

Protection and Advocacy and Client Assistance Program Services in the 2<sup>nd</sup> Congressional District

Fiscal Year 2023

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DISABILITY RIGHTS ARKANSAS (DRA) is a private, non-profit agency located in Little Rock, Arkansas. Since 1977, DRA has been designated by the Governor of Arkansas as the independent Protection and Advocacy system for persons with disabilities in Arkansas. DRA operates under authority outlined in federal law, is funded primarily by the federal government, and is governed by a board of directors. DRA collaborates with other disability rights and civil rights organizations, social service agencies, the private bar, and legal services agencies to accomplish identified goals and objectives. DRA's services are offered statewide at no cost to individuals with disabilities. Following is a description of DRA's nine federal Protection and Advocacy grants, as well as a grant awarded though the Arkansas Governor's Council on Developmental Disabilities.

# Protection & Advocacy for Individuals with Mental Illness (PAIMI)

PAIMI serves individuals with a diagnosis of serious mental illness. PAIMI prioritizes services to individuals receiving care and treatment in a facility and has a mandate to investigate complaints of neglect and abuse. See the Protection and Advocacy for Individuals with Mental Illness Act of 1986, as amended, 42 U.S.C. § 10801 et seq.

## Protection & Advocacy for Individuals with Developmental Disabilities (PADD)

PADD serves individuals with developmental disabilities, including intellectual disabilities, autism, epilepsy, cerebral palsy, and neurological impairments. A developmental disability is a mental or physical impairment beginning before the age of 22 which is likely to continue indefinitely, limits certain major life activities, and reflects a need for special care, treatment, and/or individualized planning. See the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. § 15001, et seq.

#### **Client Assistance Program (CAP)**

The CAP assists individuals with disabilities who have questions or who have encountered problems while applying for or receiving vocational rehabilitation (VR) services from state VR agencies. CAP also advocates for those who receive services from independent living centers (ILCs), the Division of Services for the Blind (DSB), and for those applying for or receiving services from tribal VR offices. See the Rehabilitation Act of 1973, as amended, Title I, Part B, Sec. 112, 29 U.S.C. § 732.

#### **Protection & Advocacy of Individual Rights (PAIR)**

PAIR serves individuals with disabilities who do not qualify for the protection and advocacy services described above. It is not limited to individuals with a specific disability or a particular disability rights issue. See the Protection and Advocacy of Individual Rights Program of the Rehabilitation Act of 1973, as amended, 29 U.S.C. § 794e.

# **Protection & Advocacy for Assistive Technology (PAAT)**

PAAT serves individuals with disabilities with issues related to assistive technology devices and services. This includes investigating the denial of, and negotiating access to, assistive technology devices and services. See the Assistive Technology Act of 2004, 29 U.S.C. § 3004.

## Protection & Advocacy for Beneficiaries of Social Security (PABSS)

PABSS serves individuals with disabilities who receive Social Security Disability Insurance (SSDI) or Supplementary Security Income (SSI) and who are trying to return to work, obtain employment, or receive certain employment-related training and services. PABBS educates beneficiaries about Social Security's work incentives and provides vocational rehabilitation and employment services advice. PABSS also assists beneficiaries with understanding their rights regarding representative payees. See the Ticket to Work and Work Incentives Improvement Act of 1999, as amended, 42 U.S.C. § 1320b-21.

## Protection & Advocacy for Traumatic Brain Injury (PATBI)

PATBI serves individuals diagnosed with a traumatic brain injury (TBI). PATBI works to ensure that individuals with traumatic brain injuries and their families have access to information, referrals and advice, individual and family advocacy services, legal representation, and support and assistance with self-advocacy. See the Traumatic Brain Injury Act, authorized as part of the Children's Health Act of 2000, 42 U.S.C. § 300d-53.

## Protection & Advocacy for Voting Access (PAVA)

PAVA educates and assists individuals with disabilities so they may enjoy full participation in the electoral process. These efforts include ensuring physical accessibility of polling sites and informing individuals about the rights of voters with disabilities. See the Protection and Advocacy for Voting Access program of the Help America Vote Act of 2002, 42 U.S.C. § 15461-15462.

## Strengthening Protections for Social Security Beneficiaries (SPSSB)

SPSSB, also known as the Representative Payee program, serves individuals with disabilities whose social security benefits are managed by a representative payee. DRA coordinates with the Social Security Administration to conduct periodic onsite reviews as well as additional discretionary reviews to determine whether a representative payee is performing their duties in keeping a beneficiary safe and ensuring their needs are being met. See the Strengthening Protections for Social Security Beneficiaries Act of 2018, 42 U.S.C. § 405(j).

