On Wednesday, March 14, 2018, hundreds of people gathered at our state capitol for the 17th Annual Disability Rights Legislative Day. Our theme this year was “Let Freedom Ring”. Our emcee, was none other than Christopher Worth of St. Louis and Paraquad.

We had some last minute changes with our scheduled date, but overall we had a great turn out. Our topics for this year were the ABLE Act, Ticket to Work Program, Employment First, Guardianship, and Community Directed Services. Our guest speakers came from all over our state. We were honored to have the following guest speakers this year: David Pearce from the State Treasurer’s Office, Barbara Arnold, Senator Sifton, Steve Foelsch, Representative Sarah Unsicker, Glen Stilley and Samantha Bartshe, Representative Jim Neely, Elizabeth Moran, and Tammy Teal.

We all shared in a moment of silence for Carl Debrodie, along with his family and friends, who joined us for our rally.

Thank you to all that made this year’s rally a success! Next year we hope to have some new committee members with us and an exciting event planned for all.

Our Executive Director, Vicky Davidson, always manages to sneak in a picture of us!

Charlie German, Chaz Nickolaus and Christie Holterman
Hundreds of disability rights advocates arrived Wednesday at the Capitol for the 17th Annual Disability Rights Legislative Day. They packed the ground floor beneath the dome so tightly, those in wheelchairs had to be careful not to run over any toes.

"We're here to advocate for people with disabilities," Angie White said. She's a client of Life Unlimited in Kansas City. She and her fellow client and friend, Mary Ann Arnold, traveled all the way to Jefferson City to speak with representatives about the needs of people with disabilities. "I'm going to tell them that we need to have people look after other people," White added. Arnold said she was concerned about the treatment of people in group homes and other types of supported living situations. "People in group homes are being mistreated," she said. "I believe in friendships and I believe in Jesus Christ." She does not, however, believe people with disabilities in Missouri are receiving the best care and support possible.

Event organizers brought up Carl DeBrodie, the young man with developmentally disabilities who vanished from a group home in Fulton and was found dead in April, as an example.

"I cannot believe that something like that could ever happen, especially to someone who is under the auspices of a public (entity)," said Leslie Anderson, Director of Public Policy and Advocacy for Services for Independent Living in Columbia.

Wednesday's rally included a moment of silence in DeBrodie's memory. However, activists were doing much more than simply remembering DeBrodie, they were advocating for legislative changes to help prevent future tragedies.

Continued on next page.....
One change is House Bill 1553, which introduces revisions to Missouri's guardianship law. "That law is 30 years old," Anderson said. HB 1553, sponsored by State Rep. James Neely, R-Cameron, would introduce a series of changes designed to bring greater oversight to the guardianship process. Neely also hopes to reduce the number of people unnecessarily put into or kept under guardianship.

"People hear the word 'guardian' and think guardian angel," said Elizabeth Moran, an attorney and disability rights advocate. "For many people, what guardianship is, is a 10-minute hearing that strips you of your civil rights."

According to advocates, the current system isn't focused on individuals. The new legislation would put a heavier focus on "least restrictive alternatives," putting individual needs front and center.

There were other talking points as well, such as HB 2130, which establishes the "Missouri Employment First Act" to require state agencies to promote integrated employment.

Speakers discussed ABLE accounts, which allow people with disabilities to have savings accounts that don't count as an asset. If a person with disabilities who receives services, pensions, or other types of support or funding accumulates too many assets, they could lose that assistance. This makes saving for the future nearly impossible, advocates say.

Article and photos by Helen Wilbers /News Tribune

A disability rights activist holds a sign protesting the cutting of consumer-directed service hours during Wednesday's Disability Rights Legislative Day at the Capitol. Last year, state budget cuts led to the capping of consumer-directed care at 60 percent of previous hours, meaning that people trying to live independently with disabilities have less access to help.

Photo by Helen Wilbers /News Tribune.

