



Protection and Advocacy and Client Assistance Program  
Services in the 1<sup>st</sup> Congressional District

Fiscal Year 2020

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## BACKGROUND

**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.

### **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 spectrum disorder, 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)**

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 confronting a particular 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. PABSS educates beneficiaries about Social Security's work incentives and provides vocational rehabilitation and employment services advice. 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 carrying out 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).

## CLIENTS

The United States Census Bureau's 2019 American Community Survey indicates the 1<sup>st</sup> District's total population is estimated to be 719,048, with a civilian, noninstitutionalized population of 695,986. Of that total, 135,500 (19.5%) have a disability. In FY2020 (October 1, 2019-September 30, 2020), DRA received 151 new service requests from the 1<sup>st</sup> District, or an average of 12.6 service requests per month, a decrease of almost 33% over FY2019.

## Clients by Age

While DRA assisted every age demographic in the district, the table below shows that 40% of service requests were for clients under the age of 20 and 17% of requests were for those ages 55 or older.

Age Group	Number of Service Requests	Percentage
Unknown	1	0.6%
4 and Under	5	3.3%
5-9 Years	25	16.6%
10-14 Years	17	11.3%
15-19 Years	13	8.6%
20-24 Years	6	4.0%
25-34 Years	15	9.9%
35-44 Years	24	15.9%
45-54 Years	19	12.6%
55-59 Years	11	7.3%
60-64 Years	8	5.3%
65 or Older	7	4.6%

## Clients by Race and Ethnicity

DRA seeks to provide services to underrepresented groups in our state. The following chart compares race and ethnicity demographics for the entire 1<sup>st</sup> Congressional District with that of DRA's requests for services in the 1<sup>st</sup> Congressional District. The district's Hispanic population of 24,421 comprises 3.4% of the population.

Race	Estimate	As Percentage	DRA SR's	As Percentage
<b>Total Population</b>	719,048	---	---	---
<b>One Race</b>	696,990	96.9%	---	---
<b>White</b>	556,680	77.4%	108	71.5%
<b>Black or African American</b>	126,465	17.6%	32	21.2%
<b>American Indian and Alaska Native</b>	1,951	0.3%	3	2%
<b>Asian</b>	3775	0.5%	---	---
<b>Native Hawaiian/Other Pacific Islander</b>	1,837	0.2%	---	---
<b>Unknown or some other race</b>	6,282	0.9%	3	2%
<b>Two or more races</b>	22,058	3.1%	5	3.3%

SERVICE REQUESTS

DRA received 151 requests for services in FY2020 from residents of the 1<sup>st</sup> Congressional District. The charts below show the distribution of the requests by grant funding and by priority. The “None” category represents requests for services that did not fall into one of the established priority areas; callers with issues that do not meet a priority are still provided assistance, but usually will be offered information and referral services rather than case-level advocacy.

**Service Requests by Program**

<b>Program Funding Source</b>	<b>CAP</b>	<b>PAAT</b>	<b>PABSS</b>	<b>PADD</b>	<b>PAIMI</b>	<b>PAIR</b>	<b>PATBI</b>	<b>PAVA</b>
<b>Count of Service Requests</b>	7	1	6	50	21	63	3	0

**Priority Areas Covered by Service Requests**

<b>Priority Area</b>	<b>Count of Service Requests</b>
<b>Abuse, Neglect, and Exploitation</b>	15
<b>Institutionalization of Youth</b>	3
<b>Medicaid/Managed Care</b>	4
<b>Education</b>	28
<b>Employment</b>	6
<b>Self-Advocacy</b>	2
<b>Voting</b>	0
<b>None/Other</b>	93

Service Requests in the 1<sup>st</sup> Congressional District continue to include issues related to DRA’s efforts to tackle abuse, neglect, and exploitation and resulted in the second highest number of service requests in the 1<sup>st</sup> Congressional District in FY2020, despite the limitations imposed by the pandemic. Video monitoring, while not ideal, did provide a means to monitor some facilities during the year. Issues impacting youth through placement in treatment and/or detention facilities continue to be a major focus for our attorneys and advocates; while the inability to monitor youth facilities impacted case numbers, much of DRA’s systemic work revolved around issues in these facilities. DRA serves as a primary resource for parents and guardians requesting assistance with special education issues, which continues to be the most requested service not only in the 1<sup>st</sup> District but throughout the state. Many of the requests in the “None/Other” category are education-related; they are not represented in the Education priority because they did not rise to the severity level necessary to be served under that priority, which is limited to issues involving expulsion/exclusion, nursing services, and transition services. While we

understand the need for assistance with education issues is significant, we do not have the resources to serve everyone who requests our help, so we must limit education cases to the most serious issues and/or the issues where we might achieve a systemic impact. Assistance was provided for clients wanting to return to work and clients needing sufficient supports to continue to live in the community; DRA has focused particularly on cases where a decrease in services authorized through the state's Medicaid managed care system threatens an individual's ability to remain in the community, which means more costly institutional care. Access issues such as architectural accessibility and effective communication, as well as various housing issues, remain a focus for callers as well, even as limited resources prevent DRA from making them a priority.

