retain SSI eligibility, beneficiaries must not have countable resources in excess of \$2000 for an individual or \$3000 for an SSI eligible couple. However, numerous resources are excluded from this limit that can be used to save.

Many important SSA [Social Security Administration] provisions allow accumulation of assets and provide work incentives. For example, regulations permit a beneficiary to own one home of any value as long



Photos by Susan Urry/Vanderbilt University

Above: Alexander Santana and Sharon Lewis. Below: Sharon Lewis.



as one is living in it. Business ownership is possible as well. The rules allow for unlimited accumulation of assets, including cash in a business account, for the operation of a small business or microenterprise under the exclusion of properties essential for self-support. The same is true for Medicaid eligibility because states cannot adopt Medicaid income and resource rules that are more stringent than SSI. Our fortunes are tied to these rules.

Additionally, Social Security offers several resource exclusions to allow SSI beneficiaries to save or pay for postsecondary education, and Plans to Achieve Self-Support (PASS) are an opportunity for individuals with disabilities to accumulate income or resources without causing either ineligibility in SSI or reduction in benefit payments. No simple strategy or solution will overcome these barriers to advance greater self-sufficiency for persons with significant disabilities, but there are tools and strategies for building assets. Learn more about this.

HEALTH CARE. ADD is one of the HHS [Health and Human Services] offices responsible for work on implementing health care reform,

in particular, long-term services and supports, and the Community Living Assistance Services and Supports (CLASS) Act, which creates a national voluntary insurance program to provide benefits to working individuals with disabilities to purchase nonmedical services and supports necessary to maintain independence.

The Affordable Care Act has many moving parts and policy changes that will benefit, and are already benefiting, people with disabilities and their families. Its implementation is important to people with disabilities. For example, the law prohibits insurance companies from denying children coverage based on pre-existing conditions. Going forward, the Act will prohibit insurance companies from denying coverage or charging more to any person based on their medical history, including genetic information. All lifetime limits on coverage are eliminated and insurance companies are banned from dropping people from coverage for utilization. The Act also restricts the use of annual limits in all new plans and existing employer plans until 2014, when the new law prohibits all annual limits.

The law will provide access to health insurance through state exchanges to those without job-based coverage and provides premium tax credits to those who cannot afford coverage, significantly increasing access to choice of health insurance plans for individuals with disabilities. This also will enable people to get and keep their jobs, rather than having to choose between health insurance coverage, that is, Medicaid, and employment. The Act requires the development of ADA [Americans with Disabilities Act] standards for accessible medical diagnostic equipment, such as examining tables, weight scales and x-ray machines, so that people with disabilities can receive routine preventative care like mammograms and x-rays.

The HHS Web site, www.healthcare.gov, has extensive information, including state-based information. ADD's recent newsletter has a simple graphic representation of the various components of the Affordable Care Act implementation process; see www.acf.hhs.gov/programs/add.

COMMUNITY LIVING. In these times of scarce resources, we have to be smart about our money and expertise and combine forces to make a real difference. President Obama has charged the federal government with taking collaboration across agencies seriously. Collaboration should improve people's lives in visible, measurable ways in their communities. The Community Living Initiative was announced on the 10th anniversary of the Supreme Court's *Olmstead vs. L.C. and E.W.* decision. *Olmstead* held that the unjustified isolation of people with disabilities is unlawful under ADA. ADD is working with other federal agencies to address barriers to community living. The HHS Secretary charged the Office on Disability with convening an Interdepartmental Council, which includes ADD, to guide the work of the Community Living Initiative.

The Centers for Medicare and Medicaid Services released a Community Living letter to State Medicaid Directors reaffirming commitment to policies identified in previous *Olmstead* letters, and offering tools and information to help states make greater strides in achieving the promise of ADA. HHS and HUD [Housing and Urban Development] have announced two rounds of funding for vouchers for people with disabilities to live in the community or transition out of institutional care. HHS is using its network of State Medicaid agencies and local human services organizations to link eligible individuals

and their families to local housing agencies. The Office on Disability awarded a contract to establish a Center of Excellence in Research on Disability Services, Care Coordination and Integration to create the data infrastructure to support the development of comparative effectiveness research on services and supports and quality models of care for persons with disabilities.

Another critical Community Living activity under the Affordable Care Act, Section 2402A, requires the Secretary to promulgate regulations regarding the oversight and assessment of home and community-based services across systems, not just Medicaid. Under 2402A, regulations will be developed to ensure that all states develop and support coordinated home and community-based systems. Resources are to be allocated to respond to changing needs and choices of the beneficiaries receiving home and community-based services. Strategies should maximize the independence of beneficiaries and provide individuals, their families, caregivers or other representatives the support and coordination needed to design an individualized, self-directed, community-supported life.

Community Living has brought together various departments and organizations operating under the values-based proposition that all people have the right to live self-determined lives in communities of their choosing. This core principle is consistent with the concept of Beloved Community that Dr. King espoused. The engagements and supports of our neighbors, friends, family and the broad community will ultimately be the factor that turns the tide on some of those grim statistics I shared, not just the public policy data and program implementation.

"BELOVED COMMUNITY". In mentoring and supporting families and self-advocates, it can only partially be about services. In large part, it needs to be about community and reciprocity. How do we help families and people, who are often isolated and struggling to take care of daily tasks that others take for granted, develop and nurture relationships in the community? How do we help people understand that the path to competitive, integrated employment is as dependent upon community relationships as it is upon education and skills?

