



RIGHTS REPORTER

protecting and promoting the rights of kentuckians with disabilities

Winter 2016-17

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2016 Annual Meeting

The Annual Meeting of the PADD Advisory Board and The PAIMI Council was held at the Thomas D. Clark Center for Kentucky History. The focus of the meeting was the identification of barriers to a successful future for Kentucky's children with disabilities.

The meeting was facilitated by The Facilitation Center of Eastern Kentucky University. There were participants from the Department of Behavioral Health Intellectual/Developmental Disabilities, Client Assistance Program, the KATS network, Human Development Institute, the Commonwealth Council on Developmental Disabilities, Department of Juvenile Justice, Department of Public Advocacy, Kentucky SPIN, Kentucky Partnership for Families and Children, Commission for Children with Special Healthcare needs, Kentucky Autism Network, the Down Syndrome Association and P&A staff.

The PADD Advisory Board and PAIMI Advisory Counsel awarded the Billy Cox/Victoria Scott Self-Advocacy Award to Robin Rider-Osborne and the Jean Gossick Advocacy Award to the Seven Counties Services Rural ACT Team.



Workshop facilitated by Eastern Kentucky University



Jeff Edwards, P&A Director, Robin Rider-Osborne, recipient of Billy Cox/Victoria Scott Self-Advocacy Award, and James Light, PAIMI Council Member



Seven Counties Services Rural ACT Team, recipients of the Jean Gossick Advocacy Award



Targeted Voter Education Outreach Project

Beginning in 2012, Kentucky Protection & Advocacy (KY P&A) began a targeted voter education outreach project to individuals with developmental & intellectual disabilities. Supports for Community Living (SCL) Medicaid Waiver Adult Day Treatment providers located in two to three chosen regions received letters offering the education at their sites for the individuals they serve. The goals of the project were to provide voter education in every region of the Commonwealth and learn the realities of barriers/triumphs experienced by individuals with disabilities.

The training dubbed “Your Voice: Your Vote” consists of two parts: 1) a brief history of federal and state voting laws that impact individuals with disabilities and 2) an interactive, game-show like portion that features real-life scenarios. This format lends itself to better holding the attention of those attending the sessions than simply lecturing.

This year marks the conclusion of the project. During the first weeks of April, eight trainings were provided at as many sites. A total of 265 individuals with disabilities and staff members who work with them received education.



Beth Metzger providing voter training

Since “Your Voice: Your Vote” was first piloted 4 years ago, 857 individuals with disabilities and their staff were educated about their rights. Along the way, the trainers gained knowledge of individual triumphs/issues with the voting process. This knowledge allows KY P&A to work with colleagues at the KY Secretary of State’s Office and the State Board of Elections in our efforts to ensure that all eligible voters have the opportunity to vote independently and privately.



System of Care Update 2016: How do the changes in the SOC relate to consumers?



The State Interagency Council (SIAC) was created in 1990 by the legislature to oversee and make improvements to Kentucky's system of care for children. A "system of care" is the coordination of services available throughout the state to children with or at risk of developing a behavioral disability or other challenges. SIAC is made up of representatives from Kentucky's Cabinet for Health and Family Services (including the Department of Medicaid Services, Public Health, and the Department of Behavioral Health Developmental and Intellectual Disabilities, the Department for Community Based Services and the Family Resource and Youth Service Centers), the court system, the Justice Cabinet, and Kentucky's Education and Workforce Development Cabinet, a parent of a child with a behavioral health need, and a child who is diagnosed with a behavioral health need. Kentucky is working through the SIAC to create a better network of services, build meaningful relationships between families and youth, and address children's and families' cultural and linguistic needs so Kentucky's children can thrive and grow.

SIAC's efforts have positively impacted children with behavior disorders covered under Medicaid. Children with disabilities may qualify for Medicaid because their parents meet the income requirements or because they qualify for a Medicaid Waiver—in which the income requirement is not considered or "waived" because of the nature or severity of the child's disability. The state sets out the type and number of services available to Medicaid recipients in the State Plan. Regardless of how a child qualifies for Medicaid, federal law requires that children 21 and under receive medically necessary services through Early Periodic Diagnosis Screening and Treatment (EPSDT), even if the child has already met the limit for the type or number of services available through the State Plan.

In an effort to expand services available to children with a behavioral health disability, the Department of Medicaid Services (DMS) increased services available to children with behavioral health disabilities. DMS opened its provider network to allow individual providers, who historically could not bill to Medicaid, to become Medicaid providers. DMS also expanded the types of therapeutic services providers could bill.

Despite these changes, P&A continues to get calls from parents experiencing difficulty obtaining needed therapeutic services for their children through Medicaid. Most frequently, parents report that requested services are not approved or that there is no service provider in their area. DMS has worked to simplify billing codes to ensure that qualifying services are approved and paid. SIAC has responded to the lack of provider concerns by mapping out all of the services that the State Interagency Council believes a child should be able to receive and is surveying providers across the state to determine what areas do not have providers for certain services.