Whenever possible, DRA seeks to inform and educate clients 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 client and the other party less adversarial than when a third party such as DRA intervenes, and is a means for DRA to serve more individuals with fewer resources.

### **Service Requests Specific to the 1<sup>st</sup> District**

**Example 1:** While investigating allegations of abuse at a residential treatment facility for youth, DRA became aware of a student who had been placed at the facility as a result of a Family in Need of Services (FINS) petition filed by the student's school district. The FINS petition resulted from behavioral incidents involving the student, although he had never been evaluated for special education services. The student's guardian wanted to discharge him from the facility due to concerns of abuse; however, the prosecuting attorney filed a new FINS petition to prevent this, since the first case had been dismissed upon the student's admission to the facility. A DRA attorney filed a response to the FINS Petition, protesting that the student had completed treatment and that the guardian had not been served. The judge subsequently signed an order dismissing the FINS case, and DRA continues to work on addressing the issues related to the student's eligibility for special education services as well as the allegations of abuse while at the facility.

**Example 2:** A student diagnosed with autism spectrum disorder was being restrained excessively at school following the implementation of a due process settlement agreement, and the school district subsequently decided to remove the student from school for the remainder of the school year in violation of the Individuals with Disabilities Education Act (IDEA). DRA responded on the student's behalf by filing a second due process complaint. The student's parents and the school district executed a second settlement agreement in which the school district agreed to allow the student to return to school and provided the student with a new paraprofessional, compensatory education, and a behavior intervention plan (BIP) developed by a Board-Certified Behavior Analyst (BCBA). The school district also agreed to train school staff on the BIP. The student started the new school year in regular classes and has remained in regular classes without a single incident of being physically restrained.

**Example 3:** An individual originally from Lincoln county but incarcerated in the state prison system requested DRA assist him with obtaining a second hearing aid. He had arrived in the system with two, but one eventually quit working and prison medical staff were not assisting him in procuring a replacement. Not being able to hear in prison put this client at risk, ranging from the danger of not understanding what is happening around him to being disciplined for not following orders from guards. DRA advocated for him to receive a second hearing aid to assist him in both complying with guards' commands and being safer in his environment. The hearing aid was ultimately secured for the client only after DRA contacted the prison's medical services contractor, the chief medical personnel at the Arkansas Department of Corrections (ADC), and the ADC's general counsel.

**Example 4:** An individual who had been denied services by the Division of Services for the Blind (DSB) contacted DRA to request assistance with accessing services. He reportedly had been deemed ineligible for services because they said he had received services within the past year and was not yet eligible to receive services again. A DRA attorney was able to contact DSB to determine the facts of the case, whereupon a DSB counselor was assigned to the client and a new case was opened. An appointment was made for the client with the technology center to determine what assistive technology might be useful for him to reach his long-term goal of becoming a physician.

**Example 5:** A woman with an intellectual disability requested DRA's assistance with removing a guardianship. Her mother had originally been appointed her guardian; however, when her mother became unable to continue as guardian, the state's Office of the Public Guardian (OPG) became her guardian. Prior to this client contacting DRA, the OPG had voluntarily removed the guardianship of the estate but was still guardian of the person. A DRA attorney worked with the client's case manager, therapist, and treating advanced practice nurse (APN), who all supported removal of the guardianship, and filed a petition to remove the guardianship. Affidavits from the therapist and APN in support of removing the guardianship were filed with the court. The OPG did not respond to the motion, so the DRA attorney provided a proposed order terminating the guardianship, which the judge then signed.

**Example 6:** A family member of an individual with Down syndrome contacted DRA on behalf of this individual for assistance regarding another family member filing a petition for full guardianship of the individual. The client had been adopted by her grandmother as a child and continued to live with her after she turned 18. Once her grandmother passed away, her sister filed a petition for guardianship against her wishes. A DRA attorney filed a motion to dismiss the petition based on improper venue because the sister filed the guardianship petition in her county of residence instead of the county where the client was living with her cousin following the death of her grandmother. The client's sister did not respond to the motion, and the Court dismissed the petition for guardianship.