As we continue the policy debate about services and supports in an era of shrinking resources, reliance on Medicaid, diversity of cultures, increasing need, how does community fit in? We will continue to struggle to close the sheltered workshops, eliminate segregated classrooms and get rid of institutions if we cannot engage the broader community, and unless we hold ourselves to the high expectations we espouse. We need to move the DD Systems Change discussion along to help people see that often a little bit of support in community goes a long way, getting out of the all-or-nothing paradigm of the dependence upon Medicaid that has been fostered in the disability community. This is not to diminish care of individuals who have significant levels of direct support and resource-intensive needs. We must make sure that the self-determination of individuals with disabilities by family and caregivers always comes first, even when it is hard for parents, especially as we talk about families supporting adults over the lifespan. The irony in this conversation may lie in some of our greatest public policy successes. For example, under IDEA we have legal process protections, but still cannot achieve consistent, meaningful inclusion and academic success for students with disabilities across this country. We contribute to the inherent conflict by focusing on separate services and systems at the cost of real and equal participation in the

CONTINUED ON PAGE 8 →

rest of the community. Sometimes we are our own worst enemy and the silos we create make it too easy for everyone else to assume that the disability system is taking care of people with disabilities, which minimizes the shared responsibility that an interdependent society depends upon.

How do we reconcile our value system with our practice? We need specialists but not special places. In classrooms, students need pedagogy and content access. People with disabilities need both a neurosurgeon and a primary care physician to provide their care. At work, employees may need accommodations, but people with intellectual and developmental disabilities can be productive and achieve the workplace goals—and should be paid a living wage to do so. We all need healthy, reciprocal relationships in our lives, with our friends, family, neighbors and colleagues. We must help people with disabilities and family members remember the importance of these relationships and contributions, reciprocity and social capital in the community. It is as important as keeping up to date on the latest research, regulations and best practices.

The DD Act tells us that disability is a natural part of the human

experience, which does not diminish the rights of individuals to live independently, to exert control and choice over their own lives, and to participate in their communities through full integration and inclusion in all aspects of society. In order to achieve this vision, we need to focus not only on disability-specific policy but also on the relationship between mainstream policy and interdependent community relationships.

We need to walk our talk regarding inclusion. We need to expend our energy to use our decades of developed disability knowledge, research, practice, and policy to inform and improve the greater community—instead of building our own world of specialized supports and services. It is not the easy path, but it is the right journey towards inclusive, integrated, reciprocal, BELOVED COMMUNITIES. As Dr. King said, “Our goal is to create a beloved community, and this will require a qualitative change in our souls, as well as a quantitative change in our lives.”

Commissioner Lewis’s full presentation is available at kc.vanderbilt.edu, News & Events, Podcast & Video.

UNCLIPPED WINGS BY RAMONA HARVEY

AUTHORHOUSE, 2010, 95 PAGES

POETRY BOOK REVIEW BY NED ANDREW SOLOMON

Between Worlds

I was born into a world of walking people, but I am not one of them. In the very beginning I belonged, loved, and lived in a world of people like myself, even though my parents and family walked. From the very beginning, I learned that I was less than them because I was not of their world. I would always be as long as I stayed with my people. My parents wanted me to be more and took me to a normal school. I didn’t like being there. The people didn’t want me. I didn’t complain. It made my mom happy. I liked her happy, so I stayed. I also wanted to be better. They tried to isolate me. They hurt me and I don’t think I’ll ever heal the cuts are too deep.

Now I stand on a line between two worlds:

One of walkers that opened their doors, but never really allowed me in. I spent most of my life adapting to them. The other is a world I once belonged, but when I left so long ago, I left that world for good. They resent me for going to the walking world and even though I visit them, I really don’t belong. Even though I pretend to belong, I’m really set apart.

So, I stand between the worlds seemingly all alone. Looking in windows but never getting in. The best of both worlds is what I got, and that is good I know. Sometimes though I want to go back to the world I once belonged, loved, and lived, but no longer is that world my home and that I have to live with.

Unclipped Wings is a collection of poems by Ramona Harvey. Although Ms. Harvey lives out of state now, she spent three years in Nashville working as an independent living specialist at the Center for

Independent Living of Middle Tennessee, a senior career facilitator in the Career Access Network, and a volunteer lead counselor during the Summer Youth Leadership Forum of the Tennessee Council on Developmental Disabilities.

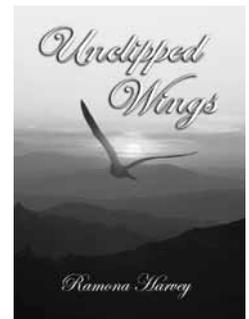
Born with cerebral palsy, Ms. Harvey began a writing “career” very early, completing her first short story at age four. For the most part, this collection has little to do with disability. It contains reflections on life relevant to anyone of any ability.

I was impressed by the “accessibility” of the poems included here. Often poetry (for me at least!) can be very difficult and so rooted in the writer’s personal feelings and experiences that they are hard to relate to, let alone comprehend. This is not the case in Ms. Harvey’s book. Although many are still interesting enough to be open to interpretation, they can be read and enjoyed on several levels.

There is sadness, in the poems that address loneliness and a feeling of isolation. There is joy, as the author reaches for freedom and describes “casting off protective armor”. There is hope and love and the quest for honesty and fulfillment. And there is empowerment, as Ms. Harvey encourages readers to not stand still, to not be complacent, to not accept the challenges life has given you without a fight.

To order copies of *Unclipped Wings* and for more information about Ms. Harvey and future book signings, please visit onecandream.com.

Ned Andrew Solomon is director of the Partners in Policymaking™ Leadership Institute of the Council on Developmental Disabilities.



DISCOVERING THE IMPORTANCE OF LEGISLATIVE ADVOCACY

BY LYNISE PARISIEN As a parent of a child with a disability, I have been vaguely aware of the impact of disability policies on my family. With my daughter only eight years old, my focus has been on her current and short-term needs, rather than seeing the larger, long-term picture.

As the 2010-11 Family Trainee in the Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) Training Program, I attended the 2011 Disability Policy Seminar in Washington, DC, sponsored by the Association of University Centers on Disabilities (AUCD), The Arc, and other national disability organizations. As I sat there, alongside the other 600 advocates, parents and individuals with disabilities, reality started to sink in. I realized that the policies that are being implemented now will be reaching maturation by the time my daughter graduates from high school and will potentially need these services.