Dolores Sparks and Steve Foelsch
this quarter is Council, Chairperson, Kit Stahlberg

Born in Normandy, Missouri, raised in St. John, Missouri until 1994. Kit took care of his adoptive parents until their passing. In 1994 he moved to Ironton, Missouri to find his real blood family. Kit was able to find them and it became the joy of his life after 34 years of not knowing them. Kit was semi-homeless for about a year and then moved into an apartment in Ironton. Kit was working part time in Leadington, Missouri to earn money. He moved to Fredericktown, Missouri in 2003. He started working at the Madison County workshop and is currently working on a job for MOCAP. Kit has one brother and one sister still living. They live in Perryville, Missouri. Kit visits them often and spends time with his nieces and nephews.

Kit has been an active member of People First in his community. Kit found his voice as a self-advocate while participating and graduating from the Partners in Policymaking program with the state of Missouri in 2005. Kit was appointed to the Missouri DD Council and currently serves as the Council’s chairperson. In this role, Kit has participated in the annual Disability Policy Seminar to include meeting with members of the Missouri Congressional Delegation. Kit also represents the Council as a member of the state’s Division of Developmental Disabilities’ Quality Assurance Committee that addresses improving supports for individuals with I/DD.

Kit reaches out often to fellow co-workers and teaches them about guardianship and their options. He shares information that he receives as the Chair of MOCDD with his fellow co-workers as well. Kit has been a consistent advocate for the ABLE program, Medicaid, and the Disability Benefits 101 (DB 101) website and toolkit. Kit helps connect others and gives them referrals when they need assistance with personal matters.

Kit is very active in his church, Calvary Church of Fredericktown. He belongs to the Celebrate Recovery group for people that have “hurts, hang-ups and addictions”. He supports and helps everyone that he can, no matter their issue, and always encourages others to do the same.
On February 16, 2018, educators and administrators were given a different perspective on inclusion. Four extraordinary and passionate women, who are active members of their children’s school district, shared their stories. They wanted to share their thoughts and personal experiences on why it is so important for children to be included in the general education classrooms. They wanted teachers and administrators to think about what it was like for them, as parents, to work with the schools and try to get what is best for their kids. Lisa said that, “they shared stories about what has worked and what has not worked in areas of being proactive and communicating.” Laura spoke about how peer support from her son’s classmates had been the most successful, as he observes and models those around him. One part of her son’s journey, shared by JJ, was his experience in kindergarten. She spoke about the importance of keeping inclusion at the forefront of conversations with teachers and administrators and not assuming they already know all of the good things about inclusion, or about how to provide an inclusive environment. Rebecca’s story began with her son’s experiences in his previous elementary school where he was in a self-contained classroom, compared to his current school which practices inclusion. Rebecca highlighted the value of inclusive education for all children, not just those with disabilities.

Many in the audience shared their thoughts and stated that, “they really felt that they should go to all buildings in their district to share their message more widely.” Rebecca added, “One thing I realized later is that the family structures of the four of us who presented are similar: we each have two children, one of whom has a disability and one of whom does not. So, I think for us who have kids who are naturally included in all educational experiences, the discrepancies between our children’s experience are more blatant. Why should one child get X and not the other child, simply because of a diagnosis?”
There seems to be one common thread, and that is how important it is for inclusion of all children, in every aspect of their education. “I Choose Inclusion” was the message they were delivering to their audience. Not just as parents, but speaking for the children who experience inclusion and want to continue to have that right, and for those who have not yet been included. Laura stated that, “Other parents need to be sharing the same things with their schools. There are too few families that believe in true inclusion. An inclusive setting where all students are learning in the same classrooms, helping each other, can work. Continued training and communication can be keys to success.” JJ added, “Change happens with the parents, careers, and self-advocates, because at the end of the day, it’s not just a job, it’s our life and the implications for positive change, or implications for things staying the same, are too great not to say or do anything. It is our job to learn, understand, and educate the people who might not understand. Do not assume that they know.”

