

# COALITION QUARTERLY

## EMBRACING OPPORTUNITY IN 2011

Welcome to 2011, a year of beginnings for a new administration, and a new General Assembly. As 2011 gets underway, it is a time to reaffirm our core agenda and to share it with our new leaders in Tennessee.

### **Our Agenda – Individualized Empowerment**

The late disability rights hero, Justin Dart wrote of the ability of individualized empowerment to transform not just the lives of people with disabilities, but all people. It strengthens individuals, families, communities, and the American way of life.

Our goal in Tennessee is to create a culture that focuses the full force of science and free enterprise on the individualized empowerment of all people to achieve their unique, personal, God-given potential. It is based on the value that every human life is equally sacred and equally worthy of personalized empowerment to achieve his or her best possible independence, productivity, and place in the community.

The empowerment of all is the American Dream. It is the pledge of liberty and justice for all. It is familiar work. Good families and businesses do it. They give the tools of empowerment to their members so that each can be more self-reliant and contribute to the whole.

Too often, this is not the way we approach supports and services for those with disabilities. Structures are put in place to try to provide the minimum necessities of life to every person – but we frequently do it in messy and unwittingly degrading ways. As a result, we make people with disabilities beggars and prisoners to disability, robbing people of their health, productivity, prosperity and pride.

The budget crisis and the change of leadership in our state provide a fresh start, an opportunity to shift our paradigm and do things differently. The new paradigm should be one

of rights, responsibilities, and return on investment. Supports and services for people with disabilities need to be organized efficiently and effectively. They need to be focused on ways to give individuals, families, and communities the tools they need to move into the mainstream, to be productive, and to fully participate in our American way of life.

We need to make a shift – state government policies need to invest in people with disabilities, rather than to just “take care” of them. Police, prisons, substance abuse, and welfare cost far more than quality education and employment opportunities. Institutions, hospitals, and nursing homes cost far more than home- and community-based services. Unemployment, underemployment, welfare, and charity cost millions in crisis spending and lost productivity.

A new year and new leadership give us reason for renewed optimism. Building a culture of individualized empowerment in Tennessee will give ALL of its residents opportunities for productivity, an improved quality of life, and a strengthened social, economic, and cultural environment to share.



“Each day we choose. We can choose indifference. Or we can choose to make a difference. We can choose to view adversity as opportunity. We all have the freedom to choose how we view our situation. In coalition with others who share our vision we can reach our destination: The choices are ours. The future is ours. The world is ours. If we choose.”

—Fred Fay

Leader of the campaign for accessible transit in Washington, DC, 1965; cofounder of the Boston Center for Independent Living and the American Coalition of Citizens with Disabilities; instrumental in development of adaptive computer technology.

# THE COALITION'S POLICY AGENDA: PAST, PRESENT, AND FUTURE

Each year the Coalition's member organizations collaborate on a public policy agenda to further our mission of creating opportunities for adults and children with disabilities to be a part of the mainstream of community life. There are more than a million Tennesseans of all ages with disabilities of many types. They are a significant part of the human capital that is Tennessee. Developing the supports and systems to put that capital to good use is a critical public policy goal.

Over the past two decades Tennessee has created solutions of public-private and state-local partnerships to implement essential "infrastructure" services for children, families, seniors, and people with disabilities. This is because it is in everyone's best interest to have as many citizens as possible be productive, independent, contributing members of their communities.

Historically, the presence of a disability has meant that an individual is likely to be poorer, less educated, less healthy, and have less access to the community than others. Disability touches just about every aspect of state government work. For example:

- **Education** – Children with disabilities face more challenges than typically developing children in accessing and making effective use of a quality education. **In Tennessee 29% of adults with disabilities have less than a high school diploma, compared with 10.6% of those without disabilities (American Community Survey, 2008).**
- **Employment** – For working-age adults with disabilities in Tennessee, unemployment is a way of life. Because of the need to keep public health insurance benefits, many are not able to go to work. Because of barriers to employment, including discrimination, many cannot find work. **In Tennessee only 35% of working-age adults with disabilities have jobs (American Community Survey, 2008).**
- **Health care** – People with disabilities who have special health care needs have more difficulty accessing, obtaining, and paying for health care services. Without good health, productivity and independence are impossible. In health care provision, as in many aspects of state government, people with disabilities are the canaries in the mine. They are the first to suffer the failure of the systems designed to support citizens and communities.
- **Long-Term Care** – This is a vitally important issue for individuals, especially with significant disabilities. Without adequate home- and community-based services, individuals may not be able to get out of bed or eat – let alone get a job, support themselves and their families and build a life in the community. Institutional care is too often the service of first resort, and one at greater expense to the state.