The AUCD Conference was an eye-opening experience regarding the amount of support that individuals with disabilities need, what is available currently to help those individuals, and what still needs to be addressed. Unfortunately, many speakers painted a grim picture on the likelihood of future funding for much needed supports to help individuals with disabilities become more independent and have the opportunity to be self-directed. Nevertheless, I was glad to learn more about various programs so I can pass information along to other families.

Our federal and state governments are focused on reducing spending, which means that funding for important programs to help individuals with disabilities and their families are at risk of funding reductions or even elimination. Although programs are available for individuals with disabilities, there is a constant need for refunding or maintaining funding. Congress does not seem to be willing to initiate new programs until they can be proven viable through self-sustaining funds. This includes helping individuals with disabilities find affordable housing, health care, training skills for jobs, and employment.

The first two days of the conference were informational sessions about the federal budget and what we might address with our U.S. Representatives and Senators. The third day was “on the Hill”. Personally, I have never been interested in politics or even wanting to meet with politicians—but I must say it was an interesting experience.

A long time ago, when I realized that what I was doing for my daughter was considered advocacy, it put a whole new perspective on standing up for her needs and rights. I started to understand the importance of fighting for her needs and learning to assertively express those needs. It is no different sitting with legislators and their aides. It really comes down to helping the legislators understand the impact of programs on



Photo by Lisa Moore

Lynise Parisien with daughters Rachael (11) and Brooke (8)

individuals with disabilities and their families and what the ramifications would be if the funding to those programs were cut.

I went with a small group to see three Tennessee legislators. They were in session and unable to meet with us directly, so we met with their aides. The first aide was very interested in what we had to say and was up to speed on our organization. It was an easy conversation in which to bring up some personal stories and how any cuts would affect families. The second was unfamiliar with why we were there and was distant in the conversation. It wasn't until we were able to make it real by telling personal stories that we created some traction in showing the importance of funding these programs.

The final session was with a legislator who has been an ally for a long time and continues to support programs for individuals with disabilities. The Senate was holding a vote and the Senator needed to go to the floor during the session. The legislator knew that we were on a tight schedule and had the staff aide bring us into the Capitol so that we could meet immediately after the session. While we were waiting, the aide spoke with us for about 30 minutes and then the legislator joined us, spending about 10 minutes listening to our stories and suggesting ways to address our initiatives.

The takeaway I received that day is: one person can make a difference. I now truly believe that. It is important that everyone knows that politics will be politics, but if we learn to have meaningful conversations with our representatives, our message will go much further. It was a whirlwind of information, but overall it was a wonderful experience. I look forward to learning more about these programs, keeping up with the budget cuts, and continuing to advocate for my daughter and others with disabilities and their families.

Lynise Parisien lives in Antioch and is a member of the Autism Society of Middle Tennessee and the Community Advisory Council of the Vanderbilt Kennedy Center.

TENNESSEE PARTNERS IN POLICYMAKING LEADERSHIP INSTITUTE GRADUATES LARGEST CLASS IN PROGRAM'S 18-YEAR HISTORY!

BY NED ANDREW SOLOMON

It was a very big year for the Tennessee Council on Developmental Disabilities and its Partners in Policymaking program. Twenty-eight individuals with disabilities and family members of persons with disabilities graduated on April 16th in a ceremony held at the Embassy Suites in Franklin. The room was full of family and friends who came to recognize their loved ones for successfully completing seven intensive weekend sessions, covering a wide range of disability-related topics.

It was an especially diverse class, with several Partners representing underserved counties in Tennessee. Although many participants applied to the program to acquire information and develop skills to enhance their own lives and the lives of their family members with disabilities, most left the program with a sense of a greater purpose: to spread the word and become leaders in their communities. An evening legislative activity—where the Partners developed and presented testimony for and against a piece of legislation—and a homework assignment encouraging Partners to communicate with their elected officials, helped them realize they could take part in and have an impact on the legislative process.

Parents of young children with disabilities witnessed adults with disabilities completing homework assignments, speaking out forcefully in public, striving for independence and making major inroads into educational and employment arenas. Adults with disabilities got a sense of the challenges their own parents may have faced, as they struggled to advocate for their sons and daughters in a much less disability-friendly time.

Enough said, from me. Better that you hear about the benefits of the Partners' experience from the Partners themselves.

Photo by Peggy Cooper



Please join the Council in welcoming the following individuals into the Partners Graduate Network.

Jessica Beecham, Murfreesboro

Luz Belleza-Binns, Hermitage

Nurhan Bozkurt, Nashville

Cynthia Brandon, Memphis

Linda Brown, La Vergne

Teresa Carey, Williamsport

Stephanie Brewer Cook, Knoxville

Ann Curl, Franklin

Rosey DePriest, Hohenwald

Deborah Duncan Hyde, Chattanooga

Barbara Early, Lenoir City

Richard Ellis, Maryville

Chandra Evans, Memphis

Deborah Hale Harris, Clarksville

James Harris, Jr., Chattanooga

John Harris, Murfreesboro

Megan Hart, Nashville

Leslie Hartman, Nashville

Faith Henshaw, Gainesboro

Beth Hopkins, Nashville

Alaina Johnson, Murfreesboro

Ricky Jones, Nashville

William Lovell, Hohenwald

Donnie Moore, Pleasant View

Sharon Paris-Treadway, Nashville

Cynthia Salem, Memphis

Jodi Sztapka, Columbia

Cynthia Young, Chattanooga



"I've learned that no matter what I know, or think I know, it can always be increased or improved by the knowledge and experience of others. I've learned that no matter how many people are willing to advocate and educate, we always need more! And I know that our work will never be done."

– **Stephanie Brewer Cook**



"My way of looking at all types of disabilities has been transformed. I have learned that I am a member of a group and, therefore, I no longer feel alone. I have learned that learning, understanding, sharing, researching, making questions, asking for what is right will not only open opportunities for my loved one, but will bring hope and more chances of success for others."

