

BREAKING GROUND

SPECIAL ISSUE ON

SELF-ADVOCACY



[4] TALKING BOOKS ANNIVERSARY



[8] NEXT CHAPTER BOOK CLUBS



[18] TENNESSEE SPOTLIGHT

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Top left: Andrew Cameron (photo by Ned Andrew Solomon)

Bottom left: (Left to right) Tina Williams, Michele Adams and Jessica Horner (photo by Ned Andrew Solomon)

Center: William Lovell (photo by Kelly Ray)

Top right: (Left to right) Kelsey Herzog and Preston Vienneau (photo by Ned Andrew Solomon)

Bottom right: Megan Hart (photo by Pam Grau)

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WILLIAM LOVELL:

SELF-ADVOCATE, TRAINER, COMMUNITY LEADER

BY COURTNEY KELLY

In May of 2011, people who have been a part of the Becoming a Person-Centered System had a chance to celebrate, reflect and share their learning with each other at Tennessee's First Person-Centered Gathering. Over 100 people met at Montgomery Bell State Park and spent two days together. The agenda included presentations about emerging best practices in Tennessee regarding positive behavior supports, person-centered outcomes and actions, Level 3, or system-wide, changes, using person-centered tools for management and self-advocate training, just to name a few.

The highlight of the Gathering was a panel of Self-Advocates (People Planning Together) who shared how their lives have changed for the better, how control of their lives had returned to them, and their hopes and dreams for the future.

People Planning Together (Self-Advocate Training) is a two-day training that teaches people how to write a person-centered plan for themselves, and teaches staff how to support self-advocates in better ways. The training focuses on empowerment: teaching people to share what's important to them and how to have an active voice in the planning process. Currently, there are 13 credentialed trainers who are available to provide the training. This group includes four self-advocates who travel statewide with their support staff and facilitate the training. William Lovell is one of the self-advocates.

This year, Mr. Lovell entered The Arc US "Achieve with Us™" contest, sponsored by *ABILITY Magazine*, and was one of the top ten vote-getters. The top entry of the inspirational essay contest won a trip for two to Washington, D.C., and the opportunity to share his story with representatives on Capitol Hill.

Please read "Finding Your Voice" below and learn about Mr. Lovell in his own words.

Hello. My name is William Lovell. I was born in Roseville, Michigan, in 1973, where I lived with my parents and two sisters. When I was 13, my family moved to Hohenwald, Tennessee. I graduated at Lewis County High School and attended most of my classes in the Special Education classes. I started attending Buffalo River Services, Inc. when I got out of high school.

I have always been a very shy person and was not out in the community very much. The agency introduced a program called community participation and that opened up a whole lot of opportunities for me. You see—I have an intellectual disability but I have not let that stop me from doing the things I want to with my

life. I have my own apartment and live by myself.

I have been working at WalMart since April 2002. I love my job very much and would not want to work anywhere else. I am an active member of the Blondy Church of God, People First of Tennessee and the Lewis County Historical Society.



Photo by Rosie DePriest

I have been involved with the Person-Centered program since 2008. I am a certified trainer for the Person-Centered Planning Together program. I have been to several different agencies throughout Tennessee teaching others how to write their own plans and how to find their voices. I won the Self-Determination Award for Tennessee in June 2008. I traveled to Portland, Oregon, to attend the annual Gathering for Person-Centered Programs.

I met a lot of new friends and did a lot of "firsts" for me, such as riding an airplane, riding street cars, going down tunnels under the city, and standing up and making presentations to strangers. I sat on a panel with Michael Smull, at the MegaConference held in Nashville, to tell of my experiences with Person-Centered programs. I recently graduated from the Partners in Policymaking training this year, where each month we had to make presentations on several different subjects. I was so nervous at first but everyone was very encouraging and made me feel welcome.

When I am not working, I assist with Meals on Wheels for the local Senior Citizens Center, water flowers in the downtown area for the Lewis County Pilot Club and assist with October Heritage Festival Activities each year.

I am a registered voter and take this very seriously. I take care of paying my own bills and live independently on my earnings from my job. I want others to know just because you may have a disability, you can do anything you set your mind to. Sure, I still need assistance at times and sure, I still get nervous trying new things and meeting new people, but that does not mean I will not try. The sky is the limit!!!

Courtney Kelly is director of Person-Centered Practices with the Department of Intellectual and Developmental Disabilities.

A SPEECH ON THE ANNIVERSARY CELEBRATION OF TALKING BOOKS

BY ANDREW CAMERON • JULY 6, 2011



Photo by Ned Andrew Solomon

(Left to right) Governor Bill Haslam, Gabrielle Ward, Andrew Cameron and Marty Blackford.

On July 6th, the Library of Congress celebrated the 80th anniversary of its Talking Book and Braille program that serves people who are blind or have other disabilities that prevent them from reading books in the traditional manner. The free library program services people ranging from preschoolers through retired readers. It sends books on digital cartridges and players, as well as Braille books, to users by mail at no cost. People who use the program also can download audio books and magazines online or order them in Braille. The collection includes 400,000 titles, as well as free subscriptions to audio magazines, including Sports Illustrated,

Consumer Reports and National Geographic.

On July 6th, Tennessee's Library for the Blind organized a reception in the Old Supreme Court Chambers in the Tennessee Capitol to commemorate this date. Dignitaries were invited to attend and speak, including Tennessee Secretary of State Tre Hargett and Governor Bill Haslam. In addition, a panel of Talking Book users shared their personal reflections on the role this technology has played in their lives.

Particularly poignant was a speech by Andrew Cameron, captured in its entirety below.

I would like to say hi to all of the guest speakers, participants and special guest[s]. Thank you for inviting me to tell my story. My name is Andrew Cameron. I am 17 years old and will be a junior at Middle College High School in Williamson County. I want to tell you about me and how important Talking Books have become in my life.

I was diagnosed in Kindergarten with ADHD [Attention Deficit Hyperactivity Disorder], and in 3rd grade, at Vanderbilt, with dyslexia, and then in 5th grade, at Walter Reed Medical Center, with high functioning Autism. I guess they could not make up their minds...