All four parents are involved in their children’s education and are active members of the school district’s Parent Advisory Committee’s (PAC), three are Partners in Policymaking graduates and/or have attended Special School District, Parent Leadership training. Lisa has also given assistance to Representative Sarah Unsicker on the Employment First Bill and sheltered workshops, to help make systems change for all who want competitive employment.

When asked what lead them to do this panel discussion and other advocacy work, after Partners in Policymaking training, Rebecca stated, “Complacency is not an option. Policies don’t change and mindsets don’t change unless there are people willing to stand up for what is right and what is necessary in order to achieve equality and equity.” Lisa stated, “Knowing you have to take charge for what you want to happen. We were given the tools for working with schools and working as a team with IEP’s (Individualized Education Program). We are all constantly learning.”

We hope they have many more opportunities to speak with teachers, parents and administrators. They would also like to involve self-advocates who have had positive and/or negative experiences with inclusion, and other parents who have been down the same road as they, or perhaps those who are just beginning this long journey of fighting for their child to be included.
NCD Report Examines “Civil Death” of the Rights of People with Disabilities and the Elderly under Guardianships, Calls on Department of Justice to Ensure Full and Fair Due Process Rights

March 22, 2018

Baltimore, MD – The National Council on Disability (NCD) – an independent federal advisory body – today will release and discuss the findings and recommendations of a seminal national report that thoroughly examines guardianship – the process through which an adult can be found legally incapable of making decisions for him or herself and another adult appointed to make decisions on behalf of that individual – in view of the estimated 1.3 million Americans subject to guardianship and the goals of longstanding national disability rights policy. The report release presentation will occur in Baltimore, Maryland at the Jacobus tenBroek Disability Law Symposium.

“Former Congressman Claude Pepper famously said of guardianships, ‘The typical [person subject to guardianship] has fewer rights than the typical convicted felon… It is, in one short sentence, the most punitive civil penalty that can be levied against an American citizen, with the exception, of course, of the death penalty,’” said Phoebe Ball, NCD Legislative Affairs Specialist who worked extensively on the report. “NCD chose to examine this topic at depth given the implications for someone’s civil rights and liberty under guardianship – that an individual is losing the authority to make decisions regarding where to live, whether to work and where, where to travel, with whom to socialize, and how to manage money and property. We need to explore alternatives to guardianship such as supported decision making that enable people to avoid this civil death.”

The findings and recommendations in the report, Beyond Guardianship: Toward Alternatives that Promote Greater Self-Determination for People with Disabilities, are the product of qualitative research on the experiences with guardianship and decision making alternatives of people with disabilities, their families, and professionals within the guardianship system gleaned through interviews; in addition to an extensive review of relevant scholarship and recent studies.

Report Findings:

• Amongst its key findings, NCD’s Beyond Guardianship study found that:

• Guardianship is often imposed when not warranted by facts or circumstances, because guardianship proceedings often operate under erroneous assumptions that people with disabilities lack capability to make autonomous decisions and rely upon capacity determinations that often lack sufficient scientific or evidentiary basis.
• Although guardianship is considered a protective measure, courts often lack adequate resources, technical infrastructure, and training to monitor guardianships effectively and hold guardians accountable, which at times allows for guardians to use their positions to financially exploit people subject to guardianships or subject them to abuse or neglect.

• People with disabilities are often denied due process rights in guardianship proceedings.

• Although most state laws require consideration of less-restrictive alternatives, courts do little to enforce those requirements. Similarly, though every state has a process for the restoration of one’s rights lost through guardianship, the process is rarely used.

There is a lack of data on existing guardianships and newly filed guardianships, which frustrates efforts of policymakers to make determinations about necessary areas for reform. "People with disabilities should be given the maximum opportunity to make decisions for themselves and to live the lives that they want to live," said Neil Romano, Chairman of NCD. "At NCD, it is our responsibility to offer policymakers the best information available so that they can make decisions designed to move people with disabilities toward full inclusion and equality in our society and help them fully realize their American birthright of life, liberty, and the pursuit of happiness."

