

Summer/Fall 2018

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2018 Joint Meeting of the PADD Board and PAIMI Council

P&A's two advisory bodies, the PADD Board and the PAIMI Council, came together in Frankfort on May 25, 2018 for their annual joint meeting. The focus of this year's meeting was voting and included presentations on the history of voting rights in America and the importance that voting plays in the advancement of individual rights.

It was also announced that the PADD Board and PAIMI Council will be teaming up with the State Board of Elections, the State Long-term Care Ombudsman and the Independent Living Centers on September 25, 2018 for National Voter Registration Day. Up to 20 sites will be set up around the state to encourage voter registration. Tablets will be provided at each site for easy registration. RevUp KY, a cross-disability coalition of organizations and citizens, developed a candidate questionnaire that focuses on disability related issues.

The PADD Board, PAIMI Council and P&A staff also honored this year's recipients of the Jean Gossick Advocacy Award and the Billy Cox/Victoria Scott Self Advocacy Award. (See page 2).



Staff Attorney Leslie Jones gives a presentation on the history of voting at P&A's 2018 Annual Joint meeting.

2018 Annual Joint Meeting Award Recipients

Each year Kentucky Protection & Advocacy gives out two awards at their Annual Joint Meeting. The First award given was the Jean Gossick Award. The Jean Gossick Advocacy Award recognizes an individual and/or group of individuals who have promoted the rights of individuals with disabilities and has worked to bring about systemic changes to advance the rights of individuals with disabilities.

Sgt. Pam Oberhausen has been with the Louisville Police/ Louisville Metro Police since 1994. She is currently a Patrol Sergeant in the 4th division and the Crisis Intervention Training (CIT) Coordinator and instructor for the Police department. She is also a statewide CIT instructor. Sgt. Pam Oberhausen's combined efforts have enabled her to train over 4000 Police Officers across the state of Kentucky in Crisis Intervention Training.



Jean Gossick Award recipient, Sgt. Pam Oberhausen with P&A Director Jeff Edwards.

The second award, the Billy Cox/Victoria Scott Self-Advocacy Award, honors a strong self-advocate and a person who advocates for the rights of individuals to make their own choices about how to live their lives. P&A was pleased to present this award to Arthur Campbell for his commitment and passion as a self-advocate.



Billy Cox/Victoria Scott Self-Advocacy Award recipient, Arthur Campbell with P&A Director Jeff Edwards

Arthur Campbell spent the first 38 years of his life in virtual isolation in his parent's home. His parents did not keep him isolated intentionally, but this was done through fear, ignorance and poverty.

In 1983 through circumstances almost beyond belief, he was able to move out into his own apartment and has been living independently ever since. He did not know that there was a Disability Movement in the world. In fact, up until he was 38 he had never been around another person with disabilities.

Since 1983 he has lived his life as a Civil Rights worker and a disability activist. Working in the disability field to empower his fellow brothers and sisters with disabilities and working towards gaining full human and civil rights and self-dignity for everyone.

Over the years he learned how to use and respect civil disobedience as a tool to gain his and others full human and civil rights that the able-bodied population takes for granted as their birthright. He has participated in acts of civil disobedience many times over the years being arrested 29 times in 12 states.



The Department for Medicaid Services Rescinds Proposed Changes to the Collection of Patient Liability for Long-Term Care Waiver Recipients by Kevin McManis

In late May 2018, the Department for Medicaid Services mailed letters to approximately 20,000 Kentucky long-term care waiver recipients detailing the amount of ‘patient liability’ they were expected to pay each month to maintain their Medicaid eligibility. Patient liability, also called ‘post-eligibility treatment of income’, refers to the amount of a waiver recipient’s income that a person must pay towards their cost of care (after deductions for a ‘personal needs allowance’ and other specified expenses). Many of these recipients were surprised to learn the monthly amount they were expected to pay would increase dramatically, or that they owed a patient liability at all. There was no explanation given for the changes, but phone numbers were provided.

In early June, Medicaid mailed follow-up letters to recipients explaining that many of the original letters were not right or were sent to the wrong people. They stated the letters could be ignored for the time being. In late June, corrected letters were mailed to those who, in fact, owed a patient liability and stated the changes would be implemented starting August 1, 2018. These letters created considerable confusion among recipients and providers alike and generated hundreds of calls to Medicaid, state legislators, and advocacy organizations, including Protection and Advocacy.

On July 18, 2018, representatives from Medicaid appeared before the legislative Medicaid Oversight and Advisory Committee in Frankfort to address the changes. They explained that for many years Medicaid had not been collecting full liability from all waiver recipients and these changes were needed to comply with federal regulations and the existing waivers. Five waiver recipients, several of whom would have to pay over \$1,000 per month, testified before the Committee and vividly described the detrimental impact this would have on their lives and health. All said they would have to choose between trying to stay in their homes without services and ending up in a nursing facility, or worse.

