



2023 Annual Report

Protecting and promoting the rights of
Kentuckians with disabilities.

“IF YOU WANT TO IDENTIFY ME, ASK ME NOT WHERE I LIVE, OR WHAT I LIKE TO EAT, OR HOW I COMB MY HAIR, BUT ASK ME WHAT I AM LIVING FOR, IN DETAIL, ASK ME WHAT I THINK IS KEEPING ME FROM LIVING FULLY FOR THE THING I WANT TO LIVE FOR.”

— THOMAS MERTON

The work of Kentucky Protection and Advocacy (P&A) in 2023 can easily be distilled into the above words of Thomas Merton. Since 1977 we have worked to ensure that the voices of Kentuckians with disabilities are heard and that their wishes, dreams, fears, frustrations, hopes, anger, and joys are acknowledged.

We had contact with Kentuckians with disabilities in 114 of 120 counties. In those 114 counties, we met people who were isolated, victimized, ignored, exploited, and institutionalized. These situations seemed unsurmountable for some. However, with assistance from Kentucky P&A and a great deal of determination, frustration, and patience they realized their goals and, hopefully, they begin to live fully for the things they want to live for. Not what is easy, or just good enough, or in someone’s best interest, but what Kentucky P&A clients want to live for.

The Third Amended Settlement Agreement (TASA) with the Cabinet for Health and Family Services (CHFS) has increased the services for adults with behavioral health needs in a few Community Mental Health Center (CMHC) regions, while other CMHCs are not. There has been a dramatic increase in the number of placements of Kentuckians with intellectual/developmental disabilities being institutionalized due to the lack of regulation enforcement by CHFS. Those are just two examples of the myriad of issues facing Kentuckians with disabilities.

The work of our advisory boards Protection and Advocacy for Individuals with Developmental Disabilities (PADD Board) and Protection and Advocacy Individuals with Mental Illness Advisory Council (PAC) have been integral to this work and their dedication to the mission cannot be overstated.

My hope is that everyone who reads this report is motivated to support the choices of Kentuckians with disabilities, find ways to improve their community and discover the thing they want to live for.

Sincerely,

Jeff Edwards, Director



OUTREACH SPOTLIGHT: ADVOCATING FOR EMPLOYMENT RIGHTS AND LIVABLE WAGES

While the overall number of Kentucky entities allowed to pay subminimum wages has decreased marginally, more than 20 sites continue the government-approved poverty cycle perpetuation. Kentucky P&A began a two-prong educational approach to eliminate subminimum wage existence within our commonwealth. The first prong involves providing employment rights training to individuals employed at the sites that pay subminimum wages, while the second involves educating the public about the accepted practice.

Prior contact with individuals at sheltered workshops revealed a woeful lack of understanding and perpetuation of misinformation, especially for Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) recipients. Kentucky P&A performed employment rights trainings at 14 sites across the Commonwealth. Three hundred ninety-eight (398) individuals learned that anyone with a disability who wants to have competitive, integrated employment has the right to try.

Kentucky P&A participated in three events to educate the public regarding subminimum wages and employee rights. Kentucky P&A was interviewed for Avocado Press's Demand and Disrupt podcast and by WAVE 3 News (Louisville). Block by Block Creative, an entity that assists non-profit organizations in creating different forms of accessible media, interviewed two PADD Advisory Board members who successfully transitioned from sheltered workshops to competitive, integrated employment. Finally, Kentucky P&A had an exhibit table at the Kentucky Chamber of Commerce's Inclusive Workforce Summit.

We want to hear from you! Please complete a public comment survey today!



Outreach by the Numbers

Total Outreach Events: 58

Nationwide: 1

Statewide: 16

County/Regional: 41

Total P&A publications distributed: 3,955

Presentations/Trainings: 44

Individuals educated: 1,088

Topics included:

Supported decision making

Self-advocacy

IEP/504s

Employment

Voting

Resources/benefits

Exhibit/vendor booths: 14

Individuals who asked questions: 787

TECHNOLOGY HELPS DOUG DO WHAT HE LOVES

Doug became paraplegic from spinal cord injuries sustained in a motor vehicle accident. At the time, he had worked as a high school custodian for over 20 years. Upon return to work, Doug was placed in an administrative assistant position that did not require much physical labor. He worked with the Office of Vocational Rehabilitation (OVR) to meet appropriate return to work needs.