**Example 7:** An individual diagnosed with schizophrenia was acquitted of a crime, but the order was never filed with the clerk. Because they did not have an order, the Arkansas State Hospital (ASH) was forced to hold the client under a previous order. Eventually, this client's therapist



reached out to DRA to help him. After several failed attempts to reach the local prosecutor, a DRA attorney reached out to the Prosecutor Coordinator regarding the local prosecutor's non-responsiveness and failure to provide the Court with a proposed order. The Prosecutor Coordinator contacted the local prosecutor's supervisor, whereupon the order of acquittal was finally entered, and the client was subsequently discharged to a less restrictive environment.

## PROJECTS

### **Systemic Issues**

DRA has been working to address the overreliance on institutional placements to treat youth diagnosed with serious mental illnesses, as well as youth with less severe mental health and behavioral disorders. These adolescents are often placed in psychiatric residential treatment facilities (PRTFs), juvenile treatment facilities, and/or juvenile detention facilities due to a lack of community-based resources, the proliferation of for-profit residential treatment entities, lax regulations, and a lack of understanding regarding the utility of institutional-based services. Like many other states, Arkansas lacks sufficient community-based resources, and while this issue has been acknowledged by various stakeholders in relation to the state's juvenile justice system, tangible steps to increase community-based services have yet to be formulated. DRA has discovered an alarming overlap between the juvenile justice system and PRTFs. Among our observations: children being continuously cycled amongst the PRTFs and acute care facilities, children committed to the Arkansas Department of Human Services, Division of Youth Services (DYS) prior to and upon release from PRTFs and acute care facilities, and PRTFs being used as a diversion option from DHS without officials understanding the true nature of the programs or experiences of youth institutionalized in these facilities. Minimal regulations and lax oversight by the state have led to a proliferation of for-profit PRTF beds and facilities in the state, mostly for out-of-state placements. The monitoring of facilities by the state is disjointed and has not adequately addressed health and safety concerns for residents, much less examined the quality of care and outcomes for the youth receiving treatment. DRA monitored, and will continue to monitor, all 12 PRTFs and all five DHS juvenile treatment centers, with a goal of issuing a public report in FY2021 on the overreliance of institutionalization in the state, specifically focusing on PRTFs. The hope is this report will bring attention to the issue and persuade more stakeholders to engage in these issues. We also plan to assess and compare Arkansas' regulations with other states' regulations and work with DHS to propose and advocate for meaningful changes to the state's regulations and oversight of these facilities.

Arkansas- like the rest of the United States and indeed the world- faced an unprecedented public health crisis in FY2020 due to the COVID-19 pandemic. The risk of infection, serious illness, and possible death from this coronavirus, especially among vulnerable populations, led Arkansas to take the extraordinary measure of declaring a public health emergency and closing public schools for much of the 2020 Spring semester; yet the rate of COVID-19 infection in Arkansas continued to rise. COVID-19 infections in the state's correctional facilities made up a substantial portion of the infections statewide; in fact, it was one of the highest prison infection

rates in the country. Of particular concern to DRA is the vulnerability of incarcerated people with disabilities, advanced age, and/or underlying medical conditions that could easily render a COVID-19 infection a death sentence. Those individuals with chronic underlying health conditions such as diabetes, heart disease, chronic lung and liver diseases, respiratory disease, and compromised immune systems are at particular risk for grave outcomes from infection. People incarcerated in prisons overall are more likely to have diagnoses of hypertension, diabetes, heart disease, various respiratory diseases, and various infectious diseases, all of which have been found to increase the mortality of a COVID-19 infection. As a result of the sweeping rate of infection within the state prison system due to inadequate precautions, DRA collaborated with the NAACP Legal Defense Fund and the Arkansas chapter of the ACLU in filing a class action lawsuit seeking the implementation of Centers for Disease Control (CDC) recommendations to minimize the risk of an unchecked spread of COVID-19 throughout the prison system. We requested the court mandate CDC precautions including personal protective equipment, social distancing, and access to hygiene and cleaning products. Litigation has continued into FY2021.

As the COVID-19 pandemic began its sweep across the United States, we observed concerning circumstances occurring in other states related to the potential to ration medical care during this crisis. Some states adopted “crisis standards of care” (sometimes called “altered standards of care”) to respond to the anticipated or realized shortage of medical resources, particularly ventilators. Other states have had ventilator allocation policies in place for some time and are now altering or considering altering such policies to meet the current crisis caused by the pandemic. DRA’s research determined the Arkansas Department of Health (ADH) had not adopted such a plan in anticipation of the needs of the community during the current COVID-19 health crisis. We wrote to the Governor to request he empower the ADH with the authority to issue crisis standards of care in a way that does not discriminate against individuals with disabilities. In response, the ADH contacted us through their equity office to discuss the standards they had observed. This resulted in communications between DRA, the ADH, and the University of Arkansas for Medical Sciences (UAMS) about the application of bioethics to crisis standards of care and the proper modification of current crisis standards of care. While the Governor subsequently refused to mandate crisis standards of care for the state, DRA was able to collaborate with the ADH and UAMS to ensure a mutual understanding of ethical crisis standards of care that do not discriminate against people with disabilities. DRA was also invited to participate in a committee that was developed to ensure adequate information and education about the COVID-19 pandemic is provided to individuals in unserved and underserved communities around the state.