– **Luz Belleza-Binns**



"When I embarked on Partners, I honestly had no idea what I was in for. I knew what my goals were (are), I knew that I needed a stronger foundation, and I knew I could not get it on my own. I did not know that my world as I know it would be turned upside down with knowledge and understanding that would only leave me hungry to get more knowledge and understanding... and to be more and do more...I think that should be added to the tag line of Partners in Policymaking – "Do more...Be more".

– **Chandra Evans**



"Partners helped me see that I still have things to offer to individuals with disabilities. It helped me to promise myself to never give up, or to think about retiring or quitting. Partners rejuvenated me."

– **John Harris**



"Along with being eye opening, making strong ties with friends, education...all the things you might expect, my Partners experience has given me hope."

– **Faith Anne Henshaw**



"For many years, friends have told me, "Oh, you have to go through Partners in Policymaking", "Partners in Policymaking is AMAZING!", and have given the program many other praises...Although I wanted to participate, it was hard to commit one weekend per month for seven months. Now I could kick myself for not applying to Partners in Policymaking earlier."

– **Jessica Beecham**

Photos by Ned Andrew Solomon

EMPOWERING FOR CHANGE

A Q & A WITH TIMOTHY SHRIVER

BY JENNIFER WETZEL Timothy P. Shriver

is a social leader, educator, activist, film producer and business entrepreneur. He is chair and CEO of Special Olympics, which serves nearly 3.5 million Special Olympics athletes and their families in more than 170 countries. He has helped transform Special Olympics into a movement that focuses on acceptance, inclusion and respect for individuals with intellectual disabilities in all corners of the globe. In his 14 years at the helm of Special Olympics, Mr. Shriver has created exciting Special Olympics initiatives in athlete leadership, cross-cultural research, health, education and family support. Special Olympics Healthy Athletes® has become the world's largest public health screening and education program for people with intellectual disabilities, and Special Olympics Get into It®, together with Unified Sports®, promotes inclusion and acceptance around the world. In addition, he has worked to garner more legislative attention and government support for issues of concern to the Special Olympics community. A member of the Scientific Advisory Board of the Vanderbilt Kennedy Center (VKC), Mr. Shriver visited the VKC and Vanderbilt University on April 4, 2011.

Q. *What is the impact of Special Olympics Healthy Athletes®?*

A. What we found in Special Olympics is that there are enormous disparities in the ways that people with intellectual disabilities are provided health care. There are preventable, avoidable health problems that are not addressed simply because systems are not set up to do that. There's either active or passive bias in the system that excludes people with intellectual disabilities from health care systems. As a result, adults with intellectual disabilities end up having poorer health than would be the case if the care were just and fair.

We need to find ways to make the case that

there are health disparities, because most Americans don't think there are. We need to find ways to make the case so that health care education institutions, medical schools and professional schools will intensify the training that students receive related to people with intellectual disabilities. We need to make the case so that systems like health care insurers and governments will respond to the gaps that exist for individuals with intellectual disabilities. We need to make the case so that parents become empowered within their communities to fight for better health care. We need to make the case so that people with intellectual disabilities themselves can be empowered by understanding their health needs and health histories and ultimately understanding ways to make themselves more healthy.

We have not made that case today. The gaps in information in this country and around the world are scandalous. Most countries don't track people with intellectual disabilities as a population. They don't track the health problems they have, they don't track the extent to which the health care is successful, they don't track or monitor interventions. No data means no policy, no policy means no remediation of the problems, no remediation of the problems means injustice in the health care system. If we can put the data together, if we can mine the data to make the case and learn how to better serve persons with intellectual disabilities and learn how to remediate the problems in the systems, then we have a chance to make a difference in the life outcomes of persons with intellectual disabilities.

Q. *What changes are needed in our thinking about disability?*

A. For too long, we've seen people who are different as people who have problems. That language has crept into the way people think. As we think, so we will respond. We will help "them". We will fix "them"—as though "they" were the problem.



Photo by Tony Maupin

Timothy Shriver, chair and CEO of Special Olympics, and Portia Carnahan, AmeriCorps member at the Vanderbilt Kennedy Center and Special Olympics athlete.

Being around the Special Olympics movement for most of my life, I have come to believe that some of the greatest moments of personal transformation exist when people who don't have disabilities see for the first time that differences are not negatives, that a vulnerability is not an evil, that openness, courage and bravery are not qualities limited to those who are strong in body. And so I am a firm believer that people with intellectual differences can become powerful agents of healing and hope for their communities. Movements like the Special Olympics movement are fundamentally about healing the misunderstanding and intolerance and fear that separate us all.

When we work in research, in sharing best practices, in professional training and in public policy—all work that takes place at great institutions like Vanderbilt University and the Vanderbilt Kennedy Center—we work not just for the chance that a child with an

intellectual disability will have a full life, but, very close behind that goal, is the chance that every member of the community in which that child lives will also be changed and with openness and acceptance will have as full a life as the child with an intellectual disability.

Q. *What is your sense of what's needed to empower change?*

A. If you look at the lives of people with intellectual disabilities, they experience a range of services that are so frequently fragmented. They'll get a service here, a service there, a resource here, a resource

there. This is not what children and adults with disabilities and their families need. They don't need a series of categorical service providers. They need a holistic approach to growth and development.

An integrated approach is called for, with medical practitioners, psychologists, basic researchers, translational researchers, educators all working together. That's the great promise.

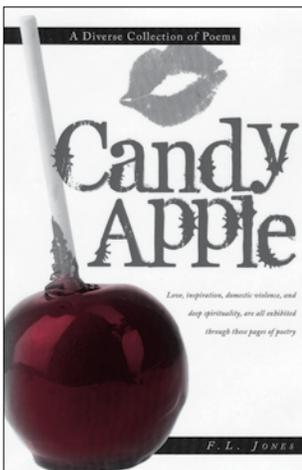
As much as we need to know more, we need to integrate more. We need to translate better. We need to build community. That, too, is an art. That, too, is a science. We need

to be thinking about ways that people with intellectual disabilities can contribute to their communities. That, to me, is the big question that we face in the future—how to build authentic communities around this country and around the world for persons with intellectual disabilities and their families, and for all those who will not grow up afraid, will not grow up stigmatizing disability, will not grow up excluding people with differences from their lives.