Two years later, he requested that OVR assist him with obtaining a standing wheelchair. When this was denied, Doug requested a reconsideration. However, the denial was upheld based upon his current job not requiring standing. Doug then contacted Kentucky P&A for assistance with an appeal.

Kentucky P&A noted that the reconsideration request merely mentioned Doug changing jobs beginning in the 2023-2024 school year. He was returning to his prior position as a high school custodian. Doug told his advocate that he was now physically able to perform the duties at the school he dearly loved. A standing wheelchair would allow him to do those duties even more safely.

Kentucky P&A filed an appeal and OVR reversed the denial, based upon information about the new job. Doug received his specialized wheelchair less than 3 months from the appeal date. This allowed him to become familiar with the chair functions before the new school year started.



MEETING DAVID'S COMMUNICATION NEEDS

David has autism, intellectual disability, and limited oral communication skills. He had encountered difficulties receiving a proper education through his local school district. He experienced segregation into a small room, a reduction of instructional time, and the denial of behavioral supports. The school even recommended that David's parents institutionalize him.

After Kentucky P&A opened a case to assist David and his parents address the issues, a request was made that the school perform an assistive technology assessment, specifically for augmentative communication. When this, like the other requests, was denied Kentucky P&A assisted parent in filing a state educational complaint with the Kentucky Department of Education (KDE).

KDE found that the school district had violated his entitlement to a Free Appropriate, Public Education (FAPE). As a result, David received compensatory hours for speech and occupational therapies, behavioral supports, and an assistive technology assessment. His communication is now facilitated with the use of a durable Via Pro with LAMP Words for Life.



Photo courtesy of Hopebridge Autism Therapy Centers at [hopebridge.com](https://www.hopebridge.com)

REPRESENTATIVE PAYEE PROGRAM: POSITIVE INDIVIDUAL AND SYSTEMIC CHANGES

On April 13, 2018, the President signed the Strengthening Protections for Social Security Beneficiaries Act of 2018. The law requires the Social Security Administration (SSA) to make annual grants to a National Association Grantee, and Protection & Advocacy (P&A) organizations serving each state, territory, or the American Indian Consortium, for the purpose of conducting all representative payee reviews.

The P&A conducts a review, which includes:

1. An interview with the individual or organizational representative payee,
2. A review of the representative payee's financial records for the requested beneficiary or sample of beneficiaries served,
3. A home visit and interview for each beneficiary included in the review, and
4. An interview with legal guardians and third parties, when applicable.

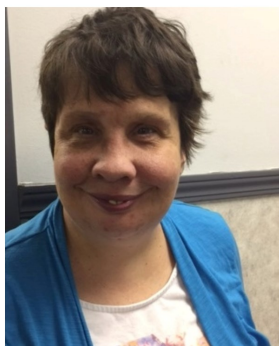
Results of Reviews

If the results of the review find that the representative payee is not fulfilling their duties as required by SSA, corrective action(s) may be required in order for them to continue to serve. The P&A or SSA contacts them to explain the findings and initiate a corrective action. Once all corrective actions are satisfactorily completed, the P&A or SSA notifies them in writing that the review is complete.

OUTCOMES FOR 2018-2023 GRANT CYCLE

1. Interviews conducted for over 1,000 beneficiaries, which included visits to their home or facility living area.
2. More than 150 referrals made to protective entities (Adult Protective Services & law enforcement) and for resource provision (Office of Vocational Rehabilitation, Medicaid waivers, Long-Term Care Ombudsman, Kentucky STABLE, etc.).
3. More than 300 representative payees interviewed and reviews completed.
4. Over \$165,000 returned to beneficiaries because of fund misuse or mismanagement identified by KY P&A reviewers.