## Arkansas Alliance for Disability Advocacy (AADA)

AADA consists of an alliance of advocacy programs that work in concert to provide self-advocates, parents, peer advocates, and state leaders with the tools they need to be active within the disability advocacy movement. AADA is comprised of Partners in Policymaking, a training program focusing on developing relationships with elected officials to influence public policy impacting people with disabilities; Self-Advocate Network Development, which provides advocacy training and leadership development to people with disabilities across Arkansas; and Community of Champions, a community project that provides people the tools to be disability advocates in their everyday life.

## **CLIENTS**

The United States Census Bureau's 2022 American Community Survey estimates the 2<sup>nd</sup> District's total population to be 761,676, with a civilian, noninstitutionalized population of 752,116. Of that total, 130,087 (17.3%) have a disability. In FY2023 (October 1, 2022-September 30, 2023), DRA worked 162 active service requests from the 2<sup>nd</sup> District. DRA received a total of 1,946 requests for services statewide, in addition to investigating abuse and neglect and addressing critical systemic issues, including cuts to vital services by Medicaid managed care organizations.

## **Clients by Age**

While DRA assisted every age demographic in the district, the table below shows that 52% of service requests were for clients under the age of 20 and 2.5% of requests were for those over the age of 55.

Age Group	Number of Service Requests	Percentage
Unknown	0	
0-9 Years	18	11%
10-19 Years	66	41%
20-39 Years	43	26.5%
40-55 Years	31	19%
56-65 Years	3	2%
66 or Older	1	0.5%

#### Clients by Race and Ethnicity

DRA strives to provide services to underrepresented groups in our state. The following chart compares race and ethnicity demographics for the entire 2<sup>nd</sup> Congressional District with that of DRA's requests for services in the 2<sup>nd</sup> Congressional District. The district's Hispanic population of 38,632 comprises 5.1% of the population, while 3% of the service requests worked by DRA were for individuals who identify as Hispanic.

Race	Estimate	As Percentage	DRA SR's	As
				Percentage
Total Population	761,676		162	
One Race	712,502	93.5%	158	97.5%
White	522,687	68.6%	90	55.5%
Black or African American	154,834	20.3%	59	36.5%
American Indian and Alaska Native	1,600	0.2%	1	0.6%
Asian	13,064	1.7%	2	1.2%
Native Hawaiian/Other Pacific Islander	203	0.1%	0	0%
Unknown or some other race	20,114	2.6%	6	3.7%
Two or more races	49,174	6.5%	4	2.5%

## **SERVICE REQUESTS**

DRA worked 162 requests for services in FY2023 from residents of the 2<sup>nd</sup> Congressional District. The charts below show the distribution of the requests by grant funding and by issue (problem) area. Callers with issues that do not meet a priority are still provided assistance but will usually be offered information and referral services rather than case-level advocacy.

#### **Service Requests by Program**

Program Funding Source	САР	PAAT	PABSS	PADD	PAIMI	PAIR	PATBI	PAVA
<b>Count of Service</b>								
Requests	17	5	9	49	47	29	4	2

#### **Problem Areas Covered by Service Requests**

Problem Area	Count of Service Requests
Abuse/Neglect/Suspicious Death	44
Education	43
Home- and community-based services	20
Rehabilitation Services	19
Employment	6
Assistive Technology	5
Healthcare	5
Access (architectural and programmatic)	3
Housing	2
Guardianship	3
Post-secondary Education	3
Other	9

Service Requests in the 2<sup>nd</sup> Congressional District continued to include issues related to DRA's efforts to tackle abuse and neglect, including suspicious deaths, occurring in facilities; for the first time ever, abuse/neglect/suspicious death reports surpassed education requests to become the leading category of service requests in the 2<sup>nd</sup> District. Rehabilitation services issues nearly tied home-and community-based services for the next greatest number of service requests behind education, with other issue areas significantly trailing these four priority areas of DRA's work. DRA staff continued to monitor residential facilities, particularly the human development centers (HDC) and psychiatric residential treatment facilities (PRTF), by various methods, including reviewing incident reports submitted to regulatory agencies, reviewing surveys conducted by credentialing entities such as the Office of Long-term Care, and monitoring facilities in person. Because issues impacting youth through placement in treatment and/or detention facilities remain a major focus for our attorneys and advocates, much of DRA's systemic work revolved around issues identified through surveys and incident reports. In our education work, we continue to prioritize issues involving suspension,