Since my first OT [occupational therapy] evaluation in 3rd grade, all areas of my visual processing were very low. I have good vision, but I cannot process things like cursive and some types of fonts. I often get daily headaches when I try to read a document that has too many words, lines or fancy art work. Using Talking Books reduces the amounts of headaches I have.

When I was in 5th grade, I was reading on a 1st grade level. Teachers would tell me and my family to just keep practicing to read. My mother then decided to homeschool me, and she did so for 6th and 7th grade. With the help of speech therapy and specialized reading instruction during my two years of home school, I could read much better, but still not as well as everyone else. I used Talking Books to keep me listening to novels that other kids read while I was working hard on learning to read.

Since my mom is a teacher, we have bookshelves full of books of all different reading levels; silly and serious books, fiction and nonfiction books. Even by 5th grade, I could only look at the pictures in those books. I never enjoyed reading because I only knew a few words.

Reading is still difficult because I lose my place a lot and I skip over all the words I don't know.

Talking Books helps me recognize the word when I see it. Also, listening to the story takes the stress away from reading words and allows me to understand what is happening.

Before using Talking Books, I was never able to be like everyone and read books by myself. When in elementary school, I would pretend I was reading in class. My parents had to help with my homework when it required me to read something. So, you can imagine how long it took me to finish my homework each night.

Keeping up with time is hard for me, but all I could remember was how stressful it was, doing homework each night. I was worn out from working so hard and long on just reading words. Once I started using Talking Books to listen to novels during home instruction, my mom could give me an assignment and walk away. I could listen and answer

comprehension questions independently.

Since I have been back in public school, I have been able to be involved in discussion of novels like *The Crucible* and *The Great Gatsby* without depending on an adult to read to me.

Currently, I am expanding the use of technology to help prepare me to read other types of documents, like job applications and memos, for my future work environment.

My mother found out about Talking Books when she attended a CHADD conference (Children and Adults with ADHD) and an IDA conference (International Dyslexia Association). My mom still wants to help me with homework, but now I have to keep reminding her, "I can do it by myself."

Thank you again for inviting me.



Andrew Cameron

Photo by Ned Andrew Solomon

BREAKING GROUND

Tell us what you think – all year long!

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In the past, we've included a hard-copy survey in one of our *Breaking Ground* Spring issues, asking you to send us your comments about what you like the best, and the least, about our publication. Although we appreciate the few comments we receive each year, and try to implement those suggestions, we would love to have more than a "few" readers' responses!

We want our readership to know that you can tell us what's wrong, what's right, what we should do more of, what we should do less of, or just your opinion of a particular story or feature. Anytime you want to. All year long.

So, please speak your mind by contacting us at
breakingground@vanderbilt.edu

or by taking the on-line survey at
www.breakingground.org

Thanks for reading!

EXPANDING SELF-ADVOCACY EFFORTS IN TENNESSEE

BY COURTNEY TAYLOR

When the Administration on Developmental Disabilities (ADD)

approached national disability and self-advocacy organizations and called for the formation of state teams to expand self-advocacy efforts across the country, Megan Hart immediately was identified as being an ideal candidate for the Tennessee team. As coordinator of Education and Training Services at Tennessee Disability Pathfinder, Ms. Hart has been advocating for the rights of individuals with disabilities for years. However, her journey as a self-advocate began as a child.

"I have to give my family a lot of credit for encouraging me to become an effective self-advocate," said Ms. Hart. "I was always encouraged to make choices and express and follow my interests. For example, when I went to public school, I required a personal assistant. My family made sure that I was always involved in deciding who that person would be. I'm not sure that always happens with school-age kids. I learned from a very early age to advocate in terms of my own participation. I have lived my life not allowing my disability to prevent me from reaching for my own needs and desires."

Ms. Hart defines self-advocacy as a process of speaking up for oneself and being empowered to express one's own needs, goals and desires. Moving beyond that—and equally a part of the definition—is speaking up on behalf of other self-advocates.

"I attended a college in Tennessee that did not have much in the way of disability services," remembered Ms. Hart. "It was not a very accessible campus either, and I had a hard, if not impossible, time getting to my classes and other activities. I decided to advocate for more curb cuts and ramps into buildings. By the time I graduated, there was a beautiful stone ramp leading into the chapel and elevators in the buildings. It is an example of how speaking up for my own needs allowed other college students who use wheelchairs to reap the benefits. This is advocating for my own needs and the need of others."

The ADD Southeastern "Allies in Self-Advocacy" Summit was held March 10-11, 2011, and Ms. Hart was selected as the Middle Tennessee chair. In addition to the Vanderbilt Kennedy Center, organizations represented included the Tennessee Council on Developmental Disabilities, the Disability Law & Advocacy Center of Tennessee, the Tennessee Department of Intellectual and Developmental Disabilities, People First of Tennessee, National Youth Leadership Network, and University of Tennessee Boling Center for Excellence in Developmental Disabilities. In addition to Ms. Hart, members are Nicole Anderson, Leanne Boyce, Gina Brady, John Chase, Suzanne Colsey, Courtney Kelly, Gatha Logan, Jenness Roth and Wanda Willis.

Ms. Hart reported that Tennessee's representatives are committed to creating more opportunities for individuals with disabilities to become self-advocates. To achieve this, better access to information, resources and training will be developed through a collaborative network of organizations.



Photo by Pam Graub

Center: Megan Hart

The first order of business is to develop a self-advocacy resource center. This would be a central entity for providing training and disseminating information related to self-advocacy.

"I see a lot of room for growth in our state," Ms. Hart said. "There are so many organizations that work on behalf of people with disabilities to provide services, but the people who are accessing the services are not the people who are expressing how the services should be provided. I would like to see that changed. This is an exciting new initiative and I look forward to the important work ahead of us."

For information on national self-advocacy summits, visit the ADD Web site at www.acf.hhs.gov/programs/add.

Courtney Taylor is associate director of Communications and Dissemination at the Vanderbilt Kennedy Center.