The Protection and Advocacy for Individuals with Developmental Disabilities (PADD) Advisory Board is comprised of geographically and ethnically diverse citizens from across the Commonwealth of Kentucky. The majority of members are individuals with developmental disabilities who are eligible for, have received, or are receiving services through the system. Members create and advise Kentucky P&A on policies and priorities to be carried out in protecting and advocating for the rights of individuals with developmental disabilities. The PADD Board also educates state and federal policy makers about the impact of regulations and policies that affect individuals with developmental disabilities throughout the Commonwealth.



PADD Advisory Board



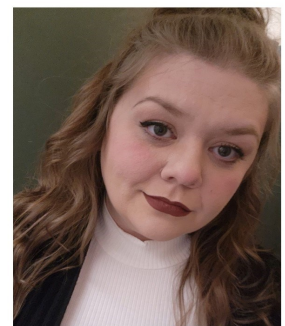
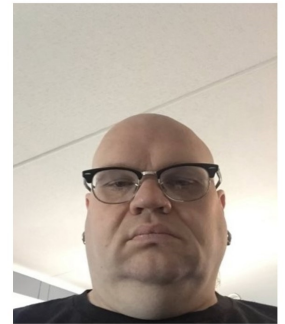
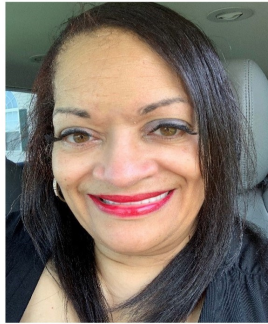
PADD Board members: Arthur Campbell, Tina Jackson, Floyd Mendoza, Brittany Freebody, Holly McDaniel, Sherri Pickett, Tyler Levy, Corey Nett, Shelly Bozarth, and Chris Ryder

Doing advocacy work, or serving on boards and committees is a privilege, and we can say that we save lives.

- ARTHUR CAMPBELL

Federal law requires Kentucky Protection and Advocacy to have a Protection and Advocacy for Individuals with Mental Illness Advisory Council (PAC). Membership is comprised of individuals with mental health diagnoses, family members of individuals with mental illness, mental health service providers, and individuals interested in expanding the rights and services of people with mental health diagnoses. Sixty percent (60%) of members must be persons with mental health diagnoses. The PAC meets quarterly and advises Kentucky P&A on policies and priorities; they also provide education and training in the community about the protection and expansion of rights for individuals with mental health issues.

PAIMI Advisory Council



PAC members: Gayla Lockhart, Virginia Bland, Austin Nugent, Brandon Banks, Destiny King, Robert Johnson, Melissa Mays Rodden, Lisa Paxton, and Erin Conley.

We are fighting for inclusion by watching out for those who cannot watch out for themselves.

- BRANDON BANKS

PATRICK MOVES OUT/MOVES ON

Patrick has a mental health diagnosis and a history of substance use disorder. His sister, who was formerly his legal guardian, contacted Kentucky P&A with concerns about state guardianship unnecessarily restricting him. At the time, Patrick was living in a Personal Care Home (PCH) and working full-time. He did not want to live in a facility. Despite Patrick being clean and sober for two years and receiving ongoing community mental health treatment, state guardianship would not consider community living due to his history of substance use. Instead of supporting Patrick's goal of independence, state guardianship restricted the use of a car after getting his driving privileges restored and limited contact with his sister.

Kentucky P&A advised Patrick and his sister about opportunities to help him live the independent community life he wished to have. His advocate also spoke numerous times with his state guardianship worker about loosening Patrick's restrictions.

Patrick's sister petitioned the court to become his legal guardian again to help build a stronger pathway leading to his independent life. The day his sister was reappointed, he was able to move out of the PCH into his sister's home and into his own apartment two week later.

Later, with Kentucky P&A's help, Patrick's rights were fully restored. He continues to work, receive services, remain clean and sober, drive, and live independently in the community.