A commitment to provide cost-effective, humane, and enabling services to people with disabilities is one of the most important jobs of state government. Failure to make this commitment risks the loss of human potential for Tennesseans today and poses greater costs in lost productivity for the state down the road. It is here where we support or waste human capital.

With this in mind, a significant part of the Coalition's policy agenda is to help policymakers understand the most effective and efficient ways to invest limited dollars on behalf of people with disabilities and their families. When the state does so, it is investing in the future and feeds our economic engine in ways that promote personal independence, generate jobs, and enable families to care for themselves.

# COALITION LEGISLATIVE RECOMMENDATIONS FOR 2011

**Funding for the Family Support Program** – Since 1992 the Family Support Program has assisted thousands of families who are working hard to maintain their family members with disabilities at home. The Family Support Program is widely recognized as one of the most successful services in Tennessee. This is documented by annual consumer satisfaction surveys that are maintained by the state. Today the Family Support Program serves approximately 4,300 families. In the past 2 years the \$7.2 million allocated for the program was eliminated from the state's recurring budget. It has only continued because of federal stimulus money. This funding is soon ending, and the program will end unless the Family Support Program is returned to the state's base budget.

**Children with Hearing Loss** – The Coalition program, Family Voices of Tennessee, provides family-to-family supports to parents of young children who have been diagnosed with hearing loss. Many of these families struggle to get their children the hearing aids they need. We do not believe that a child's ability to hear should be determined based on family income.

Thanks to Clare's Law, Tennessee now requires that all newborn babies be screened for hearing loss. To diagnose deafness and then fail to provide intervention is unacceptable. Research shows that by the time a child with hearing loss graduates from high school, more than \$400,000 per child can be saved in special education costs if the child is identified early and given appropriate educational, medical, and audiological services.

**Death Penalty and Mental Illness** – The mental health community in Tennessee, including the National Alliance on Mental Illness (NAMI), Disability Law & Advocacy Center of Tennessee, and dozens of other advocates working on issues affecting those with mental illness and disability, are proposing a law that will exclude people with severe and persistent mental illness (SPMI) from the death penalty. Under the proposed law, life without the possibility of parole would be the maximum punishment for violent offenders with SPMI.

Life without parole provides swift justice for surviving families and ensures violent offenders remain behind bars – away from society. The Coalition membership voted to support this effort. Our state already excludes people with intellectual disability from the death penalty. This law would simply treat people with SPMI the same way as we already treat people with an intellectual disability.



## DISABILITY DAYS ON THE HILL

Empowerment, inclusion, and education are hallmarks of Disability Days on the Hill. This unique three-week event at the General Assembly in Nashville provides a unique opportunity for people with disabilities, their families, and friends to meet with legislators, build relationships, and discuss important issues facing our state.

**February 23** – West TN Residents

**March 2** – Middle TN Residents

**March 9** – East TN Residents



**Disability Days On The Hill**

To learn more about how you, family, and friends or an organization can participate in DDH, contact Courtney Jenkins-Atnip at (615) 383-9442 or [ddh@tndisability.org](mailto:ddh@tndisability.org).



# FAMILY-TO-FAMILY OUTREACH CONFERENCE



Family Voices of Tennessee is excited to announce our 2nd annual Family-to-Family Outreach Conference. This year's focus will be transitions, and will include two breakout sessions and feature keynote speaker James E. Maurer.

## **Legal Options**

Many families hear about conservatorship or special needs trusts but don't understand the process of securing one. Mr. Maurer will draw upon his years of legal experience to shed light on these and other options. In doing so, he will address important questions such as "who needs a conservatorship or trust?" and "what are the most important considerations in crafting them?"

## **Breakout Session #1 – Employment and Community**

Representatives from the Center for Independent Living of Middle Tennessee, Work Incentive Planning Assistance Program, Tennessee Career Centers, and Vocational Rehabilitation will be on hand to discuss the resources and supports offered to young adults as they enter the work force and the community. The speakers will be available during lunch to have small table discussions with families.

## **Breakout Session #2 – Health Care and Your Youth**

Family Voices and Vanderbilt Pediatric Nurse Practitioner Jennie Bowers will discuss the changing roles around health care for families as their youth become adults. Discussions of how to approach uncomfortable topics will help families facing with these situations and decisions. Many families know what typical health care encounters are like for growing youth but may be uneasy about addressing certain issues for children with significant disabilities. Topics that may be addressed include puberty, physical exams, and recommended vaccines such as the HPV Cervical Cancer vaccine.

## **Fellowship and Networking**

Families will have an hour and half to enjoy lunch, network with other families, and to visit with the vendors who will be focusing on transitioning youth with special health care needs to adulthood. Vendors will include state programs such as Children's Special Services and private agencies that provide support to families and youth in the midst of transition.