BECOMING A PERSON-CENTERED ORGANIZATION

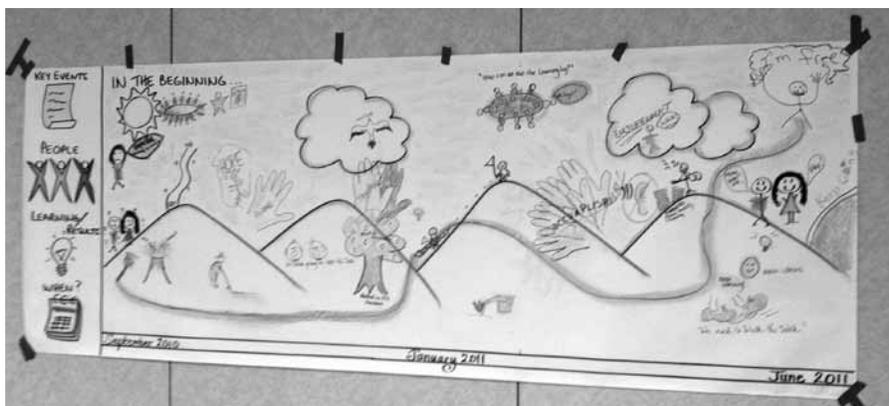
BY LAURA DOUTRE “Person Centered”

is something that people in the business of providing services and supports to people with intellectual disabilities strive to become. It is a way of doing business, a philosophy, a movement and requires a change in the way that business has been done. The Tennessee Council on Developmental Disabilities recognized that our State needed to make some changes in the way business was done and partnered with the Department of Intellectual and Developmental Disabilities (DIDD) to begin making those changes to the service delivery system that support people with intellectual disabilities.

In the Fall of 2010, the Council and DIDD continued efforts to move the service delivery system toward becoming a person-centered one by ensuring the work that began in 2007 did not end. Michael Smull, president of Support Development Associates (SDA), and his partner, Mary Lou Bourne, worked with DIDD to develop a project plan that includes adding five more project sites from across the State. With the new sites in place, DIDD would continue to train Person-Centered Coaches and Leaders, identify the barriers in the system that prevent person-centered work, and try to eliminate barriers wherever and whenever possible.

Pacesetters in Cookeville, Rochelle Center in Nashville, Support Solutions of the Mid-South in Memphis, Greene County Skills and Greene Valley Developmental Centers in Greeneville were selected as the sites. Independent Support Coordinators, Regional Office and Central Office staff, advocates from The Arc Tennessee, and staff from the Kennedy Center and the University of Tennessee were invited to serve as coaches or leaders at each of the residential provider agency sites, so that important partners' perspectives were recognized in the learning and the work that took place as a result.

For the first time, Tennessee Credentialed Person-Centered Thinking trainers provided the foundational two-day training for



Time line of achieving person-centered organizations in Tennessee.

everyone involved at a project site. The in-state capacity to provide this training is monumental in the movement towards a person-centered organization. Tennessee has the good fortune of having some outstanding trainers who are passionate about and dedicated to the people we are all paid to support. All of the trainers' time is given in addition to their duties in their current jobs. Their passion is contagious! The demand for the two-day training quickly outgrew the resources, so during the 2010-2011 fiscal year, six more people in the field began the process of becoming credentialed trainers. More than 1100 people in Tennessee have attended Person-Centered Thinking trainings as a result of the newly developed in-state capacity for trainers.

The learning at the new sites quickly resulted in recommendations for Level 3, or system-wide, changes needed to support a real person-centered organization. One of the barriers identified early on was issues related to Tennessee's Individual Support Plan (ISP). Since the ISP is the key to improving quality of life, the obstacles were addressed quickly. As a result, Tennessee developed a "Person-Centered ISP training". The initial training of this kind was completed in August 2011, and was very well received. Feedback from the session was overwhelmingly positive and participants felt it would definitely assist ISP developers and implementers support people to have a better life.



People in Tennessee who use DIDD services now have the opportunity to participate in self-advocate training. People Planning Together (Self-Advocate Training) is a two-day seminar that teaches individuals how to write a person-centered plan for themselves and helps others learn how to support them better. The training focuses on empowerment by teaching people to share what's important to them and to have an active voice in the planning process of their plans.

Over time, expectations are changing in Tennessee. People who use our services are expecting more, and deserve more, control over their lives. People deserve to be happy and listened to, and peoples' lives should be filled with things that are important to them. We need to continue learning and evolving to make sure that Tennesseans with intellectual disabilities have what we all want. The journey will continue until the system is truly person centered.

Laura Doutre is deputy director of Policy and Innovation with the Department of Intellectual and Developmental Disabilities.

Photos by Laura Doutre

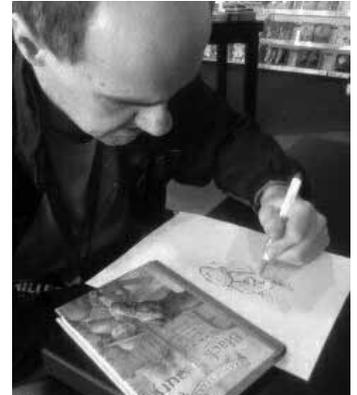
Photos by Lorrie Willbergh Crockett



Sevier County



Knox County



Anderson County

NEXT CHAPTER BOOK CLUBS TAKING OFF IN EAST TENNESSEE

BY LORRIE WILLBERGH CROCKETT

The East Tennessee
Technology Access

Center (ETTAC) has started seven Next Chapter Book Clubs (NCBC) in East Tennessee since receiving a grant from the Tennessee Council on Developmental Disabilities in July, 2010. The Book Clubs are scattered throughout Knox, Anderson, Blount and Sevier Counties.

Each club is as individual as the members who attend. One key factor in making the NCBCs successful is the wonderful volunteer staff, who use their creativity as they share stories and make the books real for NCBC members. It also helps that members have the ability and willingness to be flexible and try new things. E-mail and text messaging are used to communicate with facilitators between meetings and a Facebook page, "ETTAC Next Chapter Book Club", allows members and facilitators to share their great ideas.