Jennifer Wetzel is senior information officer in the Public Affairs Office at Vanderbilt University.

CANDY APPLE BY F.L. JONES

AUTHORHOUSE, 2010, 80 PAGES



POETRY BOOK REVIEW BY
NED ANDREW SOLOMON

F. L. Jones, (better known to this community as Leora Jackson, Partners 07-08 Graduate) is a poet, writer, storyteller and motivational speaker. She enjoys writing articles about children's issues, disability issues, spirituality, relationship conflicts and romantic love.

In her book, *Candy Apple: A Diverse Collection of Poems*, Ms. Jones covers emotions and feelings from different perspectives. She writes

about the love women want to feel and how men should exhibit that love. She writes about the hurts that children suffer, how male youth might struggle to be heard, or the wisdom that older people can impart to a younger generation.

"Teacher Behold This Child" is an inspirational invitation to educators, daycare workers, tutors, mentors and anyone who might touch and shape the mind of a child. It also recognizes that teachers need to be appreciated for the challenges they face in the classroom, with parents, with co-workers, with school politics, with lack of recognition. This poem reflects on students with disabilities as well. Teachers are reminded to treat all students, those with or without disabilities, fairly.

In "You Are Awesome Girl", Ms. Jones tells young women to be all they can be, even in the midst of dysfunctional family homes and a lack of positive role models. It says that they are designed and perfected by God for an extraordinary purpose, to become teachers, counselors and mothers. It encourages them to hold their heads up high with pride and to respect themselves as women.

My favorite poem is "I Can't Hear You Whisper".

*Baby, you say that you love me
But I can't really hear you.
Because you whisper to me
the words "I love you."*

*The words that I long to know,
To reflect how you feel about me,
Seems to be unnoticed to my ears.
That's why I feel you don't love me.*

*If you would only show me more
In your actions and in your touch.
I would be so very grateful
To know you care so much.*

*I wish I could understand
Those lovely words you say.
But my hearing is not so good.
I don't hear your whispers that way.*

*Please be patient with me
And turn my face towards you.
Move your lips slowly, and
Say the words "I love you!"*

F.L. Jones is a single mom and she enjoys mentoring youth and volunteering in the community and at her local church. Originally from Marianna, Arkansas, Ms. Jones currently resides in Memphis. She holds a Master's degree from the University of Arkansas at Fayetteville.

Ned Andrew Solomon is director of the Partners in Policymaking™ Leadership Institute, a program of the Tennessee Council on Developmental Disabilities.

Photo by Roy Critte



Left to right: Judy Carlson, Carmel Johnson, Marvina Leatherwood and Christy Howlett

A NEW VISION FOR EMPLOYMENT

BY CARMEL JOHNSON AND JUDY CARLSON

New Visions is an agency that has been supporting individuals since 2010. We founded New Visions out of a passion for helping individuals with disabilities find healthy and appropriate employment at businesses in the community. It is our vision that as more individuals are placed at jobs in the community, the community will not only accept individuals with disabilities, but will embrace them. As a result, people with disabilities will become meaningful members of their communities.

New Visions has a seasoned staff that represent over 20 years of experience and operates under Letters of Understanding with the State of Tennessee, the Division of Rehabilitation Services, Rutherford, Davidson and Sumner Counties. Three Letters of Understanding comprise Supported Employment, Job Placement and Trial Work.

The agency's placement services are tailored to an individual's abilities. We help individuals fill out on-line applications, contact employers, encourage clients and provide accountability based on their needs. Many times, we will take clients to meet a number of employers in the hope that a good match is found. Filling out an on-line application in today's market is not enough to secure a job—often, there are hundreds of on-line applicants for each job, so an applicant needs to go that extra step to stand out.

We take great pride in not just placing individuals at jobs, but placing them at jobs that are about choice and that are gratifying to the individual. We also find it rewarding to see how the employers embrace and offer their support as well.

Since October, 2010, we have placed 20 individuals at jobs and the retention rate at the placements has been excellent. New Visions' staff maintain the viewpoint that everyone can work with the right support and attitude, and so far the approach has been fruitful. We stay very motivated and enthusiastic about supporting individuals in obtaining jobs that are rewarding and that make positive life changes.

Here are some comments from employers and supported individuals.

"When Carmel brought Marvina for an interview, the first thing that

caught my attention was her smile and personality. Marvina always brings her smile to work every day, she is very personable and a hard worker. She was the first employee to be recognized by another employee through their Recognition Program." — Christy Howlett, general manager at Hampton Inn, regarding Marvina Leatherwood, a New Visions client.

Marvina Leatherwood:

"I first want to thank you, Sheila Doris VR [Vocational Rehabilitation] counselor, Judy Carlson and Carmel Johnson for helping me and believing in me. So far working at the Hampton Inn has been rewarding for me. I have met some really nice people, including some from other countries. I work from 7 to 11/11:30 am Tuesday through Thursday. Once again thank you and I thank God because I couldn't ask for anything better."

Barbara Biehler, New Visions client:

"As someone with a disability who has been out of the traditional job market for a number of years, Judy's skills have been invaluable to me. She is very aware of what today's employers are looking for in prospective employees, and knows how to prepare her clients to meet the employers' needs. Judy also understands how to emphasize her clients' abilities rather than limitations. I am optimistic that, with her help, I'll secure a position very soon."

What keeps us motivated? We have seen the life enrichment that a job brings. The joy of a first paycheck, the happiness that comes with new friendships, increased self-esteem and financial independence are some of the life enriching positives that come from having healthy and appropriate employment.