After lunch, families will enjoy a parent and youth discussion panel. Panelists will include families who are at different stages of transition and also those who have accessed different types of services. A family will be among the panelists to share experiences from both a parent's and a youth's perspective.

## **For Registration and More Information**

Please call (615) 383-9442, email Tonya Bowman at [tonya\\_b@tndisability.org](mailto:tonya_b@tndisability.org) or see the conference announcement at [www.bit.ly/tnfamily](http://www.bit.ly/tnfamily). For more information about Family Voices of Tennessee, visit [www.tndisability.org/familyvoices](http://www.tndisability.org/familyvoices).

**Conference Co-Sponsors:** Library Services for the Deaf & Hard of Hearing at the Nashville Public Library and the Vanderbilt MIND/LEND Program.

## **CONFERENCE DETAILS**

**Date:** March 26, 2011

**Time:** 9am to 2:30pm

**Where:** Nashville Public  
Library

615 Church Street

**Cost:** \$10

*- includes parking/lunch -*

## GETTING-OUT-THE-VOTE

Last fall the Coalition led a statewide non-partisan Get-Out-the-Vote (GOTV) and civic engagement campaign. With the hard work of our six organizers and wide participation throughout many communities, our GOTV efforts were the most successful ever.

The Coalition registered hundreds of new voters! We attended more than 50 outreach events across the state, including non-partisan appearances at a variety of events related to Congressional and state legislative races as well as gubernatorial events. In doing so, our organizers served as a valuable resource to candidates when disability-related policy questions arose while also strengthening relationships and developing new alliances across the state.

Furthermore, we called more than 600 potential voters and hosted two calling nights just for the disability community. These events were instrumental to encouraging voters to get out and vote. These nights were also a lot of fun for



## YOUR SCHOOLS AND COMMUNITY: THERE'S MORE TO LEARN ABOUT TBI

A concussion is a Traumatic Brain Injury (TBI). Health care professionals may describe a concussion as a "mild" brain injury because concussions are usually not life-threatening. Even so, their effects can be serious. Brain injuries are the leading cause of death and disability for children, and this is just not talked about nearly enough.

Therefore, Project BRAIN is hosting a TBI Education Conference to talk about Mild TBI/ Concussion with families, school staff, athletic trainers, community members and everyone who wants to learn more.

The TBI Education Conference will be 8am-4pm February 22, 2011 at the Gaylord Opryland Resort and Convention Center.

The theme of the day will be the continuum of care for individuals with a Mild TBI/ Concussion. Introducing the topic will be **Ann Glang, PhD**, a Special Education Researcher who also directs several Department of Education projects on childhood brain injury at the Teaching Research Division of Western Oregon University.

**Dr. Gary Solomon** will be speaking about Mild TBI/ Concussion in sports, as well as the neuropsychological concerns and care for those who've experienced a TBI. Dr. Solomon is an Associate Professor in the Departments of Neurological

everyone involved! We are so proud of this campaign and all the work the organizers did on the Coalition's behalf!

### The Next Step

It is our expectation that the successful GOTV campaign will serve as a springboard for our Disability Action Network. The purpose of the network is to energize and coordinate grassroots activities among people with disabilities for the purpose of promoting positive public policy changes.



One organizer told us that when she spoke to new voters they were shocked that their voice mattered! We believe this is exactly why an informed, organized network is critical to demonstrating the strength of our community so that people with disabilities can make meaningful contributions to public policy decisions at the General Assembly this spring. To learn how you can help, contact **courtney\_j@tndisability.org**.



Surgery and Psychiatry at Vanderbilt University Medical Center, Team Neuropsychologist for the Nashville Predators and the Consulting Neuropsychologist for the Tennessee Titans.

**Michael de Riesthal, Ph.D., CCC-SLP** will be presenting strategies for working with focus and attention changes experienced by some students with TBI. Dr. de Riesthal is the Director of the Pi Beta Phi Rehabilitation Institute at Vanderbilt Bill Wilkerson Center.

In addition to our featured speakers, you can expect a morning and afternoon panel of experienced, impassioned professionals. The TBI Education Conference will be a day of learning, and you will leave with the knowledge of what to do about Mild TBI/ Concussion as you'll experience it, personally, professionally, and in your community.

Our Conference Registration is full! We will be posting information and resources discussed at the Conference on the Project BRAIN website after the event.

To learn more about Mild TBI/ Concussion now, visit our website: **www.tndisability.org/brain**; or call us at (615) 383-9442 ext. 8616.



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*Placing one foot in front of the other, I've climbed to higher lengths. Reaching beyond my own limitations, to show my inner strength. No obstacle too hard, for this warrior to overcome. I'm just a man on a mission, to prove my disability hasn't won.*

—Robert M. Hensel



T E N N E S S E E  
D I S A B I L I T Y  
C O A L I T I O N

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