After pointed questioning by members of the Committee, Medicaid officials agreed to review the proposed changes to patient liability and explore all available options surrounding the issue. They acknowledged that each state has discretion to set the ‘personal needs allowance’ for long-term care waiver recipients at any level and they would review current policies as part of their ongoing waiver redesign efforts. Two days later, on July 20, 2018, Medicaid announced they were not going to change patient liability and would provide further guidance after review. This was followed up by a letter telling Medicaid recipients who pay patient liability of this decision.

2018 Kentucky Legislative Session Review by Heidi Schissler



Each year, P&A follows the legislative session of the Kentucky General Assembly as legislators consider bills that could affect persons with disabilities. This year's legislative session ended on April 14, 2018. P&A staff followed 147 bills. Of that number, 27 became law this year. Here is a review of some of the bills that P&A followed that became law as well as other highlights from the session:

House Bill 1, which reformed Kentucky's child welfare system. The bill established the Child Welfare Oversight and Advisory Committee to review, analyze, and provide oversight over all aspects of the state's child welfare system. The Committee must meet at least two times per year and issue reports to the General Assembly. The bill also created specialized "family preservation services" to provide in-home services to children and youth who are emotionally disturbed, and established a putative father registry. It also gives foster parents the right to be notified of a foster child's move, and the right to attend and be heard at court proceedings. It includes additional periodic court reviews of all foster children and their permanency plans, and puts time limits that are more stringent on various court proceedings.

House Bill 5, which allows a bench trial rather than a jury trial in guardianship cases. P&A has not been in favor of bench trials in these cases for a number of years. Many significant individual rights can be lost during guardianship proceedings and a jury is one of the most important protections against unnecessary loss of rights. In addition, HB 5 limits the types of individuals for whom the Cabinet for Health and Family Services can be appointed guardian. House Joint Resolution (HJR) 33, also passed. HJR 33 creates the Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) program to improve adult guardianship. P&A is a WINGS member.

Senate Bill 19, which increased the criminal penalties for certain sex crimes against an individual with an intellectual disability. The bill also changed the law on consent for sexual activity. Now, each individual's ability to communicate consent or understand the nature of the act or its consequences shall be considered.

Other highlights include bills that increased private insurance coverage for autism (HB 218), excluded ABLE accounts from state income tax (HB 306), and bolstered Peer Support Networks in public schools (SJR 52).

P&A followed some bills that did not become law. Three bills (HB 376, SB 173, and SB 266) addressed amending the Kentucky Constitution to allow certain felons and persons with intellectual disabilities and mental illnesses to vote. The existing language in the Kentucky Constitution says that "idiots and insane persons" do not have the right to vote. Similar bills to change this antiquated language have been filed in previous sessions but, like this year, failed to pass.



P&A also followed the legislature's passage of the biennial state budget. Some highlights of this year's budget include increased funding for brain injury services, Supports for Community Living (SCL) waiver services payments, private child care agencies and for state social worker salaries. It also includes language requiring all qualified individuals living in an ICF/ID to move to the community. This year's budget did not include specific funding for additional SCL or Michelle P. waiver slots, as it has in the past. The budget went into effect on July 1, 2018.

Information on all of the proposed bills in this year's legislative session may be found here: <http://www.lrc.ky.gov/record/18RS/record.htm>

The 2019 regular legislative session begins on January 8, 2019.

Kentucky P&A Receives New Grant to Protect Social Security Beneficiaries by Jeff Edwards

On April 13, 2018, President Trump signed into law the Strengthening Protections for Social Security Beneficiaries Act (H.R. 4547). The law increases oversight and protection for some of our nation's most vulnerable citizens. Specifically, it increases independent oversight of the Social Security Administration's Representative Payee Program and authorizes the nationwide P&A system to monitor and investigate how representative payees are administering the Social Security funds of beneficiaries. (A representative payee is a person or entity who is appointed to manage the Social Security Disability or Supplemental Security Income of a person who is not fully capable of managing his or her own benefits.) Unfortunately, many representative payees have been investigated for stealing or misusing funds and have exploited, neglected, and even abused the people with disabilities they were supposed to be helping. The new law will allow state P&A's to conduct onsite reviews of representative payee activities, develop corrective action plans and submit reports and findings to the Social Security Administration.

Kentucky P&A Director Jeff Edwards is working with five other P&A directors and the National Disability Rights Network (NDRN) on implementation of the new grant for all 57 Protection and Advocacy systems.