In response to the COVID-19 pandemic, we had to alter the way that we monitor facilities while simultaneously trying to track and understand these facilities’ responses to infectious disease. The increased risk of infection inherent in congregate care settings was not the only risk COVID-19 posed to residents; it also meant no visitation for the residents, no trips outside the facilities, decreased oversight of the facilities, and the potential for substantially decreased staffing due both to infection and attrition based on unwarranted risk. Early in the pandemic, we recognized these realities would exacerbate the problems we had already encountered and foster

environments ripe for abuse and neglect. Tracking cases by facility would not be sufficient; therefore, we developed a survey to send to all youth treatment facilities. In developing the survey, we were mindful of balancing our need for comprehensive feedback and an overly cumbersome survey that would negatively impact our response rate, which ended up being 100%. As the pandemic continued, we updated the survey and periodically sent it to facilities. These survey results allowed us to gauge the efficacy of facility precautions and be alert to potential red flags such as high infection rates or significant staff vacancies. Through these efforts we were also able to identify and report discrepancies between infection rates reported to DRA and those reported to the Arkansas Department of Health.

DRA received several complaints from staff at a PRTF regarding the infection control protocols implemented in response to the COVID-19 pandemic. Staff reported that they were not provided masks and had to bring their own, many staff were not wearing masks, residents were not wearing masks, new residents were not being quarantined, and while facility-wide testing occurred, staff were not notified of their results, or the results were inconclusive. DRA monitors conducted video interviews with residents in which they reported that mask-wearing was lax and that if a resident tested positive for COVID-19, they were quarantined in their room, essentially in solitary confinement. Upon receiving this information, DRA staff spoke by telephone with the person responsible for infection control at the facility, who agreed to reinforce the facility's mask policy with staff, ensure masks are provided to all staff and residents, and investigate allegations that youth testing positive were being kept in their rooms instead of on a dedicated unit that would allow for some movement and interaction.

In FY2020, Arkansas Rehabilitation Services (ARS) informed the Arkansas Rehabilitation Council (ARC) about a proposed merger between ARS and the Division of Services for the Blind (DSB). A meeting was held between the ARC and representatives from ARS to discuss the details of the potential merger. ARS explained that combining the two state agencies would result in a savings that could then be used to increase services to its clients. During the discussion, however, no details were provided as to when services would be consolidated, what the potential savings would be, how that savings would be created, and how funding would be directed towards client services after Year Two. ARS representatives admitted they had not conducted any fiscal impact studies, but still urged the ARC to vote in support of the merger. An ARC member developed a white paper, endorsed by ARS, that provided some insight into a potential merger while still leaving many unanswered questions regarding the impact on client services. During a subsequent ARC meeting, ARS again urged the ARC to support the integrated program, even as the DSB Board was submitting a letter to the Governor in opposition to the merger. In response, the ARC formed a subcommittee and developed a series of questions for the Commissioner to respond to prior to the ARC taking any position on the merger. As FY2020 ended, the ARC was still trying to obtain additional information from ARS and the Governor's office related to any cost savings and the impact a merger would have on client services.

DRA adapted our voting outreach activities during the pandemic to minimize risk both to the individuals we serve and to our staff. To that end we adapted our voter training materials for remote presentations conducted over Zoom. As the pandemic also created issues with

travelling around the state to monitor polling sites, we scaled back this work accordingly but still conducted surveys during early voting and on election day. We also began using an online survey tool for polling site monitoring that would allow us to organize our data more efficiently, and we will continue to develop this protocol as pandemic restrictions are lifted in the state. We continued to be in contact with state and county officials regarding accessibility and helped several of them with planning and access concerns in the lead up to the election. We also continued to partner with other voter outreach organizations for training events and registration activities which were conducted remotely, as well as educating individuals on the absentee voting process.

### **Coalition Building**

DRA continues to partner with the Governor's Council on Developmental Disabilities (GCDD) and Partners for Inclusive Communities (Arkansas' UCEDD) to collaborate on issues impacting the developmental disabilities community in Arkansas. DRA also continues collaborations with the Trauma Rehabilitation Resources Program and the Traumatic Brain Injury State Partnership Program at UAMS to work on issues impacting individuals who have sustained traumatic brain injuries. DRA is continuously seeking additional opportunities to develop partnerships with various disability communities in Arkansas to address systemic issues impacting those groups.

### **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 us for assistance.

We hope this report has been 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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