Carmel Johnson has helped to train and place individuals with disabilities in meaningful employment since 1991. He is director of operations at New Visions.

Judy Carlson has a professional background in Business and Sales in the Insurance and Real Estate industries. For the past three years, she has successfully placed individuals with disabilities in jobs and provided job readiness training.

Gray Matters. Brain Injury: The Inside Perspective

BY HEIDI LERNER • AUTHORHOUSE, 2006, 268 PAGES

"Disabled"

I must analyze

*The definition of this word,
For the underlying meaning
Is somewhat absurd.*

Disabled?

Do you mean UN-abled?

No, not me,

To that I say "hey!"

*I'll get through that obstacle,
My own little way.*

Are you diss-ing me,

Just because I have trouble

With my memory?

Please understand,

I don't think that I'm so great.

I've just learned to compensate.

We're moving on in time,

For sure,

*"Handicapped" isn't politically correct
Anymore.*

People with disability

Are not handicapped,

Not necessarily passive,

Potential is there to be tapped.

Our challenges

We want you to understand,

But in your mind,

Don't put us in the "handicap" brand.

We're in a different time,

It's a different paradigm,

We look at ourselves

In quite a different light,

We believe we can do

Almost anything we put in sight!

"Disabled"

If you assume my inability

Through this name...

ADA, IDEA,

My rights and integrity I can legally claim.

Overcoming challenges

Makes a person strong -

Strength in mind,

Togetherness in heart,

Help us to keep on keeping on!

BOOK REVIEW BY FRANK MEEUWIS

Gray Matters is a book of poetry, first published in 2006, with personal insights into the life of Heidi Lerner, a traumatic brain injury survivor. I also sustained a traumatic brain injury and can directly relate to Ms. Lerner's expressions and experiences.

The purpose of the book is to educate about brain injury and its complications—or sequelae. Reading this book gives support to people who have had brain injuries and helps readers know more about brain injury itself from an insider's perspective. Ms. Lerner explains that the brain conducts who we are and she wants the reader to know "what it's like to walk in [her] shoes!"

The book is arranged by the typical stages that a brain injury survivor may move through. Ms. Lerner begins with poems that describe brain injury and sometimes uses technical brain injury terminology, which commonly is learned as you go through recovery. *Gray Matters* also defines each unfamiliar term in a glossary in the back of the book—helpful to me for a term or two that I thought I had forgotten after my own rehabilitation experience! Through her emotional and inspiring poetry, Ms. Lerner also describes her experience of rehabilitation and the following positive psychological developments that may result from (and I agree resulted from mine) rehabilitation.

- Survivors become more in touch with themselves and others; more 'in-the-moment' living.
- After accepting personal limitations, a person tends to develop a more accepting attitude.
- Due to the loss of previous functions and skills, it is common for survivors to find new, previously unrecognized strengths.

Ms. Lerner then explores and describes many of the possible symptoms or complications that result from a traumatic injury to the brain. Her poetry recounts different aspects of rehabilitation and how they each fit together to build a new life for the survivor. She describes her experience of returning to academia—a journey that I too completed and found much in common in terms of our perceptions of the



experience. *Gray Matters* also covers the specific structure of the brain, what the different areas are responsible for and some of the deficits that may come from an injury to a specific area of the brain.

Ms. Lerner shares a very unique experience that she had with a sea otter off the coast of California in her kayak. Here she tackles an issue of personal concern: that every day high intensity sonar and ocean noise pollution cause brain injuries in thousands of mammals and other ocean life. She tells the reader what Web sites to visit and what they can write to their elected officials to raise awareness of the devastating effects of high intensity sonar used, for example, by the U.S. Navy.

I found, after reading *Gray Matters*, that I remember feeling much the same as Ms. Lerner describes in her poems. Reading her experience did not open sore wounds for me, but allowed me to more vividly recall and move through my memory of the stages following my brain injury. Most important, I think, is Ms. Lerner's hope that we need to better understand that brain injury can happen to anyone we know at any time, and that life is forever changed for the survivor and the people to whom they are connected.

Frank Meeuwis is a member of the Tennessee Traumatic Brain Injury Advisory Council and project director of People Talking to People at The Arc Tennessee. Mr. Meeuwis sustained his brain injury on March 15, 1997.

NEWS FROM PATHFINDER

BY MICHAEL FLOYD AND ANGELA BECHTEL

As the school year winds down, kids of all ages anxiously anticipate Summer, their favorite time of year. For parents, however, Summer can be stressful, with the challenge of securing appropriate, affordable activities to fill the expanse of unstructured days. A Nashville mom, who has a child with autism, recently expressed the following: "Not only is it difficult to find programs and activities that my child actually enjoys, but then there is cost to consider. Limited options and limited resources can take the fun right out of the season."

Fortunately, there are many recreational activities across the State that either welcome children with disabilities or are designed specifically for them. Families across Tennessee can go to the Pathfinder Web site, www.familypathfinder.org, search under the "Arts and Recreation Programs" service category and find dozens of recreational resources.

The biggest statewide organization is Special Olympics of Tennessee. Special Olympics provides opportunities for people with disabilities of all ages to compete in many different sports. Bowling, soccer, Summer Games, and flag football are just some of the activities available throughout the year. Log onto the Special Olympics Web site at specialolympicstn.org to find your local chapter and get more information.

There's a growing demand for recreational activities that children with disabilities can enjoy and many organizations are striving to meet that demand. The Cox Family Martial Arts center, located in Murfreesboro, specializes in training kids in the art of Taekwondo. Back on their lineup because of popular demand is "Caden's Kickin Buddies". This program is specifically tailored for children with disabilities and provides therapeutic martial arts training.

The Special Needs Athletics program was created in Beech Bluff, Tennessee, to serve the wider Western Tennessee region. It began at first as a baseball league for children with disabilities and it has grown to include bowling, basketball, miniature golf and soccer. There are approximately 120 people in each league and they are currently fundraising to expand their facilities.