The changes in the children's mental healthcare system are ongoing. There continues to be questions about how families can access mental health services for their children. Managed care organizations, which administer Medicaid benefits to Medicaid-eligible children not on a waiver, must provide a "case manager" or "care coordinator" to assist parents with the coordination of services. A Medicaid-eligible child who is on a waiver can receive a case manager, who will also coordinate the child's services. Also, the State Interagency Council meetings are open to the public, so anyone interested can attend and provide feedback at the meetings. Please feel free to contact Protection and Advocacy at 502-564-2967 if you have a specific question about your situation.



Us and Them, a Concept Worth Changing

By Robbin Richie

In 2015, Kentucky Protection and Advocacy (P&A) received 461 calls related to educational issues. In 2016, the agency received 327 by the end of September, so roughly the same number of calls will be received for 2016. Most of those calls come from the parent or guardian of a child with a disability. Although there are a variety of issues discussed, with either an attorney or an advocate, one reoccurring comment is how the parent feels intimidated when attending an Annual Review Committee (ARC) meeting.

Typically, the parent is the last to enter the room, as the school professionals have already taken their seats and left one chair available for the parent/guardian. The chairperson will go over the purpose of the meeting, offer parent rights, which is typically a statement like: "Basically (which we all know to be a "filler" word) what these procedural safeguards say is we are not going to do anything to your child without your permission." Followed by: "Would you like for me to review these rights with you?" Already, there is a hurried feeling by the parent and they surely don't want to waste the time of the professionals. Why not just take the time to review them? If the parent/guardian cuts you off and says it is not necessary, then he/she is the decision maker and since the parent is in the minority (compared to all of the district personnel at the table) what an immediate sense of being an "equal" could be felt by the parent.

Next, the round table discussion/presentation on how the child is progressing begins. Some committee members may bring data to support what they are saying, some may have forgotten to print it off, others will have elaborate color coded graphs and charts. Parents rarely get these documents before the IEP meeting and do not have time to review or process the data before the conversation begins. And, with the exception of a few psychological evaluations that require a parent to fill out a survey, parents are not included in the many conversations that go on in schools about what to include or change in the "draft" IEP. This severely limits the ability of parents to understand and participate fully in any discussion about the student's progress.

The Individualized Education Plan (IEP) is written and even though the word "draft" is plastered across the top of every page, in the mind of those who created the document, it is the final copy and nothing mom, dad, or grandma says is going to change it. The creator of the IEP draft may tell mom he/she will honor the request she has made, but including the input of the true professional (the parent or guardian) when it comes to this child is not practiced in all districts. Why not value the input of everyone at the table? Togetherness will change the life of a child, not the power struggle of the professional who spent roughly a couple of years studying one specific area of special education eligibility compared to the parent who will have a life-long commitment to the overall educational well-being of the child.

"We" should be the focus on the appropriate development of an Individualized Education Plan. Educators and Administrators are faced with increasing demands every year. For the Special Education Teacher, there is mounds of paperwork that comes with the job but "we" should be committed to the human being whose name appears on top of each page of the IEP. Perhaps what the Shelby County School District instills in all of their employees: "Begin with the end in mind" will help eliminate the concept of "us and them," strengthen the



team concept of IEP development by truly considering the parental input, and eliminate the intimidation most parents feel at an ARC meeting. Who knows? With the appropriate plan in place “we” may end up working for the student who received an appropriate plan, which was appropriately implemented every year of his/her school career.

Changes to the Home and Community Based Waiver Program by Bill Dolan

Kentucky recently made significant changes to the Home and Community Based (HCB) Waiver program. HCB provides community-based services to adults and children that meet nursing facility level of care. HCB services include conflict free case management, adult day health care, attendant care, specialized and non-specialized respite, goods and services, environmental and home modifications, home delivered meals, participant directed coordination, and home and community support delivered under the participant directed model.

The Department for Aging and Independent Living (DAIL) is now the operating entity for HCB. DAIL will oversee the daily operations of HCB while the Department for Medicaid Services will continue to set policy. Independent assessors, rather than home health care providers, will now intake a HCB applicant into the Waiver. The provider base expands to include home health agencies, adult day health care centers, centers for independent living, area agencies on aging and independent living, approved meal providers, public health departments, and participant directed service employees. Other changes include an increase in the adult day health care centers pay rate, combining personal care and homemaking with attendant care, and therapies move to the state plan.

Many current HCB recipients are concerned about the change in the pay rate for participant directed services. The agency provided pay rate for attendant care is \$24 per hour while the participant directed rate is just \$11.52. Current HCB recipients that participate direct in their care will most likely be forced to drastically reduce the pay rate of their employees. An additional barrier to participant directed care is the increased scrutiny family member employees will receive.