The first NCBC started in Knoxville at Panera's, with the book, *Where the Red Fern Grows*, loaned by the Nisonger Center. That club is still reading their first book and hopes to finish it this month. They were also the first to use technology. Sara, one of the members, pulls out her Smart Phone whenever there's a word that confuses the group, and Google has become a wonderful resource!

The original group has transitioned into two NCBCs that meet at different tables on the same day and time. Noise is a factor, and speech amplifiers are going to be tried in the near future to see if they help. Two groups have had to change locations because noise interfered with their ability to hear others read out loud.

Another NCBC consists of a group of young ladies who have been

involved in a social group together for many years. They are currently reading *Beezus and Ramona*, and planned from the beginning to watch the movie together at a member's home as an end-of-book celebration. One of their volunteer facilitators brought embroidery to show the women and made paper bunny ears to illustrate a scene in the story.

The Anderson County Club meets at Books-a-Million. One of their facilitators made scones for their end-of-book party for *The Secret Garden*, and had ginger snaps and oatmeal cookies when they read *Black Beauty*. She reported that members were budgeting their finances to buy a copy of the book to keep and that they would also like to meet twice a week instead of once!

At the Emory Valley Center in Oak Ridge, the NCBC is incorporated into their "meaningful day" community activities. This seems to be a successful way to start a book club. If there is a center-based group with available staff or volunteers who are open to new activities, it's much easier to agree on time and place and get started quickly. This group includes a man who said he "hates to read". When asked what he likes to do, he said, "draw," and drew a picture of the book the group was reading. Sometimes it's easier to get people to participate when they're engaged "where they are", even if reading is far from their favorite activity.

Another NCBC meets in the public reading area of the Sevier County Library. This group consists of students who spend part of the day in classes and part of the day working. Within five minutes of hearing the NCBC presentation, they said, "OK, let's start today; the library has sets of books we can check out and let's go see what they have." This

group was reading the introduction to *The Outsiders* within the hour. They're using NCBC as a fun way to instill a love of books. This library has sufficient technology on-site and classroom sets of books available for groups to use.

A location was selected in Blount County a year before there was a club to meet there. The Blount County Library has a café in the lobby and ETTAC has a long-standing partnership with library staff because of their desire to be accessible to citizens in Blount County. The club was off to a small and slow start until the Maryville *Daily Times* wrote an article about the Next Chapter Book Club; then, within days, others were calling and expressing an interest in joining.

An ETTAC client once told us he had never been to a library because he couldn't read. This is one reason ETTAC embraces the "reading to learn" philosophy of NCBC that also supports library partnerships.

ETTAC's interest in starting NCBCs comes from our desire to find technology to help Book Club members read and communicate better. The Blount County Club includes a member who uses an augmentative communication device. Technology has been utilized to scan the books so this member can read aloud with everyone else. After the newspaper article highlighted this technology, another augmentative communication user called to join one of the Knoxville clubs. The

challenge is finding funding for this technology for adults. ETTAC is able to lend devices, when they are available. We believe everyone has a place in NCBC, even if a person can't read, speak or hold a book.

With a supporting grant from the Dollar General Literacy Foundation to provide literacy training to adults with disabilities, two members of the NCBC are expanding their literacy skills. We already have noticed a difference in one woman's reading confidence.

We have found interesting and inexpensive sources of books. Target has a line of classic books for \$1 from Dalmation Press and Books-a-Million has classic titles for \$3. Comparing on-line sources for each title has proven to save the clubs money as well.

NCBC has been a wonderful experience and we really look forward to expanding our program to other adjacent counties this year. If you are interested in joining or starting a club, please call the NCBC Coordinator at ETTAC, Lorrie Willbergh Crockett, at 865-219-0130.

Lorrie Crockett provides education technology services to clients, teachers, families and agencies through ETTAC's service area in East Tennessee. She has a Master's degree in Special Education from the College of New Jersey and years of training in the field of assistive technology.



SAVE THE DATE

The **2012 Tennessee Disability MegaConference**
will take place **May 31st** and **June 1st**
at the **Nashville Airport Marriott**



Photos by Ned Andrew Solomon

TENNESSEE YOUTH LEADERSHIP FORUM GRADUATES ITS 11th CLASS

BY NED ANDREW SOLOMON

It may have been a smaller than usual group of Student Delegates, but what they lacked in numbers, they made up for in energy and enthusiasm! Fourteen high school students from across the State gathered July 11-14 on the Vanderbilt University campus to hone their advocacy and leadership skills.

They heard presentations on overcoming personal obstacles, learning to speak up for themselves and others, getting ready for the working world, college resources for students with disabilities, and the legislative process. They also identified information about themselves for one-page plans, which outlined what was important to them and for them as they become adults and think about moving beyond high school.

Besides listening to national and local speakers, the Delegates participated in small discussion groups, where they talked about the presentations they'd attended and how the speakers' information was relevant to their own lives.

It wasn't all work. There was a drum circle, a tour of the Capitol, a talent show, and opportunity for the Delegates to visit the Vanderbilt bookstore, to take pictures of each other and their surroundings, and roam the Vanderbilt campus.

The Delegates had wonderful role models! Besides lead counselor

extraordinaire, Anthony Sledge, all of the staff were returning YLF graduates from previous years. I am so thankful for the creativity, compassion, intelligence and problem-solving skills of Tabitha Burns, Michele Adams, Tina Williams, Jessica Horner and Beth Hopkins. And all of us know we couldn't have done it without our incredible and exceptionally responsible Night Staff, Meredith Schlandt and Julia Henderson. Please tell me you'll all be back next Summer!

At the end, as we do every year, we asked the graduating YLF-ers to tell us about how the experience affected them. Their comments were illuminating and surprising.

What did you like about the Forum?

Social Interactions. Laughing. Loving. Supportive.

Learning how to love yourself.

I can be myself. I don't have to hide who I am. I met new people, learned new things, and most importantly, I loved the chance to have a new experience.