SCOPE: NCD undertook this report to foster a greater understanding of guardianship within the context of disability law and policy; to examine the treatment of people with disabilities within the legal system that establishes guardianship; to examine the use of alternatives to guardianship such as supported decision-making; and to make recommendations that will help align the use of guardianship and decision-making alternatives with the Americans with Disabilities Act (ADA) with particular focus on the integration mandate. The report’s findings and recommendations are the product of qualitative research on the experiences with guardianship and decision-making alternatives of people with disabilities, their families, and professionals within the guardianship system gleaned through interviews; in addition to an extensive review of relevant scholarship and recent studies.

For more information, please go to: https://ncd.gov/publications/2018/beyond-guardianship-toward-alternatives
Report Recommendations:

For each major finding, NCD offers recommendations to federal and state policymakers to address areas of concern.

A small sampling of the report’s recommendations includes:

- The Department of Justice (DOJ), in collaboration with the Department of Health and Human Services (HHS), should issue guidance to states (specifically Adult Protective Services [APS] agencies and probate courts) on their legal obligations pursuant to the Americans with Disabilities Act (ADA).

- The Administration for Community Living (ACL) currently funds the National Resource Center for Supported Decision-Making and several demonstration projects at the state and local levels. These grants should be expanded to be able to fund more geographically- and demographically-diverse projects and pilots that specifically test SDM models and use SDM and the court systems to restore people’s rights as a matter of law, particularly for people who are older adults with cognitive decline, people with psychosocial disabilities, and people with severe intellectual disabilities.

DOJ should make funding available to train judges in the availability of alternatives to guardianship including, but not limited to, supported decision making. This training should also include information about the home and community-based–services system and the workforce development system so that judges understand the context in which decisions are being made by and for people with disabilities.

A state guardianship court improvement program should be funded to assist courts with developing and implementing best practices in guardianship, including training of judges and court personnel on due process rights and less-restrictive alternatives.
The Missouri Developmental Disabilities Council is pleased to announce that as of June 30th 2018, the Center for Human Services, a very large developmental disabilities provider in Sedalia, MO., will be closing the doors of their sheltered workshop. This has been a long journey between the MODDC and CHS, way back in 1966 the MODDC gave CHS a grant to fund the first sheltered workshop in the state of Missouri.

In 2015 the MODDC awarded CHS with another grant, this time to go to an APSE and US Dept. of Labor Training, in Detroit MI called Workshops to workplaces. The training gave staff from CHS the opportunity not only to hear the philosophy, but to learn the nuts and bolts in how to convert an organization from facility based employment to community based. That training and some great leadership from CEO Ann Graft, and the Director of Employment at CHS, Kim Anderson, and some big changes were made.

Center for Human Services Transitions from Sheltered Workshop to Community Employment

After five years of successful community employment placement, the Center for Human Services is closing its sheltered workshop this summer and fully transitioning to the community employment model.

Center for Human Services provides a variety of services including employment, community living, child and family development, and case management for individuals with intellectual and developmental disabilities in 36 counties.

As part of its employment services, CHS opened Missouri’s first sheltered workshop in 1966 to give such individuals a place of employment. Over the years, contracts have included filling shampoo bottles for ADCO, sewing aprons for the U.S. Navy, putting together first aid kits for the U.S. general services administration, and assembly line work for local companies like Waterloo, Gardner Denver and Duke.

CEO Ann Graff noted that when it opened, the shelter was “cutting edge” and offered the best opportunities for individuals with disabilities, but in the last five years CHS has focused on helping people gain employment with area businesses. A news release notes this is a national shift as well. As decided by the board, the sheltered workshop will close June 30; employees and their families and CHS staff were notified Tuesday.