The move to the updated HCB has begun. On September 15, recipients began migrating to the new HCB based on their recertification month. Please contact KY P&A if you want additional information or need advice regarding your particular situation.





Reflections on Prison Monitoring by Rebekah Cotton

Kentucky Protection & Advocacy (KY P&A) conducted monitoring in all of the Kentucky Department of Corrections (KY DOC) state prisons in 2016. We created a monitoring tool which focused on issues concerning inmates with disabilities including inmates with diagnosis of mental health disorders, intellectual disability, brain injury, deaf or hard of hearing and other physical disabilities. During monitoring, KY P&A interviewed each warden and many of the administrative staff including the recreation directors and the designated Americans with Disabilities Act (ADA) Coordinators. The focus on the monitoring effort was to learn more about the KY DOC system, with a specific focus on the treatment of inmates with disabilities who are being held in restrictive housing units, where the inmates spend 23 hours per day in their cell. KY P&A also made a point to interview all of the mental health services staff at the prison including psychologists, psychiatrists and some social workers and support staff. We interviewed inmates with disabilities currently housed in restrictive housing cells at every prison and have opened records reviews on many of those inmates. KY P&A has a new priority in 2017 to summarize the information gathered during the 2016 prison monitoring of mental health units and restrictive housing units. We will compile all of the statistical information and interview content provided by the prison staff and use this information to determine next steps in advocacy for inmates with disabilities. KY P&A has made advocacy buttons with the number 23 to raise awareness of all inmates with disabilities who are being held in a segregation cell for 23 hours per day. In addition to our prison advocacy, KY P&A has a new priority to conduct monitoring in four local jails in 2017. We are continuing to have a presence in the criminal justice system of our state and to advocate for inmates with disabilities state wide via client representation, records reviews, information and referral and commenting on regulation and policy amendments made by KY DOC. KY P&A is just one of many protection and advocacy agencies that are advocating for criminal justice reform efforts on behalf of inmates with disabilities. KY P&A prison advocacy efforts were reported on by the Amplifying Voices of Inmates with Disabilities Prison Project report "Locked Up and Locked Down, Segregation of Inmates with Mental Illness" issued September 8, 2016. You can see this full report with nationwide information at <http://avidprisonproject.org/>.





Farewell to Leslie Lederer by Beth Metzger

Kentucky P&A bid long-time advocate, Leslie Lederer, “bon voyage” on June 28, 2016 at a beach themed retirement party. Leslie came to Kentucky P&A in 2000 after working for the Disability Rights New Mexico. She was especially passionate about inclusion of people with disabilities in every part/setting of life. Her son, Danny, certainly reaped the benefits of her advocacy and was used as a shining example of inclusion. Through her work with TASH, the Arc, and other organizations, Leslie’s advocacy efforts and leadership were known on state and national levels. She received a number of awards, including the Jean Gossick Advocacy Award in 2007. Leslie and her husband have moved to Florida to be closer to their daughter and her family. Kentucky P&A greatly misses Leslie’s creativity, passion, and energy.



P&A Bids Farewell and Good Luck to Malicia Hitch by Heidi Schissler

Malicia Hitch, an attorney with P&A for ten years, recently accepted a position with the Office for Civil Rights, United States Department of Education. Malicia came to P&A in 2005 as an attorney with the Children and Youth team. During her tenure here, she represented children and youth in various forums, including federal court; reviewed administrative regulations and statutes related to persons with disabilities; and provided trainings on disability-related topics. Her new position is located in Atlanta. Ms. Hitch stated, “I thoroughly enjoyed my time with the agency. I learned a great deal over the past 10 years from clients and coworkers. Thank you for being willing to mentor me and allow me to gain new experiences.”



Malicia was a great asset to the agency and we were sorry to see her go, but wish her luck and continued success in her new job. At the OCR, Malicia will continue to advocate for the rights of children with disabilities as an agency attorney pursuing complaints of disability discrimination in schools.



Upcoming Events

February 9, 2017: 13th Annual Children's Advocacy Day, Capitol Building in Frankfort, 9:00am-3:00pm

February 22, 2017: 874K Disabilities Coalition Advocacy Event, Frankfort, KY, Capitol Annex and Rotunda, Gather in the Annex: 10:00 a.m. Rally in the Rotunda: 1:00 –2:00 p.m

March 16-17, 2017: The Arc of Kentucky 2017 Annual Conference & Jefferson Co. & Simpson Co. Parent Resource Centers Conference
Best Practices for People with Intellectual and/or Developmental Disabilities and their Families, "Building a Brighter Future"
Ramada Plaza and Convention Center, 9700 Bluegrass Parkway, Louisville, KY



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