I got to meet new people and learn that I am NOT the only student out there that has a disability.

My attitude changed about ...

The perspective of people with different disabilities.

My disability. My way of seeing things in a new way. People with other disabilities.

How to talk about my disability.

How I feel inside about myself, as far as confidence and self-comfort.

How to be nicer to my mom, and not to blame my disability on her, because it's no one's fault. I hope to have a brand new life starting TODAY!

What I learned ...

To advocate for myself. Stay Healthy. Get back up.

Believe in yourself. Believe in others. Know what you want. Fulfill your dreams. Set new ones.

I learned that speaking up is important. That you can help other people with disabilities by being an example.

I learned that...it is ok to be different.

My voice can be heard and I can lead myself in any direction. I have control over myself and most important to me is that I'm not less important than anyone else, and I can only be set back by what I let set me back. And, even when I do get knocked down it's up to me to get back up.

Not to let anyone get you down, and always speak up for yourself.

What resources I will need for college.

I learned to speak up and not let people talk down to me.

I learned a lot about my disability, and what I can do to help myself throughout the rest of high school, college, and the rest of my life. I also learned that I never "need to give up".

Please join The Council in congratulating the following 2011 YLF Student Delegates:

RANDY BIGHAM, *Huntington*

CYNTHIA CACCIOLA, *Paris*

JOSHUA CARLTON, *Lewisburg*

WILLIAM "HK" DERRYBERRY, *Nashville*

KELSEY HERZOG, *Germantown*

TAYLOR JACKSON, *Germantown*

RONALD "JOSH" KEENER, *Knoxville*

CHRISTINA LYNN, *Big Sandy*

KIRA MCCALL, *Nashville*

MICHAELLA MICHAEL, *Tullahoma*

CHRIS PETULLA, *Chattanooga*

KENDYL SCHWINDT, *Hendersonville*

PRESTON VIENNEAU, *Nashville*

NAQUISHA WILLIAMS, *Nashville*

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



SELF-ADVOCACY NATIONAL RESOURCES

COMPILED BY COURTNEY TAYLOR **ADAPT** is a national grassroots community that organizes disability rights activists to engage in nonviolent direct action, including civil disobedience, to assure the civil and human rights of people with disabilities to live in freedom.
www.adapt.org/main

The **American Association of People with Disabilities** organizes the disability community to be a powerful voice for change—politically, economically and socially. The organization was founded to help unite the diverse community of people with disabilities, including their family, friends and supporters, and to be a national voice for change in implementing the goals of the Americans with Disabilities Act (ADA).
www.aapd.com

The Council on Quality and Leadership provides person-centered supports and services for people with disabilities, people with mental illness and older adults. Through its services, publications and public presence, the Council works to ensure that all people lead lives of dignity and quality.
www.thecouncil.org/factorthreedisability.aspx

Disability.gov is a federal government Web site that provides an interactive, community-driven information network of disability-related programs, services, laws and benefits. It promotes self-advocacy for students with disabilities by providing education resources.
www.disability.gov/education/student_resources/self-advocacy

The **Disability is Natural** Web site encourages new ways of thinking about developmental disabilities. Its resources are based on the belief that attitudes drive actions and changes in attitudes and actions can help create a society where all children and adults with developmental disabilities have opportunities to be included in all areas of life.
www.disabilityisnatural.com

The **Disability Rights and Independent Living Movement Project** was launched to capture the history of a remarkable movement by people with disabilities to win legally defined civil rights and control over their own lives. More than 100 oral histories with leaders, participants and observers of the movement in the 1960s and 1970s have preserved the living memory of the movement. A rich collection of personal papers and the records of key disability

organizations join the oral histories in the Bancroft Library at the University of California, Berkeley, comprising an in-depth research resource for the study of a contemporary social movement which has altered the social, cultural and legal landscape of the nation.
<http://bancroft.berkeley.edu/collections/drilm/index.html>

Qualitymall.org has a resource section that contains books, electronic media, on-line forums and other products that show the ways in which people with developmental disabilities are taking and can take greater control over their services and their lives.
www.qualitymall.org/directory/dept1.asp?deptid=2

The Riot is an e-newsletter for self-advocates about self-advocacy. A newsletter, blog, on-line art gallery, toolkits, games and services are provided to help individuals become stronger self-advocates.
www.theriotrocks.org/

Self Advocates Becoming Empowered (S.A.B.E.) believes that people with disabilities

- should be treated as equals;
- should be given the same decisions, choices, rights, responsibilities, and chances to speak up and empower themselves as everyone else;
- should be able to make new friendships and renew old friendships just like everyone else; and
- should be able to learn from their mistakes like everyone else.

It is a national self-advocacy organization with members and representatives from every state in the United States.
www.sabeusa.org/

TASH is an international association of people with disabilities, their family members, other advocates and professionals advocating for a society in which inclusion of all people in all aspects of society is the norm. TASH is an organization of members concerned with human dignity, civil rights, education and independence for all individuals with disabilities.
www.tash.org/index.html

Courtney Taylor is associate director of Communications and Dissemination And coordinator of the Disabilities, Religion, & Spirituality Program at the Vanderbilt Kennedy Center

MY EYES ARE MAKING PICTURES IN MY HEAD

BY NANCY W. MUSE Matthew Copaus is a 20-year-old aspiring filmmaker who has just produced his first film short, the very funny *The Comic Book Convention*, for the Nashville Film Institute's "Get Your Shorts On" competition. Mr. Copaus served as writer and director as well as the star of the film, which also features his father, Marvin. The director says he "saw the story in my head", and told it to his father, who then typed it out to create the script. He describes the experience of making the film as "living my dream".

Mr. Copaus has been writing and drawing constantly since the age of five, when he began "drawing his stories," as his mother, Rita, puts it. Even when he couldn't write words, he had stories at his fingertips in the form of drawings. His is a rich world, populated by his own creations, but always with himself as the main character, whether it's "Secret Agent Matthew" or a detective character like Inspector Clouseau from *The Pink Panther*. He and his 16-year-old brother, Christian, are both fans of the "Kingdom Hearts" video game. Mr. Copaus creates scenarios based on the game, which he and his best friend, Josh, enjoy acting out, complete with costumes carefully crafted by Ms. Copaus.