expulsion, and referral to the justice system related to a student's disabilities. While we understand the need for assistance with less serious education issues is significant, we are not provided with sufficient resources to serve everyone who requests our help and must limit education cases to the most serious issues. By focusing on the most egregious cases, we are attempting to staunch the school-to-prison pipeline, recognizing not only the benefit to a student when they can stay in school rather than being expelled or routed to a juvenile placement, but also the cost benefit of providing services in a school setting versus placement in a residential facility. DRA has experienced a significant uptick in cases where an individual's supported-living services are being reduced by Medicaid managed care organizations; while these cuts may result in short-term savings, the state ultimately will spend significantly more to serve individuals who end up in long-term care facilities because they couldn't access more cost-efficient services in their own home. DRA also assisted clients receiving services from Arkansas Rehabilitation Services, and have identified some troubling agency practices, which have been shared with the Rehabilitation Services Administration. DRA continues to assist individuals with disabilities experiencing employment discrimination, clients hoping to be released from oppressive guardianships, and clients needing assistive technology. Architectural accessibility and program access issues like effective communication during medical appointments and reasonable accommodations in post-secondary settings continue to elicit complaints; while we limit the number of these cases we accept owing to a lack of resources, we do accept some cases simply because there are no alternative resources available to assist these individuals.

Whenever possible, DRA seeks to inform and educate callers so they may effectively self-advocate. In addition to empowering an individual to resolve issues for themselves, this serves to make the relationship between the aggrieved individual and the other party less adversarial than when a third party such as DRA intervenes and is also a means for DRA to serve more individuals with fewer resources.

#### Service Requests Specific to the 2<sup>nd</sup> District

**Example 1:** DRA received an anonymous complaint alleging an overuse of restraints and verbal abuse towards a patient at the Arkansas State Hospital (ASH). DRA investigators reviewed patient safety events and watched videos of the two incidents reported to DRA and determined staff did not follow the patient's positive behavior support plan (PBSP) on either occasion. DRA investigators met with ASH administrators on 5/23/23 and 8/11/23 to review our findings and discuss our concerns. DRA subsequently received staff training logs from ASH for the employee who was implicated in both events; his training included handling behavioral emergencies and the appropriate use of seclusion and restraint. The patient was discharged from ASH in June 2023 to a community service provider, and the employee resigned from ASH in July 2023.

**Example 2:** DRA received anonymous complaints stating a patient on an adolescent unit of ASH was being subjected to abusive restraints, including excessive chemical restraints. DRA's review of records and video of two incidents identified by the reporter confirmed these reports. Our investigation substantiated physical abuse and the use of chemical restraints when the patient

was calm, and also identified issues related to insufficient and inaccurate documentation of incidents and insufficient quality control measures. In one of the incidents reviewed, the description of the incident in its entirety states, "patient and peer got into a verbal altercation which led to a required physical hold and chemical restraint." The report narrative clearly leaves out pertinent details, including the type of restraint and- in this case- the patient being thrown to the ground and laid on top of by a staff member. A physical hold or chemical restraint are never required for a verbal alteration; any quality control check should have rejected this report outright. Seclusion was not listed as an intervention despite seclusion being used for six minutes post-restraint. The patient told DRA that the staff member who restrained him threw him to the ground and put his elbow on his throat; this is not mentioned in the reports anywhere nor was it investigated internally. Video review did not appear to corroborate a face-to-face assessment taking place at 21:00 hours while the patient was "sitting down on the floor in his room" or that the staff debriefing occurred at 20:40 hours. This information, along with information related to numerous other simultaneous investigations, was first shared with ASH personnel in a meeting 5/23/23; an outline was then provided on 6/2/23, and a follow up meeting was held on 8/11/23. The staff identified in the 2/12/23 incident as body-slamming this patient was terminated on 08/07/23 as a result of this incident as well as another incident with a different patient that was also brought to the attention of ASH administrators. Without DRA's investigation and continued advocacy, the staff member identified as the assailant would likely not have been terminated. A new therapeutic milieu review process is also being instituted hospital-wide, one unit at a time, as a result of DRA's investigations. The program started with the adolescent units based on the numerous concerns DRA has raised over the last few years, including those related to the aforementioned incidents.

**Example 3:** DRA received an anonymous complaint concerning an ASH patient losing a testicle due to medical neglect. Our investigation concluded that both the action and inaction of facility and nursing staff amounted to medical neglect resulting in the patient having to endure a significant amount of pain and the surgical removal of his testicle. The patient was able to articulate to the emergency room doctor that he had been experiencing scrotal pain for at least two weeks. The ASH records make no mention of this other than a delayed entry in his records made after he was admitted to the hospital. A review of his medical records and subsequent consults with the hospital's medical staff also created concerns related to overmedication. Issues identified include failure to properly examine the patient, failure to chart or late charting, staff not taking the patient's complaints seriously, and possible overmedication; each of these were addressed with ASH administrators. DRA also reported the facility to the Arkansas Department of Health and reported two ASH nurses to the Arkansas State Nursing Board.