TYRONE'S SUPPORTED DECISION MAKING

Tyrone has a mild intellectual disability and was appointed a state guardian to handle his affairs. District Court Judge Sara Nicholson had attended a Kentucky Judicial Mental Health Summit presentation on Supported Decision Making (SDM) done by My Choice Kentucky, a project of Kentucky's Developmental Disability Network contacted Kentucky P&A. In addition to Kentucky P&A, the network's other members are the University of Kentucky's Human Development Institute and the Commonwealth Council on Developmental Disabilities. Judge Nicholson wondered if SDM would be an appropriate legal avenue for Tyrone in lieu of full guardianship.

Tyrone's team, which included state guardianship, had been working with him on supported decision making and he was doing well. All members supported rights restoration. Tyrone told Kentucky P&A that he wanted to restore his rights but have the state continue managing his finances.

Upon Judge Nicholson's request, Kentucky P&A provided education to Tyrone, his court appointed attorney, and evaluators on alternatives to guardianship, including SDM. Testimony was also provided at Tyrone's guardianship hearing.

Education and information on alternatives to guardianship led to collaboration spanning multiple agencies. Thanks to this, Tyrone received rights restoration.



INVESTIGATING ABUSE AND NEGLECT

Congress created the Protection & Advocacy systems to address abuse and neglect occurring at facilities that housed individuals with developmental disabilities. The systems' reach later expanded to cover these issues in community-based programs serving people with all types of disabilities.

Kentucky P&A created an Investigation of Abuse and Neglect (IAN) team which meets bimonthly to review incident reports and Office of Inspector General Type A/B citations from:

- * Psychiatric Hospitals
- * Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities
- * Nursing Facilities
- * Personal Care Homes
- * Psychiatric Residential Treatment Facilities
- * Private Child Caring Facilities
- * Supports for Community Living (SCL) Waiver Providers

During fiscal year 2023, the Kentucky P&A IAN team reviewed 230 reports to determine if further action or investigation was required. Determinations were based upon if serious harm or death of individuals were the result of:

- * Physical assault
- * Sexual abuse/assault
- * Failure to provide adequate and appropriate treatment, care, or monitoring
- * Excessive or inappropriate use of mechanical, chemical, or other restraints, isolation, or aversive measures

SYSTEMIC ADVOCACY SPOTLIGHT: SASA

Kentucky P&A entered into the Interim Settlement Agreement with the Cabinet for Health and Family Services (CHFS) in August 2013 to provide much needed community supports and services to eligible individuals with severe mental illness residing at or at risk of living in a Personal Care Home. The agreement called for CHFS to provide the following services to 600 individuals over a three-year period:

- Community-Based Supported Housing Assistance
- Assertive Community Treatment
- Peer Support Services
- Crisis Services
- Supportive Employment

Two additional agreements were signed by Kentucky P&A and CHFS. The Amended Settlement Agreement (ASA) was signed in October 2015 and called for CHFS to provide services to an additional 75 individuals over a two-year period. The Second Amended Settlement Agreement (SASA) was signed in October 2018. The SASA was to be completed in 2021 with an additional 360 individuals receiving housing assistance, including permanent housing with tenancy rights and access to community-based services. At least 75% of those people were to be transitioned out of Personal Care Homes (PCH).

In fiscal year 2023, Kentucky P&A prepared to file a state court complaint alleging breach of contract when CHFS attempted to argue that it had fully complied with all SASA requirements. Both agencies then signed the Third Amended Settlement Agreement (TASA).

The TASA adds:

- Two additional years for the remaining individuals in the SASA to transition from PCHs and 80 people under state guardianship to receive TASA services with another year to monitor transitions.
- Individuals living in PCHs will be able to receive services via telehealth and will receive more robust In-Reach.