So while it may seem overwhelming to find activities for children during the Summer, there are some great resources and programs out there. Visit the Pathfinder Web site for this information, as well as our recently published *2010-2011 Directory of Supports & Services*. This Directory, formerly printed and bound, is available for anyone to download and print. The Directory contains more than 1,800 agencies throughout the State that provide over 4,000 programs for individuals with disabilities.

As the statewide clearinghouse for bilingual disability information and resources, Pathfinder's goal is to ensure that people with disabilities,

family members, service providers and advocates can readily access information about community resources. If you are aware of disability resources that we have not included, please let us know. We appreciate the help of the numerous individuals and organizations who assisted us in the compilation of this directory.

www.familypathfinder.org

1211 21st Avenue South, 539 Medical Arts Building, Nashville, TN 37212
1-800-640-4636
615-322-8529
Fax: 615-322-1700
www.familypathfinder.org

Hispanic Resources
www.caminoseguro.org

Angela Bechtel, MSSW, is information & referral services coordinator with Tennessee Disability Pathfinder.

Michael Floyd is a sophomore at Vanderbilt University studying Economics. Mr. Floyd is a member of Vanderbilt Student Government and works for Tennessee Disability Pathfinder in the work study program.

FOR FURTHER INFORMATION **Tennessee Disability Pathfinder**

English & Español
(615) 322-8529
(800) 640-4636

TTY/TDD users:
please dial 711 for
free relay service

www.familypathfinder.org
tnpathfinder@vanderbilt.edu

Tennessee Disability Pathfinder has phone, Web and print resources in English and Spanish to connect the Tennessee disability community with service providers. Referral services, free of cost, are provided to persons with disabilities, family members, service providers and advocates. Pathfinder is a joint project of the **TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES** and the **VANDERBILT KENNEDY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES**.

I AM INVISIBLE

MULTICULTURAL SERIES - PART FIVE

"I am invisible, understand, simply because people refuse to see me ... I was looking for myself and asking everyone except myself questions which I, and only I, could answer ... That I am nobody but myself."

– from *Invisible Man* by **Ralph Ellison**

Photo by Marcus Beard



BY TRACY PENDERGRASS The impact of disability is universal. Yet there is very little discussion about how disability affects the perceptions of identity according to race, ethnic group, gender, sexual orientation and religion. The concept of identity often is viewed as a means of self-categorization. However, identity is a social construct; how a person may view themselves can be shaped by the labels society places on them. Disability may overshadow the "other" identities of a person, that is, race, gender, age and sexual orientation. Not because the person with the disability uses this singular identifier, but because society refuses to see the person as a complete individual.

Floyd Stewart, director of Accessible Builders Consortium, is an African-American man with quadriplegia. Mr. Stewart can be described as a person with a deep faith in God and a powerful commitment to advocating for people with disabilities in his community. Unlike those born with a disability, Mr. Stewart acquired his disability from an accident as an adult. "What I found out was that people with disabilities are discriminated against more or as much as black people in America. It's the same way [discrimination] in a lot ways for people with disabilities, but it's actually more overt."

Disability discrimination is particularly blatant for individuals with disabilities who are regarded as "ugly" or for individuals with cognitive disabilities. Mr. Stewart adds, "I don't know, sometimes people treat you like you are less because you have a noticeable disability."

A person with a "hidden" disability may choose to alternate between their "other" identities in certain circumstances. These situations highlight the complexities of identity for persons with a disability, especially individuals of color. Dymaneke Mitchell, PhD, assistant professor of Education at National Lewis University in Chicago, addresses these complexities in her article "Flashcard: Alternating between Visible and Invisible Identities" in the journal *Equity & Educational Excellence*. Students who are labeled as "special" or do not act "normal" like their typically developing peers may be viewed as rebellious or delinquent.

Dr. Mitchell uses her personal experiences as an African-American woman who is deaf as a foundation for the article. "My experiences in schools as a female of color with a disability often involve my attempts to resist dominant ideas about my blackness, my femaleness, and my disability." Dr. Mitchell asserts that having a healthy holistic self-image instilled by her family allowed her to develop the tools to become a self-advocate when faced with negative stereotypes about disability, race or gender. "I act outside of dominant constructs that define condition and inform educators about what is considered normal and correct for bodies or beings of color who are of a particular gender, and who possess only certain degrees of ability."

Different cultural values can have a huge influence on the way persons with disabilities are viewed, not only within their families, but also their roles within society. Aram Torabian, Kurdish outreach coordinator for Tennessee Disability Pathfinder, explains that the stigma of disability, particularly a mental health diagnosis or an intellectual disability, is much harder to acknowledge in Middle Eastern cultures than a physical disability. "It [disability in general] stays hidden within the trusted circle of the family. Families typically do not seek help from community agencies."

Political oppression in some countries is the reason for the lack of disability awareness and advocacy training. Mr. Torabian states, "Due to government suppression, some Middle Eastern immigrants with family members with disabilities may have not had access to disability education, assistive technology or advocacy training. Research in the areas of disability and cultural awareness has developed slowly in the past 10 to 15 years."

Navigating the issues of identity for individuals with disabilities is a matter of acceptance. We must choose to see individuals with disabilities completely, not by the labels or by the misconceived perceptions based on their disability.

Tracy Pendergrass is program coordinator of Disability Resources for Tennessee Disability Pathfinder at the Vanderbilt Kennedy Center and a former intern for the Council on Developmental Disabilities.

TENNESSEE SPOTLIGHT



Photo by Jon Kent

Carol Rabideau, LCSW, social worker with the **Vanderbilt Kennedy Center for Excellence in Developmental Disabilities**, has received a **Commitment to Service Award** from the **University of Tennessee College of Social Work**, where she is an adjunct faculty member. This award recognizes a social worker who has served as a field instructor for more than five years or has taken on the role

of providing field instruction or coordination of field placements for multiple students. Ms. Rabideau has supervised students for 17 years and she is active in the Vanderbilt Kennedy Center's **Leadership Education in Neurodevelopmental and Related Disabilities (LEND)** training program.