**Example 4:** A patient at ASH reported that another patient was being medically neglected to the point that he had to be hospitalized. The reporter stated the patient had been vomiting green liquid that smelled putrid, and often had purple skin. Observation and record review confirmed the patient's skin has a distinct purple tint, yet it is only mentioned twice in nursing notes and no explanation is given. This issue was addressed immediately with the clinical director; she thought the condition was a side effect of medication and seemed unalarmed. Medical records confirmed this patient had been experiencing serious bowel issues and had a

history of bowel obstructions severe enough to require hospital admission at least three times in the previous two years, yet ASH documentation showed only a sporadic mention of a PRN for constipation or his refusal to take MiraLAX, and ASH was not tracking his bowel movements. Upon learning that ASH did not have a formal bowel tracking protocol, DRA advocated for implementation of a protocol. ASH subsequently began developing a bowel protocol and conducting internal retraining on the importance of charting.

**Example 5:** DRA received an anonymous complaint alleging a patient at ASH was not receiving proper care following hip surgery, including not receiving physical therapy or assistance getting out of bed. DRA's investigation confirmed the allegations of medical neglect post-surgery and identified serious neglect prior to the surgery, as the patient's hip fracture occurred during an attack by another patient. She subsequently walked around for 25 days with a fractured hip that required surgery; on 12 of those days the fracture was confirmed through imaging. Post-surgical attempts at physical therapy were not initiated for at least two months, and the patient now walks with a limp. This incident was discussed in a meeting with ASH administrators and detailed in a written follow-up to the facility. The patient was ultimately discharged to a nursing and rehabilitation facility that could more adequately provide for her needs.

**Example 6:** A parent contacted DRA requesting an advocate for her son, a resident of one of the state's HDC's. She stated she had reason to believe he was a victim of malnutrition and neglect. A DRA advocate investigated these concerns, and the client was subsequently moved to a different living unit at the facility where he could receive an increased level of care. His mother had stated she felt he was becoming malnourished due to a malabsorption condition and the facility was failing to correct this issue. The facility initially claimed they had increased feeding, but he had continued losing weight. They also claimed there was not a bed in a living unit that provided more intensive care, but they eventually did move him to that unit once DRA became involved, and the resident is now doing much better.

**Example 7:** The guardians of an adolescent denied coverage for residential treatment in a Reactive Attachment Disorder (RAD) specialty program at a psychiatric residential treatment facility (PRTF) contacted DRA for assistance. The client was in an acute setting at the time and was about to be sent home without safe discharge measures or any new services in place. A DRA attorney filed an expedited appeal and raised issues of timeliness of the notice, medical necessity, and discharge planning. The appeal was upheld by the Medicaid managed care organization (MCO), so DRA then filed for an expedited state fair hearing. The expedited hearing was granted and scheduled; however, the MCO approved coverage prior to the hearing. DRA withdrew its filing due to the MCO reversing the adverse action, and the client was able to get treatment in the RAD specialty program the guardians had sought.

**Example 8**: A student diagnosed with autism spectrum disorder (ASD) was consistently being removed from classes, his parents were receiving calls to pick him up early from school, and the school district was not implementing any effective behavioral strategies or interventions. A DRA attorney assisted this student's parents by helping them to clarify what their goals for the student were at this time, what services they believed would be needed to achieve those goals,

and how best to communicate them to the school district. The attorney attended two interdisciplinary team meetings in which district staff were very receptive to providing a one-on-one aide and allowing an applied behavior analysis (ABA) therapist to serve the student at school. His return to school was gradual, but his hours increased as the year progressed. His parents were pleased with the progress he was making, and they were able to successfully communicate any concerns they had to the school district throughout the year so they could be addressed by working in concert with school staff.

**Example 9:** A client of the Arkansas Division of Services for the Blind (DSB) contacted the CAP after DSB capped the provision of maintenance in the form of rental assistance at two months. DSB had paid the client's rent while she participated in a medical billing training program at World Services for the Blind (WSB); however, the client was continuing to participate in job training and test preparation programming at WSB, therefore the maintenance service should have continued. The CAP advocate communicated with the DSB counselor assigned to the client, the regional area manager, and the director of field services requesting the maintenance service continue for the duration of the client's participation in and completion of job training and test preparation activities at WSB. DSB administrators agreed and an amendment to the client's Individualized Plan for Employment (IPE) was signed and implemented. This successful outcome was a result of informal dispute resolution at the lowest possible level, with DRA's CAP advocate not having to initiate formal steps to due process.