Often, emotions that were difficult for Mr. Copaus to put into words have found expression in pictures. He has a marvelous capacity to transmute traumatic events into pictorial form. He dealt with the death of his grandmother by drawing a narrative of the experience, culminating in an image of her going up to heaven. She is depicted with angel's wings as she asks Jesus whether she can stay there. Ms. Copaus says he has total recall and can remember being held in his grandmother's arms as a baby.

Mr. Copaus experienced oral surgery when he was seven, and was sent home with a sticker that read, "Be nice to me—I had surgery today." After being told what the sticker said, Mr. Copaus stuck it to a piece of



Matthew Copaus



(Kneeling, left to right) Marvin, Rita and Christian Copaus; (standing) Matthew Copaus.

paper and began drawing "like crazy" around the sticker. He has an innate sense of design and a truly unique and witty style. His work has been reproduced in several magazines, among them the August, 2001, Summer Arts Issue of *Breaking Ground*.

Filmmaking is the next logical step. When he was six years old, the young artist said to his mother, "My eyes are making pictures in my head." Ms. Copaus asked him to tell her about them, and he began describing in complete detail a story about a dog that runs away from a man with a gun. She gradually realized it was a Disney movie he had seen only once.

"When you have autism, you don't see words in your head; you see pictures," said Mr. Copaus. "Actually, I see movies rolling, all the time."

This experience can create problems with focus if someone is talking to him while a movie is, as Mr. Copaus put it, "running through my thoughts." His main problem while making the film was "smiling in the wrong places" because he was so excited about the process.

For awhile, Mr. Copaus was a typically developing child. At one and a half, he could sing "Take Me Out to the Ballgame" to his

grandmother over the phone. But around the age of two, he regressed to no language and no eye contact. Ms. Copaus felt that her son was slipping away from his family into the world of autism and was determined to "bring him back". It took two years to get a diagnosis; five years of intensive therapy—physical therapy, occupational therapy, and speech and language therapy three times a week—were to follow.

Persistence appears to have paid off. Ms. Copaus homeschooled her son, with the exception of Kindergarten and middle school. Mr. Copaus graduated from high school in June of this year.

He was able to "return" to his family through the use of pictures. The future for this endlessly creative artist will no doubt build on this solid yet imaginative foundation. He'd like that future to include being famous one day as a writer, director and actor, and being married with two children.

The Comic Book Convention will be posted on <http://vimeo.com/27563890> for the foreseeable future, as well as at www.thenfi.com.

Nancy W. Muse is information & referral services coordinator with Tennessee Disability Pathfinder.

The Tennessee Council on Developmental Disabilities Welcomes the
2011-12 PARTNERS IN POLICYMAKING™ CLASS!

On September 16 and 17, the newly selected Partners in Policymaking Class began their seven sessions of training at the Nashville Airport Radisson Hotel. From September through April, Partners from across the State will attend information sessions conducted by local and national experts in the disability field to learn about:

- The History of the Disability Experience**
 - People First Language**
 - The History of the Self-Advocacy and Independent Living Movements**
 - Best Practices in Inclusive Education**
 - State Services and Resources**
 - Supported and Independent Living**
 - Strategies for Employment**
 - The State and Federal Legislative Processes**
 - Self-Determination and Person-Centered Planning**
 - Conducting Effective Meetings**
 - Assistive Technology**
- and much more.

They also will benefit from interacting and collaborating with their fellow Partners—adults with disabilities and family members of persons with disabilities—and learning about, and from, the challenges and successes of their peers.

Please join us in welcoming the following individuals to Tennessee's ever-growing Partners network.

PHYLLIS BLACK, *Memphis*
GEROME BOWEN, *Nashville*
BRANDI BROWN, *Lenoir City*
JANIE CAMERON, *Franklin*
CYNTHIA CHAMBERS, *Jonesborough*
BROOKE CHAPMAN, *Fayetteville*
MARY ELLEN CHASE, *Memphis*
KASONDRA FARMER, *Nashville*
KAY FRENCH, *Memphis*
VIRGINIA FRIZZELL, *Gainsboro*
LAURIE HOBSON, *Germantown*
MARTINE HOBSON, *Germantown*
LARRY JOBE, *Lebanon*
KEVIN KOVACS, *Murfreesboro*
GEORGE LANE, *Nashville*
REBECCA LEWIS, *Erwin*
BILL MARTIN, *Lascassas*
DANAE MATLOCK-BRIGGS, *La Vergne*
ROSE MORELAN, *Etowah*
DEBORAH MOREHEAD, *Nashville*
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DELORIS WESTBROOKS, *Memphis*
LASHUNDA WESTBROOKS, *Memphis*

SAVE THE DATE



The 18th Annual Partners in Policymaking Reunion Conference

March 23 & 24, 2012

Nashville Airport Radisson Hotel

Tennessee Kindred Stories of Disability

Share your story and stir up the world



We are collecting stories from individuals with disabilities and families to include in a statewide database for use in disability-related advocacy and education efforts. The database is online and open to the public.

Please share your stories and experiences.

Examples of topics include:

- Health care
- Education
- Housing
- Community Inclusion
- Employment
- Adult Services
- Waiting Lists

Ways to share:

- Submit your story online by visiting kindredstories.edu
- Contact courtney.taylor@vanderbilt.edu for alternate submission options.

For agencies interested in learning how to partner in this statewide advocacy effort, contact: courtney.taylor@vanderbilt.edu

kindredstories.edu

RESOURCE SPOTLIGHT: SELF-ADVOCACY

“Self-advocacy” can either refer to organizations comprised of individuals with disabilities who advocate for themselves, or to organizations that teach individuals to advocate for themselves. Self-advocacy is an important issue in every aspect of the life of an individual with a disability. It allows that individual to have a voice, and to use that voice. More than just a tool for acquiring services, self-advocacy means making one’s desires and needs known in order to arrive at solutions that are both personal and effective.