“We did not set out to close the workshop, we set out to make sure people had access to community employment, and as a result there’s only 15 people left in our workshop and five of those are currently working on employment in the community,” Graff told the Democrat.

Continued on next page.
While CHS has been helping with community employment since the late 1980s, it became more of a focus in the last five years. According to information from CHS, 298 individuals have achieved community employment since 2013 with the help of CHS. Of those people, 62 had been working in the sheltered workshop and decided they wanted to work out in the community.

CHS clients are employed at a variety of local businesses including Mazzio’s, McDonald’s, Sedalia Parks and Recreation, Inter-State Studio and Zehpyr. “The vast difference between a sheltered workshop and working in the community is that if you work in a sheltered workshop, you get paid sub-minimum wage. You’re going to be making below minimum wage, and it’s going to be based upon what is deemed your ability to produce,” Director of Employment Services Kim Anderson explained. “In the community, you’re just as valuable walking into a company as the next person so your wages are not based on a disability you were labeled with when you were in high school.”

Anderson added that the community should not be a destination for people with disabilities, but rather where they live and work. Obtaining employment helps with that goal. “With this shift in community, people are actually starting to partake in their surroundings. I’m the only program that actually takes an individual and makes them a taxpayer rather than only gleaning the benefits from other taxpayers,” she added. “That in itself creates a huge sense of pride with the individuals we work with and they finally feel like the people that live next to them are their peers rather than some staff or people they’ll never be good enough to be like.”

The process to community employment looks different for each person, Anderson said, but it starts with them listing their likes and dislikes for a job, then being exposed to those areas and discussing the experience.

“We are there to support them throughout that,” Anderson said. “Not everyone gets supported at the same level because, again, it’s dependent on what the person and the employer needs, but we do what is called ‘career matches’ instead of ‘job placement.’ We have two customers, the individual and the employer. We want to make sure it’s the right fit for both. We have staff who can go in and assist in that process for however long the individual or employer needs.”

For more information about CHS employment services, contact Anderson at 660-826--4400 ext. 338 or kanderson@chs-mo.org.
Updates from our Council Committees

Education

Home and Community

The Home and Community Living Committee continues our work on the Victimization Task Force, Guardianship Reform efforts, and First Responder Training. The Committee is discussing possible ways to address housing barriers as well as efforts to ensure voting access.

Grassroots

Transportation and Employment
SUCCESS Ready Students

Save the date!
June 26-28, 2018

Transition Training Institute
Holiday Inn Executive Center
Columbia, Missouri

Registration fee
$85
DESE Post-Secondary Transition Training Institute

Enrollment Open

The 2018 Transition Training Institute will be held from June 26-28, 2018, at the Holiday Inn Executive Center, 2200 Interstate 70 Drive SW in Columbia, Missouri.

The theme for 2018 is Success Ready Students. The training will focus on programs and structures to support students in graduating and moving toward post-secondary goals. There will be a variety of presentations which will focus on compliance, school-based enterprises, self-advocacy, employment, social/emotional intelligence, and career readiness with an emphasis on students who experience intellectual disabilities within each area. Schools are encouraged to bring teams of individuals including general education and special education teachers, administrators, and counselors to gather information, create action plans, and disseminate information for the coming year. A draft agenda will be posted at a later date. Enrollment for the institute is now open. Specific enrollment instructions and additional information can be found at [https://dese.mo.gov/special-education/effective-practices/transition-summer-institute](https://dese.mo.gov/special-education/effective-practices/transition-summer-institute).

If you have additional questions or concerns, please contact Dr. Barb Gilpin at 573-751-7661 or Barb.Gilpin@dese.mo.gov. If you should need special accommodations (dietary, braille, physical assistance, etc.), please contact Regina.Miller@dese.mo.gov or 573-751-0187.
Successful Transitions from School to Work

This one day workshop will provide attendees with tools, tips and strategies to improve employment outcomes for students with disabilities leaving school and entering the world of work.