Example 10: A college sophomore with autism spectrum disorder (ASD) enrolled in an out-ofstate college on an academic athletic scholarship had an open case with ARS to fund housing expenses related to his college enrollment. He contacted the CAP for assistance after an arbitrary cap on his funding was set at \$5,000 and approved only for Spring and Fall semesters. The student participates in summer classes due to the college's academic calendar functioning on trimesters. Enrolling year-round also allowed the student to manage lighter course loads throughout the year to better accommodate his disability. DRA's CAP advocate participated in an administrative review to request increased funding and support of housing throughout the year as it related to college enrollment. When the administrative review did not find in favor of the client, the advocate and DRA's CAP attorney requested an impartial hearing. Negotiations between the CAP and ARS counsel resulted in a settlement offer of a substantial increase in support, but with a stipulation that the student participate in a psychoeducational evaluation. As the client was already determined eligible for services and was not requesting new or additional services in a plan amendment, this stipulation seemed unreasonable. While preparing for the hearing, the CAP advocate and attorney continued negotiations for increased funding for maintenance services for housing and related expenses without the evaluation stipulations. A settlement was reached allowing for a physician's statement regarding the student's diagnosis in lieu of an evaluation, and ARS agreed to provide housing costs, including reimbursement for summer expenses at a rate of \$737 per month, an amount that met the needs of the client.

#### **PROJECTS**

## Achieving impactful systems change for people with disabilities

As a result of several individual investigations conducted by DRA at the Arkansas State Hospital (ASH), changes in policies and procedures have been implemented at ASH that have the potential to impact every patient. DRA launched several investigations based on allegations submitted anonymously to us; these allegations involved profoundly serious issues, some of which are articulated in the case examples in this report. Others include:

- A patient who repeatedly ingested harmful items, which then led to restraints. Ten incidents of foreign body ingestion in six months at ASH resulted in the patient enduring four gastroenterology procedures.
- A new patient who allegedly did not receive treatment for HIV despite testing positive. While this allegation was not substantiated, our investigation did identify issues with reporting critical lab results and charting missteps. For nearly a month it appeared there had been a positive HIV test result, but that information was not relayed or acted upon. While the test result was ultimately negative, at least some staff were reportedly not using universal precautions.
- A patient involved in several incidents that could result in head trauma, including banging her head on the walls, who did not receive proper medical assessments for head trauma. Our investigation concluded that ordered neurological checks were not completed or documented and that vital signs had also not been checked in multiple incidents involving head trauma.
- A patient whose stimulus money was stolen by hospital staff. Our investigation resulted in our substantiating the allegation after reviewing financial records and interviewing the victim and relevant staff. Staff withdrew an amount of money from an ATM above what the patient had requested, which she kept, after taking the patient's ATM card alone to withdraw money, which was allowed by hospital policy at the time. Although ASH administrators were aware of the theft, they had not initiated any relevant changes to hospital policies or practices to prevent this situation from occurring again.

After charting issues were identified in several of our investigations, hospital administration developed and implemented a Nurse Manger Performance Improvement Tool and conducted additional training with staff related to charting. Upon learning that ASH did not have a formal bowel tracking protocol, DRA advocated for implementation of a protocol, which is currently being developed by hospital staff. Following a DRA investigation into the allegation that neurological checks were not performed on a patient with a potential head injury, ASH responded to DRA's concerns by adding an update to the Electronic Health Record system that flags and forces neurological checks. Following several DRA investigations into allegations about the care and treatment of patients, particularly the excessive use of mechanical and chemical restraints and the lack of appropriate treatment for injuries and illness, a new therapeutic milieu process called Project Safe and Caring was implemented. As part of this new process, a weekly clinical leadership team review process will occur to ensure all aspects of milieu operations are therapeutic, safe, and caring. Phase Two, to be implemented in 2024, will include new violence prevention training. And while DRA was not successful in recovering a

patient's stolen funds, as a result of our investigation and advocacy efforts regarding the theft of a patient's funds by a staff member, ASH did implement a new policy regarding the process for a patient to obtain funds through debit card withdrawals that will minimize opportunities for funds to be stolen.