The Pathfinder database has many resources that promote self-advocacy. A select number of agencies that serve the entire State of Tennessee are highlighted here.

The Arc Tennessee

The Arc Tennessee is a grassroots, non-profit, statewide organization on intellectual and developmental disabilities. Its members are people with intellectual, developmental and other disabilities, their parents and friends, and the professionals who assist them in reaching their goals. The Arc is actively involved in improving life for all those within the community who have developmental disabilities by providing the following services: statewide systems, legislative and individual advocacy; training and education (including sponsorship of the Tennessee Disability MegaConference); public awareness; and information and referral.

615-248-5878
info@thearcn.org
www.thearcn.org

Tennessee Council on Developmental Disabilities

The Tennessee Council on Developmental Disabilities is an independent State office that promotes public policies to increase and support the inclusion of individuals with developmental disabilities in their communities. The Council works with public and private groups across the State to find necessary supports for individuals with disabilities and their families, so that they may have equal access to public education, employment, housing, health care, and all other aspects of community life. The Council encourages individuals with developmental disabilities and their families to play decision-making roles in policies and programs that affect them.

Two initiatives of the Council in particular focus on self-advocacy: the **Partners in Policymaking™ Leadership Institute (Partners)** and the **Tennessee Youth Leadership Forum (YLF)**. Partners is a free leadership and advocacy training program for adults with disabilities and family members of persons with disabilities to help them become advocates for themselves and for others in the community. YLF is a free leadership training program for high school students with disabilities.

615-532-6615
tnddc@tn.gov
www.tn.gov/cdd

Statewide Independent Living Council of Tennessee (SILC)

This organization provides advocacy for complete inclusion and independence for people with disabilities in their communities. There are six regional Centers for Independent Living (CILs) across Tennessee: MCIL (Memphis), JCIL (Jackson), CIL-MT (Nashville), TRAC (Chattanooga), dRC (Knoxville) and TARP (Paris). At least half of each organization’s members are persons with disabilities. The SILC advocates on behalf of persons of all ages and all disabilities in the following areas: Employment, Human Rights, Urban Planning, Transportation, Health Care and Housing.

615-255-0283
www.tnsilc.org

UT Boling Center for Developmental Disabilities

The Boling Center is a University Center for Excellence in Developmental Disabilities that provides advocacy training and resources. This includes the Self-Determination Project, which is administered by The University of Tennessee (UT) Center on Disability and Employment (CDE). The Self-Determination project works directly with individuals and their support networks to assist with the development of approaches that promote empowerment, advocacy and self-direction. The overall goal of this project is to provide opportunities for students in high schools, middle schools and elementary schools to learn about themselves, take a strong role in the Individualized Education Plan (IEP) process and learn about post-school resources that will lead to employment.

901-448-6511
Toll-free: 888-572-2249
901-448-4677, TTY/TDD
www.uthsc.edu/bcdd/

Volunteer Advocacy Project of the Vanderbilt Kennedy Center

The Volunteer Advocacy Project, in collaboration with partner agencies, trains volunteers as special education advocates to provide instrumental and effective support to families of children with disabilities.

Meghan Burke
Meghan.m.burke@vanderbilt.edu
www.kc.vanderbilt.edu

Disability Law & Advocacy Center of Tennessee

The Disability Law & Advocacy Center of Tennessee (DLAC) advocates for the rights of Tennesseans with disabilities. Three regional offices serve all Tennesseans with disabilities, but all requests for services must go through the Advocacy Assistance Unit by calling 1-800-342-1660. DLAC collaborates with disability, parent and consumer organizations in systems change advocacy activities.

888-852-2852, TTY/TDD
GetHelp@DLACTN.org
www.DLACTN.org

People First of Tennessee

People First of Tennessee is a volunteer non-profit organization that provides advocacy and training on the rights of people with disabilities in Tennessee.

615-713-1162
pftennmurf@aol.com
www.pfoftn.org

Tennessee Disability Coalition

The Tennessee Disability Coalition is an alliance of organizations and individuals who work together to advocate for public policy that ensures self-determination, independence, empowerment and inclusion for people with disabilities. The Coalition offers the following initiatives: **ADA Network, Benefits to Work Disability Action Network, Family Voices of Tennessee, Project Brain** and a **Small Grants program**.

888-643-7811, Toll Free
615-292-7790, TTY/TDD
coalition@tndisability.org
www.tndisability.org

Mental Health Advocacy Resources

The organizations below provide self-advocacy resources for individuals with mental health diagnoses.

Tennessee Mental Health Consumers Association (TMHCA)

TMHCA is a statewide, consumer-based organization that promotes recovery through education, advocacy and peer support for mental health consumers. Through the organization's Regional Advocacy Program, advocates train other consumers in self-advocacy and system change methods.

1-888-539-0393, Toll-free
info@tmhca-tn.org
www.tmhca-tn.org

National Alliance of Mental Illness (NAMI)

NAMI Tennessee is a grassroots, non-profit organization made up of families, consumers and professionals. The mission of NAMI Tennessee is to offer support, education and advocacy for

individuals with mental illness, their families and communities. There are multiple NAMI affiliates around the State. This office links individuals with a representative in their community.

615-361-6608
800-467-3589, Toll Free
For Spanish: 800-866-6062
www.namitn.org

For more self-advocacy information and resources, please see our "Disability Resources Library" found on the Pathfinder homepage at www.familypathfinder.org. A link to "Self-Advocacy Organizations" can be found under the heading "Advocacy and Law". A link to "Education Advocacy and Law" can be accessed under the "Education" heading on the same page.

Additional advocacy resources may be reached by clicking on "Services Database" on the Pathfinder homepage and searching by "Advocacy Services" under "Step 1: Choose a category" on the left and either "County" or "Region" under "Step 2: Choose a service area" on the right.