Kentucky Medicaid Waiver Redesign Update by Bill Dolan



In April 2017, the Department for Medicaid Services selected Navigant Consulting to assess Kentucky's long-term care waiver programs and recommend improvements. These programs include the Michelle P Waiver, the Supports for Community Living Waiver, the Brain Injury Waivers, the Home and Community Based Waiver, and the Model II Waiver. Following an initial yearlong review and public comment period, Navigant recommended a two-phase assessment and implementation process. Phase One focuses on review of the existing waivers and internal operational redesign of Medicaid's administration of the waivers. Phase Two focuses on a substantive redesign of the waivers themselves.

In the spring of 2018, P&A staff attended multiple Medicaid sponsored focus groups and town halls held throughout the Commonwealth to gather public comment on waiver redesign. P&A filed numerous written comments as well. Navigant released its Phase One preliminary recommendations report in April 2018. Navigant submitted 11 recommendations to Medicaid:

- standardize provider and service definitions across 1915(c) waivers
- implement needs-based care planning with a universal assessment tool, completed by an independent entity
- implement needs-based individual budgeting methodology
- conduct a cost-based study to develop a sound rate-setting methodology
- develop consistent operational guidelines and update training and workflows for each waiver oversight
- establish and implement case management standards and training
- streamline participant-directed service delivery by reducing the disparity among fiscal management agencies and strengthening program policies and procedures
- centralize operations and oversight under one quality management business unit
- implement an ongoing, formal stakeholder engagement process, including TACs & MAC
- implement a quality improvement strategy to increase emphasis on improving service outcomes and participant experience
- conduct a future assessment of the need for waiver reconfiguration, once aforementioned recommendations are implemented and reviewed for effectiveness

Navigant's initial recommendations are available in their entirety here: <https://chfs.ky.gov/agencies/dms/dca/Pages/default.aspx>

Medicaid anticipates that Phase One will conclude by December 2019 with Phase Two starting in 2020. Stakeholders will have ongoing opportunities to comment on both phases of the redesign. The public can submit comments regarding the waiver redesign process directly to Medicaid at Medicaidpubliccomment@ky.gov.

Welcome to Casey Philpot by Beth Metzger



Birthday presents come in all shapes and sizes. If you ask Advocate Casey Philpot what was the best present she received on her last birthday, she would tell you with her huge sweet smile “being hired by P&A”. Two weeks after receiving her gift, Casey became our agency’s newest advocate for the Information, Training & Outreach (ITO) and Adult Teams.

Casey came to P&A after working for Disability Determination Services (DDS) – another state agency-- for 16 years. She made this transition because she wanted to do more to help people be treated with dignity, respect and justice.

Casey, a University of Kentucky graduate, lives in Frankfort with her husband and their two children.



Welcome to Kevin Sharkey by Kevin McManis

Kevin joined Protection and Advocacy in November of 2017 as a staff attorney on the Adult Team. Kevin started his legal career as a solo practitioner in Louisville. Prior to coming to P&A, he was a staff attorney with the Kentucky Court of Appeals in Frankfort for three and half years.

Kevin earned his Juris Doctor from the University of Kentucky School of Law in 2009 and his B.S. in political science and public policy from Eastern Kentucky University in 2005.

Prior to pursuing his higher education, Kevin served five years in the United States Army. His service included tours of duty in Bosnia, Kuwait and Germany as a communication specialist.

Kevin was born in Cleveland and grew up in Ohio and Kentucky. He is a passionate Cleveland sports fan and an avid reader of classic literature. He currently lives in Lexington with his wife and six-year-old daughter.



Upcoming Events

*September 21, 2018: Kentucky Guardianship Association Annual Conference- From 8:15-4:30- Thomas D. Clark Center for Kentucky History, 100 West Broadway, Frankfort, KY 40601. www.kyguardianship.org/winds-of-change-registration

*October 20, 2018: Building Bridges For Families 2018 Special Needs EXPO- From 9:00 -1:00- Owensboro Christian Church, Owensboro KY- Sponsored by Wendell Foster and the KY Family to Family Health Information Centers. <https://wendellfoster.org/calendar/category/special-events>

*September 14, 2018: HB 144- From 1:00-3:00- The Department for Public Health. 1st Floor Conference Suites A&B. <https://chfs.ky.gov/agencies/dph/Pages/default.aspx>

*September 28, 2-18: HDI Seminar on Supported Decision-Making and Guardianship- From 1:00 to 3:00. <https://www.hdi.uky.edu/news/fall-seminar-supported-decision>

*September 27, 2018: ADA Series- From 10:00 to 11:00 online and at HDI CATS- 2358 Nicholasville Road, Suite 180, Lexington, KY. www.hdi.uky.edu/news/the-4th-thursday-ada-talks

*October 17-19, 2018: Kentucky APSE Conference- Lexington, KY. www.hdi.uky.edu/news/the-4th-thursday-ada-talks

*November 9, 2016: PAIMI Advisory Council Quarterly Meeting: 10:00 a.m. at 5 Mill Creek Park, Frankfort, KY



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