DRA investigated a school district's use of an alternative learning environment (ALE) to determine whether they are complying with the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and the Individuals with Disabilities Education Act (IDEA). Several parents of students in this district were concerned the district was attempting to use the ALE as a sort of "special school", sending a number of students with behavior-related disabilities there. Through our investigation, DRA learned about the school district's practices involving this ALE setting, including several instances of failed policies concerning elopement, restraint, and a lack of educational services. We have assisted a number of students with transitioning back to general education settings from the ALE, and because several students were successful in this transition, we are confident this school district will discontinue its use of a third-party provider to provide educational services in this alternative environment.

DRA conducted two secondary investigations at PRTF's involving incidents where residents were seriously injured, with one resident requiring surgery for a broken occipital lobe. The agency responsible for enforcing the state Minimum Licensing Standards for Child Welfare Agencies, DHS's Division of Childcare & Early Childhood Education (DCECE), investigated the incidents but did not substantiate any licensing concerns. DRA's reviews revealed several concerns, which were forwarded to the DHS Program Manager, along with relevant video clips and pictures, with a request that another investigation be conducted. DCECE did return to the facilities and conduct another review of the incidents; this time they documented findings and cited the facilities for being out of compliance with Standard 907.2, which states, "Childcare staff shall be responsible for providing the level of supervision, care, and treatment necessary to ensure the safety and well-being of each child at the facility, taking into account the child's age, individual differences and abilities, surrounding circumstances, hazards, and risks."

In FY2023, DRA added video footage of incidents occurring in PRTF's across the state to our online PRTF database. As far as we know, this is the largest public collection of videos from inside these types of facilities. Visitors to the database can now hear from law enforcement, staff, and residents firsthand by viewing video clips from police body cameras of law enforcement responses to incidents at these facilities. Visitors can also view youth interactions with staff and law enforcement and see the physical environment inside some of these facilities. Sometimes law enforcement is utilized as a form of behavior management to threaten or scare youth; sometimes they are called in response to riots or other chaotic incidents that can be traumatizing and dangerous for everyone present. We have added video footage of incidents to the database to provide a much broader perspective of how incidents with residents, who are there to receive psychiatric treatment, are managed by facility staff, which can be punitive and retaliatory rather than therapeutic. The database is located at: <a href="https://disabilityrightsar.org/prtf/">https://disabilityrightsar.org/prtf/</a>

DRA created a project in FY2023 to track causes of death in the state's five HDC's as detailed in incident reports submitted to the state, to identify potential patterns and whether abuse or neglect contributed to any of the deaths. The objective was to determine whether systemic issues could be identified in these facilities, and if certain policies or practices needed to be changed to reduce the likelihood of deaths occurring under similar circumstances. DRA investigators developed a tracking system to capture the cause of death for residents to identify any trends, and determined aspiration pneumonia and constipation were recurrent causes of death. We were subsequently able to persuade DDS and the HDC's to revise their bowel protocols based on some residents experiencing constipation resulting in bowel obstructions. Since this issue was successfully addressed, we have discussed developing a tracking system for people with chronic constipation to see if further improvements in protocols could be developed, which is a potential project in FY2024.

An unquestioned practice in place since the 1980's at one of the HDC's was changed as a result of a DRA investigation and resulted in the removal of telemetry devices from 23 facility residents. The facility administrator confirmed they had been using some type of telemetry device since the 1980's but no longer possessed the names and job titles of the staff who initially permitted the use of these devices. DRA investigators spoke with residents and with the facility superintendent, who estimated about a dozen people were wearing the devices. DRA investigators then shared their concerns with a Division of Developmental Disabilities Services (DDS) assistant director, who reviewed telemetry information about one particular resident and determined the use of the device was appropriate. DRA then submitted a records request to the facility for a list of residents currently wearing telemetry devices and guardian contact information for each resident; a list of 26 residents was subsequently provided to DRA, and in the course of an investigation involving another resident, it was determined he had been wearing a device as well. The devices had been removed from two residents, and they were then removed from six additional residents in October and early November 2022. Sixteen more residents had their devices removed mid-November 2022, upon the determination that it was "best for the facility to become mostly telemetry free for the clients [they] serve." During a phone call between DRA's Executive Director Tom Masseau and DDS Director Melissa Weatherton in December 2022, she stated she instructed the facility administrator to remove the devices immediately from any residents still wearing them.

DRA investigated several complaints about a program called Deaf Start at a PRTF; specifically, that residents of this program were not receiving mental health treatment and staff were falsifying records to reflect services being provided that were not. Our investigation substantiated an allegation that the Clinical Director, who was also the primary therapist for the program, was not routinely providing therapy to the residents and was falsifying documentation, which resulted in his being terminated. His termination paperwork states, "between February 2021 and 2022, Disability Rights found documentation deceitful towards parents and therapist documentation did not align with the Acadia standard for therapy licenses..." Discrepancies were identified in the notes of additional therapists, but none as egregious as those of the Clinical Director. Based on our findings and method of investigation, facility administrators stated they planned to implement similar internal review processes.