Photo by Ned Andrew Solomon

Tennessee Disability Pathfinder's proposal to present "Disability Etiquette & Accessibility: Providing I&R Services for People with Disabilities" at the **AIRS Conference** has been accepted. The June conference was held in Detroit/Dearborn, Michigan. AIRS is the national Information & Referral professional organization and, with this presentation, Pathfinder staff

member and recent Partners graduate, **Megan Hart**, explained how I & R services of all types can better serve individuals with disabilities.



Marion Bacon and daughter, Michelle Malone.

On Saturday, May 7th, at the DeSoto Civic Center, Partners Graduate **Marian Bacon** (97-98) received her **Associate's Degree in Social Work** from **Southwest Tennessee Community College**.



Photo by Dena Gassner

Left to right: Patrick, Katie and Casey Kelty.

Youth Leadership Forum graduate **Patrick Kelty** (2007)—**Centennial High School Class of 2010**—began his college career on May 2nd at **Beacon College** in Leesburg, Florida. He completed the Summer term in May and will return for classes in the Fall.



Dena Gassner, LMSW, Partners 07-08 graduate, director of the **Center for Understanding** and facilitator for the **Transparency Project** with the **disAbilities Resource Center of Williamson County**, gave testimony to the "**Envisioning the Future Summit**" in Detroit, Michigan, held by the **Administration on Developmental**

Disabilities. Ms. Gassner discussed the needs of individuals with non-intellectual disability autism spectrum conditions, focusing specifically on the lack of postsecondary programming and the gaps in services for vocational transition.

Ms. Gassner also has joined the **Tennessee Autism Summit** team, a statewide collaboration of agencies, universities and stakeholders that addresses the needs of individuals and families affected by autism spectrum challenges.

TENNESSEE SPOTLIGHT wants to hear great things about YOU!

- Have you or your family member been accepted into or successfully completed an educational program?
- Have you or your family member received a nomination or an award for your wonderful work in the community?
- Have you or your family member been hired for a new job or gotten a recent promotion?

Send your good news and pictures by e-mail to: **ned.solomon@tn.gov** and we'll make every attempt to get it in an upcoming issue of **Breaking Ground!**

PARTNERS IN POLICYPMAKING 17th ANNUAL REUNION CONFERENCE

Photos by Christy Wells-Reece



BY NED ANDREW SOLOMON

The Partners in Policymaking 17th Annual Reunion Conference took place

February 25-26, 2011, at the Embassy Suites in Franklin, and approximately 120 current Partners, Partners graduates, presenters and support staff attended. The event featured national keynote speakers Mark Goffeney and Geri Jewel, breakout sessions on the CHOICES program, Mediation and Due Process, People First of Tennessee, transition/employment programs for persons with disabilities, and guide dogs and other kinds of assistive technology. Attendees also experienced William Edington's state and federal legislative update, and Bob Nicholas' report on current trends for employing persons with disabilities.

Of course, the Reunion would not have been complete without Friday night's after-dinner dance, and time for old friends to catch up and meet the members of the 2010-11 Class.

VANDERBILT UNIVERSITY

Vanderbilt Kennedy Center
PMB 40
230 Appleton Place
Nashville, TN 37203-5721

Return Service Requested

Nonprofit Org.
U.S. Postage
PAID
Nashville, TN
Permit No. 85



MEMBERSHIP AND STAFF

COUNCIL CHAIRPERSONS

Stephanie Brewer Cook, Chair
Roger D. Gibbens, Vice Chair

COUNCIL MEMBERS

Sheri Anderson, Murfreesboro
Norris L. Branick, Jackson
Tina Ann Burcham, Counce
Cynthia R. Chambers, Jonesborough
Tonya Copleland, Nashville
Barron A. Garrett, McMinnville
Nancy Hardin, Dyersburg
Pamela Huber, Kingsport
Tommy Lee Kidd, Lawrenceburg
Diane T. (Sandi) Klink, Memphis
Renee M. Lopez, Nashville
Sheila Moore, Brentwood
Debbie Riffe, Humboldt
Elizabeth Ann Ritchie, Knoxville

Steven Sheegog, Memphis
Joyce Sievers, Smithville
Marilyn L. Sortor, Memphis
Sarabeth Turman, Waynesboro
Katherine A.T. Watson, Sale Creek

STATE AGENCY REPRESENTATIVES

Andrea L. Cooper
Department of Human Services,
Division of Rehabilitation Services
Joseph E. Fisher
Department of Education,
Division of Special Education
Jim Henry
Department of Intellectual and
Developmental Disabilities
Ted R. Fellman
Tennessee Housing Development Agency
E. Douglas Varney
Department of Mental Health

Richard Kennedy
Commission on Children and Youth
Mike Hann
Commission on Aging and Disability
Cathy Taylor
Department of Health,
Maternal and Child Health
Patti Killingsworth
Bureau of TennCare

UNIVERSITY CENTERS FOR EXCELLENCE REPRESENTATIVES

Frederick Palmer
University of Tennessee Boiling Center
for Developmental Disabilities
Elisabeth Dykens
Elise McMillan
Vanderbilt Kennedy Center for
Research on Human Development

PROTECTION & ADVOCACY

Shirley Shea
Disability Law & Advocacy Center of Tennessee

LOCAL NONGOVERNMENTAL AGENCY

Alexander N. Santana
Multicultural Project

COUNCIL STAFF

Wanda Willis, Executive Director
Errol Elshain, Director of Development
Mildred Sparkman, Administrative Secretary
Alicia A. Cone, Grant Program Director
Lynette Porter, Fiscal Manager
Ned Solomon, Director, Partners in Policymaking™
Leadership Institute
William Edington, Public Policy Director
JoEllen Fowler, Administrative Assistant