FINANCIAL INFORMATION

Representative Payee -PARP	\$ 525,109	14%
Developmental Disability - PADD	\$ 479,194	13%
Individuals w/ Mental Illness - PAIMI	\$ 473,700	13%
Individual Rights - PAIR	\$ 215,664	6%
Beneficiaries of Social Security - PABSS	\$ 148,190	4%
Client Assistance Program - PACAP	\$ 148,123	4%
Voting Access - PAVA	\$ 112,313	3%
Assistive Technology - PAAT	\$ 56,305	2%
Traumatic Brain Injury - PATBI	\$ 54,126	1%
State General Funds	\$ 1,457,400	40%
Total Revenue	\$ 3,670,124	

General and Administrative

\$372,567 11%

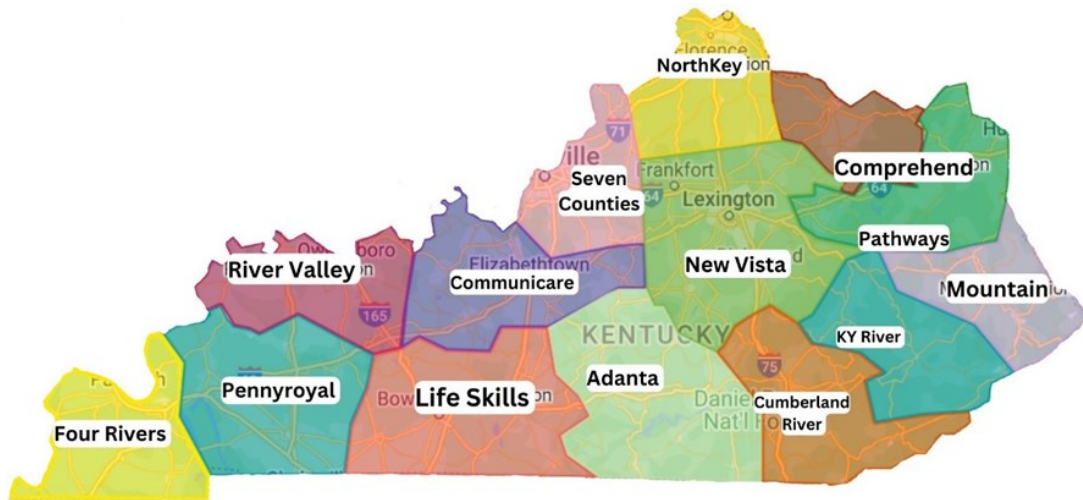
Program Services

\$2,961,419 89%



Protection and Advocacy receives funding from the U.S. Department of Education, Social Security Administration, U.S. Department of Health and Human Services, and State General Funds.

Individuals Served According to Community Mental Health Region



Four Rivers: 93
Pennyroyal: 174
River Valley: 123
Lifeskills: 158
Communicare: 115
Seven Counties: 401
NorthKey: 112
Comprehend: 5
Pathways: 75
Mountain: 51
Kentucky River: 85
Cumberland River: 64
Adanta: 100
New Vista: 481
Region Unknown: 23

P&A SERVED INDIVIDUALS REGARDING VIOLATIONS OF THE RIGHT TO:

- BE FREE FROM HARM IN PROGRAMS AND FACILITIES
- RECEIVE SERVICES IN THE LEAST RESTRICTIVE ENVIRONMENT
- RECEIVE REASONABLE ACCOMMODATIONS
- MAKE OWN CHOICES
- LIVE IN THE COMMUNITY

**Total Kentuckians Served through information & referral (I&R) and cases, combined:
2,060**

Mission

Kentucky Protection and Advocacy will protect and promote the rights of Kentuckians with disabilities through legally based individual and systemic advocacy, and education.

Vision

Kentucky Protection and Advocacy has a vision of a just society where all people are treated with dignity and respect for their expressed choices and have equal opportunities to participate in an integrated and inclusive society where different abilities are valued.

Values

Kentuckians with disabilities have a right to self-determination including, but not limited to, the right to refuse, the right to participate, and the right to choose.

Kentuckians with disabilities have the same inherent rights as Kentuckians without disabilities.

Kentuckians with disabilities will live and receive services in integrated and inclusive settings.

Kentucky Protection and Advocacy values and accepts differences and diversity.



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