They admitted they had never implemented a process of internally auditing therapy notes and were now planning to continue cross-checking daily documentation sheets with note entries as they see how this can be a beneficial quality control practice. Upon attempting to confirm an internal process had been implemented before closing out the investigation, DRA then requested "all...internal audits related to the provision of therapy services." The facility response stated, "do not exist. We have no issue in the clinical department in regards to therapy services." This response indicates the facility had not instituted a process to ensure the issue DRA cited was fully resolved and would not recur. Our investigation subsequently remained open to continue monitoring the situation and advocating for internal quality control procedures at this facility by communicating with informants, reviewing reports, and conducting facility visits; however, we did not determine therapy services were not consistently being provided. In June 2023, DRA monitors spoke with the new Clinical Director, who stated he is spot-checking notes to ensure they are entered in a timely manner by therapists but does not have a plan to cross-check or attempt to ensure notes are not being fabricated. DRA monitors discussed their concerns with him, and he has since expanded his monitoring.

A major effort of our education advocacy involves ensuring access to professional providers for students who are subject to inequitable or illegal discipline in school. We have developed a practice of seeking services for our clients who are recipients of our state's Medicaid managed care system for individuals with developmental disabilities or behavioral health needs through that system. In leveraging the obligations of our state's managed care organizations (MCO) to enhance the services available to students we serve, we are relieving school districts of a significant financial burden of providing these services. As a result of this work, we have witnessed school districts utilize those services for students with whom DRA does not have a representational relationship; in other words, this work is having a systemic impact, as many more students will benefit than just those represented by DRA. It is our hope that our continued work in this area will continue to improve access to those services across the state.

Thanks to a Public Health Workforce (PHWF) grant the P&A's received from the Administration on Community Living in 2022 and 2023, DRA was able to finance a thorough investigation at three Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) locations due to concerns about living conditions; each facility was found to be in a severe state of disrepair, featuring potentially hazardous conditions that significantly jeopardized the well-being and safety of its residents. Issues found included:

Facility One: the presence of mold, sagging mattresses, roaches in bedrooms, broken and hazardous structures such as rotted decking, and bathroom doors that were too narrow.

Facility Two: rusted or missing sprinklers, reports of rodent infestations, broken picnic tables, dirty and damaged carpets, and missing wood on bathroom vanities.

Facility Three: gaps in walls and doors leaving living units exposed to the outdoors, stained bedding, a strong odor of waste, and multiple structural and aesthetic issues like sagging curtain rods and missing caulk in the bathroom.

These conditions were extensively documented, with a link provided to photographs highlighting each issue observed during the investigation. The findings were promptly reported to the Office of Long-Term Care (OLTC) on 03/23/23, detailing each deficiency found during the visits on 03/17/23. Despite assurances from the facilities' management that, for example, all sprinklers were functional, we later received the results of a survey conducted on 03/28/23 that revealed multiple deficiencies in the sprinkler systems. DRA utilized various strategies to address these issues, including reporting the serious occurrences and the buildings and grounds issues to the OLTC, informing the Placement & Residential Licensing Unit (PRLU) of the conditions we uncovered, as well as the lack of interest and effort by one of their own staff who happened to be surveying the facility at the same time DRA was monitoring, and sharing our findings with the P&A in New Hampshire because children from their state were living at one of the facilities. Upon receiving DRA's complaint about the living conditions in these facilities, the OLTC investigated our allegations and cited the facilities for the terrible conditions, mandating the facilities rectify all reported deficiencies. This investigation effort exemplifies a successful P&A intervention resulting in hazardous conditions and deficiencies in youth treatment facilities being addressed to ensure the safety and well-being of the residents.

FY2023 witnessed DRA making great strides in how we manage cases involving our state's MCO's. These organizations are obligated to ensure Medicaid services are delivered to two populations: individuals eligible for developmental disability services through our state's developmental disabilities waiver, and individuals with behavioral health needs. DRA attorneys have managed to develop precedent at the administrative level that has enabled us to work on a greater number of cases involving an issue that is affecting all recipients – access to care coordination as defined by federal and state regulations. We have also identified and continue to work toward resolving the issue of a systemic lack of enforcement mechanisms for our state's administrative due process proceedings. While it is a tremendous benefit to our clients that we can expect an administrative order requiring the MCO to supply care coordination consistent with state and federal regulations, our clients are left with little recourse if the MCO fails to adhere to the orders, which has occurred repeatedly. We anticipate this will be a continuing issue for DRA to prioritize in the coming fiscal years.