The session is designed for Special Educators, Transition Specialist, Vocational Rehabilitation Counselors, DMH / TCM Support Coordinators and Employment Services agencies.

This workshop is offered in three locations:

- St. Louis - Wednesday, April 25
- Jefferson City - Thursday, April 26
- Kansas City - Friday, April 27

Cost: $70 for APSE members; $80 for Non-APSE members

Please visit our website www.apsemo.org for registration details.

Erik Carter, Ph.D., is a Cornelius Vanderbilt Professor of Special Education at Vanderbilt University. His research and teaching focuses on evidence-based strategies for supporting strong transitions, integrated employment, and community participation for individuals with intellectual disability, autism, and multiple disabilities. Dr. Carter directs TennesseeWorks and TransitionTennessee, two statewide projects aimed at connecting people with disabilities to meaningful jobs.

http://apsemo.org/events
The 2018 Mental Health Champions’ Banquet is scheduled for June 19th in Jefferson City. The Council approved sponsorship, which gives us a table for 10. If you would like to attend this event, please contact Christie at 573-751-8214, so that she can keep a listing to submit for registration. Thank you!
A Credo for Support

Do Not see my disability as the problem.
Recognize that my disability is an attribute.
Do Not see my disability as a deficit.
It is you who sees me as deviant and helpless.
Do Not try to fix me because I am not broken.
Support me. I can make my contribution to the community in my own way.
Do Not see me as your client. I am your fellow citizen.
See me as your neighbor. Remember, none of us can be self-sufficient.
Do Not try to modify my behavior.
Be still and listen. What you define as inappropriate may be my attempt to communicate with you in the only way I can.
Do Not try to change me, you have no right.
Help me learn what I want to know.
Do Not hide your uncertainty behind “professional” distance.
Be a person who listens and does not take my struggle away from me by trying to make it all better.
Do Not use theories and strategies on me.
Be with me. And when we struggle with each other, let that rise to self-reflection.
Do Not try to control me. I have a right to my power as a person.
What you call no-compliance or manipulation may actually be the only way I can exert some control over my life.
Do Not teach me to be obedient, submissive and polite.
I need to feel entitled to say NO if I am to protect myself.
Do Not be charitable towards me. The last thing the world needs is another Jerry Lewis.
Be my ally against those who exploit me for their own gratification.
Do not try to be my friend. I deserve more than that.
Get to know me. We may become friends.
Do Not help me, even if it does make you feel good.
Ask me if I need your help. Let me show you how you can best assist me.
Do Not admire me. A desire to live a full life does not warrant adoration.
Respect me, for respect presumes equity.
Do Not tell, correct, and lead.
Listen, Support, and Follow.
Do Not work on me.
Work with me.

Dedicated to the memory of Tracy Latimer

Written and produced by Norman Kunc and Emma Van der Klift
April 13-14, 2018
Capitol Plaza Hotel and State Capitol, Jefferson City, Missouri
Legislative Issues in Missouri with Cathy Brown of Easter Seals Midwest, St. Louis, Missouri and the Legislative Process with Chester Goad of Cookeville, Tennessee

May 4-5, 2018
Hilton Garden Inn, Columbia, Missouri
The Life Course with Crystal Bell, UMKC, Kansas City, Missouri and Person Centered Planning with Dr. Patrick Schwarz of Chicago, Illinois

June 1-2, 2018
Hilton Garden Inn, Columbia, Missouri
Housing and Inclusive Living with Wayne Crawford of Missouri Housing, Marshal, Missouri and Employment with David Mank of Indiana University, Bloomington, Indiana
2018 Council Meeting Dates

January 18-19, 2018, Hilton Garden Inn, Columbia

March 15-16, 2018, Hilton Garden Inn, Columbia

May 17-18, 2018 Stoney Creek Inn, Columbia

July 19-20, 2018, Embassy Suites, St. Charles

September 20-21, 2018, Hilton Garden Inn, Columbia

November 15-16, 2018, Hilton Garden Inn, Independence

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