If you don't have the Internet, you can still access all of Pathfinder's resources by calling our Helpline at 1-800-640-4636 or 615-322-8529. The Pathfinder staff will gladly direct you to helpful information on self-advocacy or any other disability-related topic.

Nancy W. Muse is information & referral services coordinator with Tennessee Disability Pathfinder.

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**.

Partners 2009-10 graduate, **Deborah Pearson**, recently was hired by the **Internal Revenue Service** as a Tax Examiner Clerk. She works with Small Businesses/Small Enterprises in the Collection Department, and is the first line of contact for incoming cases, sorting and distributing them for Senior Tax Examiners.

The **Vanderbilt Leadership Education in Neurodevelopmental Disabilities (LEND) Training Program** has been renewed by the **Maternal and Child Health Bureau, Health and Human Services**. The grant was approved for a total of \$3.5 million over five years to train interdisciplinary professionals in 13 disciplines, including a Family Representative. Trainees receive training in advanced clinical and research skills to enable them to assume future leadership roles in Maternal and Child Health, serving children and youth with developmental disabilities, including autism, and their families.



Photo by Tony Maupin

(Left to Right) Trainees Heather Porter and Megan Griffin and LEND Director Terri Urbano.

The LEND Program is led by the **Vanderbilt Kennedy Center** in collaboration with **Vanderbilt Pediatrics' Division of Developmental Medicine**. Other Vanderbilt programs collaborating are the **Vanderbilt Bill Wilkerson Center** (audiology, deaf education, speech-language pathology), **Nursing, Nutrition, Psychology** and **Special Education**. Other partners include **Belmont University** (occupational therapy), **Meharry School of Dentistry** (pediatric dentistry), **Tennessee State University** (physical therapy), **University of Tennessee-Nashville** (social work), and the **Tennessee Disability Coalition's Family Voices of Tennessee**. LEND also supports community and statewide training and development and dissemination of educational materials for health professionals and families.

Partners 2010-11 graduate, **Jessica Beecham**, was selected to receive one of 30 **National Federation of the Blind Scholarships**. The scholarships ranged in amount from \$3,000 to \$12,000, and Ms. Beecham was awarded at the \$7,000 level. To her credit, there were only four equivalent or higher scholarships awarded. In addition, Ms. Beecham recently has taken a job as a recreational therapist at a drug and alcohol rehabilitation facility. Initially, she will be spending most of her time working with adolescents in 7th-12th grades, but eventually will transition to splitting her time equally between adolescents and adults.

The **East Tennessee Technology Access Center (ETTAC)** is proud to announce that it has received a \$15,075 Quality of Life grant from the **Christopher & Dana Reeve Foundation**. The award was one of 77 grants, totaling more than \$508,000, awarded by the Reeve Foundation to nonprofit organizations nationwide that aid in providing more opportunities, access and daily quality of life for individuals living with paralysis, their families and caregivers. Since the program was developed in 1999 by the late Dana Reeve, over 1,900 grants have been awarded, totaling nearly \$14.8 million.

The grant will enable ETTAC to purchase one **Comlink LT**, an eye gaze-operated communication device. It will be available for loan to individuals with speech disabilities who have an immediate need to communicate, whether at home, in the hospital or some other setting, for as long as they need it, or until their equipment is available from another source. The device also has an environmental control component that allows people to turn on the TV, radio and lights.

Toni Whitaker, MD, developmental pediatrician with the **University of Tennessee Boling Center for Developmental Disabilities**, has been selected to serve as an **Act Early Ambassador** for the **Centers for Disease Control and Prevention's (CDC) "Learn the Signs. Act Early."** program. Dr. Whitaker will play a role, along with Tennessee's **Act Early Team**, in educating parents, healthcare professionals and early educators about early childhood development, warning signs of autism and other developmental disabilities, and the importance of acting early on concerns about a child's development.

The Act Early Ambassadors project is a collaboration among the **CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)**, the **Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau (MCHB)**, and the **Association of University Centers on Disabilities (AUCD)**. Dr. Whitaker hopes to work with State team members to identify agencies or community groups for targeted educational presentations, as well as to assist with distribution of materials to enhance community awareness on autism and related neurodevelopmental disorders.

Partners 2007-08 graduate, **Dena L. Gassner**, director of the Center for Understanding, has been named to the **Boling Center Community Advisory Council**. She will serve a three-year term from July 2011 – June 2014. Ms. Gassner also participated in the **National Autism Resource and Information Center's "Autism NOW!"** information gathering conferences in Orlando and in Los Angeles in July. These events are collaborative feedback sessions coordinating efforts between the **Autism Society of America**, the **Autism Society of Los Angeles**, **The Arcs** in California, Los Angeles and Orange County.

Partners 2000-01 graduate, **Lorri Mabry**, is now a member on the board of **The Arc Tennessee** and the **Boling Center Advisory Council**.



Brad Gattis and Sara Hight.

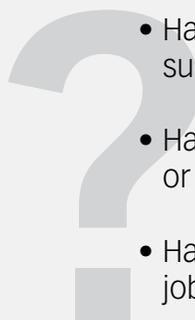
We have good news to share about **Sara Hight**, a student with Down syndrome at **Hardin County High School** in **Savannah, Tennessee**. Ms. Hight was thrilled to be graduating, but apparently even more excited to attend her first prom a week earlier, at which all the students in the senior class voted her Honorary Prom Queen. We're told Ms. Hight had a "perfect night", and a dream date with her boyfriend, Brad Gattis.

Partners 2001-02 graduate, **Baretta Stewart**, recently completed her first year of teaching special education and, at the same time, completed her special education certification through the **Memphis Teaching Fellows** program. Additionally, Ms. Stewart won the **Barbara Bolton Distinguished Teacher Award** for being an effective first year teacher for **Memphis City Schools**.

Linda Hartbarger was recently named the new **Director of the Office of Early Childhood Special Education**. Ms. Hartbarger has served in multiple roles within the **TEIS (Tennessee Early Intervention Services)** program over the last 23 years, most frequently as Part C Statewide Coordinator.

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!**

VANDERBILT UNIVERSITY

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