The State Rehabilitation Council's (SRC) CAP representative and other CAP staff participated in an SRC working group to revise the current Arkansas Rehabilitation Services (ARS) consumer satisfaction survey, with DRA's CAP staff providing input on the content of the survey and distribution methodology. ARS intends to implement the new survey in hopes of improving consumer participation, which will lead to increased data collection on service delivery experiences by consumers. CAP staff also met with Rehabilitation Services Administration (RSA) staff prior to their monitoring of ARS in August 2023. While it is too soon to know if this discussion will lead to policy change, the report from ARS's Chief of Field Services during the September SRC board meeting touched on areas DRA brought to the attention of RSA, which incidentally are areas CAP staff previously discussed with RSA prior to the monitoring of ARS in 2022. ARS is now revisiting their rate setting methodology specific to the purchase of hearing aids. New guidance has not yet been released for this and it is unclear if the changes will expand to other services or equipment. ARS also intends to address the \$5,000 tuition

threshold (cap) it has imposed on postsecondary tuition for the past several years. CAP staff successfully defeated these tuition caps for several ARS clients; however, the CAP could only assist clients who contacted the CAP, so it is unknown how many ARS clients were negatively impacted by the imposition of tuition caps. ARS also intends to review their use and calculation of consumer financial participation, which could be a result of a continued review of the large amount of rehabilitation services funds being returned to the federal government. The CAP hopes to report in FY2024 that these anticipated changes to ARS policies and practices have been implemented.

The greatest opportunity we have to ensure individuals under guardianship are able to vote is through litigation – assisting individuals with restoring their right to vote by seeking a court order to that effect. While we have been successful in achieving this goal for clients, litigation is not an approved activity under PAVA regulations; therefore, our best opportunity to ensure individuals under guardianship are allowed to vote is through educating everyone we can on this topic. We have continued to train attorneys, service providers, and advocates in our state who are interested in assisting individuals under guardianship with various issues related to guardianship. Not only have we provided training about the rights of individuals under guardianship to regain the right to vote, we have also integrated voting rights into any trainings we provide about guardianship, alternatives to guardianship, and supported decision-making.

#### **Coalition Building**

DRA is not only committed to numerous long-term collaborations; we also continuously explore opportunities for new collaborations. DRA continues to partner with the Governor's Council on Developmental Disabilities (GCDD) and Partners for Inclusive Communities (Arkansas' UCEDD) on issues impacting the developmental disabilities community. Most of these initiatives are multi-year efforts and focus on achieving impactful, systemic changes in Arkansas. Collaborations in FY2023 include the Arkansas Alliance for Disability Advocacy (AADA) and the Breakfast Club. The AADA initiative, which is a collaboration between DRA and the GCDD, consists of three components: Partners in Policymaking, Community of Champions, and Self-Advocacy Network Development. The AADA is working to develop the self-advocacy movement in the state, and partners with both DRA's PAVA program to educate new self-advocates about voting rights and with the PADD program to develop materials and training courses for parents wanting to be proficient advocates for their children with respect to special education services. DRA continues collaborating with other agencies in the TBI State Partnership Program (SPP) and holds a position on the Arkansas Brain Injury Council (ABIC), whose mission is "to improve upon Arkansas's TBI infrastructure in an effort to maximize independence, well-being and health of persons living with TBI, their family members, caregivers, and providers." DRA continues collaborating with the Federal Emergency Management Agency (FEMA), the Red Cross, and the Arkansas Department of Human Services (DHS) to ensure that the needs of Arkansans with disabilities are appropriately addressed in emergency preparedness planning. This effort is actually a hybrid of collaborating and monitoring activities, since we are collaborating to develop plans that are inclusive, but we are also monitoring the participating agencies' efforts to ensure they incorporate the needs of people with disabilities in their

planning efforts. This collaboration began in FY2019 and is now expected to continue as a long-term collaboration.

#### Veterans' Issues

DRA welcomes the opportunity to work with veterans; we occasionally receive requests for assistance from veterans, typically involving an accommodation they need on the job or at a business or some other public venue because of a traumatic brain injury or PTSD. Should your offices receive requests for assistance from veterans regarding these types of issues, we would encourage your staff to refer them to DRA for assistance.

We hope this report has proven beneficial in providing an overview of our programs and services. Please do not hesitate to reach out to us if we can answer any questions or provide your office with further information about our work.

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