



Protection and Advocacy and Client Assistance Program
Services in the 3rd 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 advice about vocational rehabilitation and employment services. 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 3rd District's total population is estimated to be 829,149, with a civilian, noninstitutionalized population of 822,276. Of that total, 124,486 (15%) have a disability. In FY2020 (October 1, 2019-September 30, 2020), DRA received 154 new service requests from the 3rd District, or an average of 12.8 service requests per month, a decrease of 27% over FY2019.

Clients by Age

While DRA assisted every age demographic in the district, the table below shows that 32% of service requests were for clients under the age of 20 and 19.5% of requests were for those ages 55 or older.

Age Group	Number of Service Requests	Percentage
Unknown	1	0.65%
4 and Under	1	0.65%
5-9 Years	10	6.5%
10-14 Years	15	9.8%
15-19 Years	22	14.3%
20-24 Years	10	6.5%
25-34 Years	17	11%
35-44 Years	21	13.6%
45-54 Years	27	17.5%
55-59 Years	12	7.8%
60-64 Years	6	3.9%
65 or Older	12	7.8%

Clients by Race and Ethnicity

DRA seeks to provide services to underrepresented groups in our state. The following chart compares demographics for the entire 3rd Congressional District with that of DRA's requests for services in the 3rd Congressional District. The district's Hispanic population of 123,805 comprises 14.9% of the population.

Race	Estimate	As Percentage	DRA SR's	As Percentage
Total Population	829,149	---	---	---
One Race	799,944	96.5%	---	---
White	695,183	83.8%	135	87.6%
Black or African American	25,683	3.1%	10	6.5%
American Indian and Alaska Native	8,771	1.1%	---	----
Asian	25,356	3.1%	2	1.3%
Native Hawaiian/Other Pacific Islander	8,879	1.1%	---	---
Unknown or some other race	36,072	4.3%	5	3.3%
Two or more races	29,205	3.5%	2	1.3%

SERVICE REQUESTS

DRA received 154 requests for services in FY2020 from residents of the 3rd 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

Program Funding Source	CAP	PAAT	PABSS	PADD	PAIMI	PAIR	PATBI	PAVA
Count of Service Requests	4	5	8	35	24	73	5	0

Priority Areas Covered by Service Requests

Priority Area	Count of Service Requests
Abuse, Neglect, and Exploitation	12
Institutionalization of Youth	7
Medicaid/Managed Care	6
Education	11
Employment	5
Self-Advocacy	4
Voting	0
None/Other	109

Service Requests in the 3rd Congressional District continue to include issues related to DRA’s efforts to tackle abuse, neglect, and exploitation and resulted in the highest number of service requests in the 3rd Congressional District in FY2020, despite the limitations imposed as a result of the pandemic. Education historically accounts for the highest number of requests for services, so this change may be indicative of DRA’s intensive efforts over the past few years to focus on serious care and treatment issues in residential settings. Because of the pandemic, DRA had to resort to video monitoring which, 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 particularly continues to be a major focus for our attorneys and advocates, and while the inability to monitor youth facilities depressed case numbers, it had less impact on DRA’s systemic work to tackle issues in these facilities. DRA does continue to serve as a primary resource for parents and guardians requesting assistance with special education issues, and

many of the requests in the “None/Other” category are education-related, but they are reflected in the “None/Other” category because they do not meet the severity level to be served under the Education priority, which targets exclusion from school and the need for nursing services and transition services. While the demand for assistance with education issues is great, we simply do not have the resources to assist everyone who requests our help, and by necessity we limit cases to those with the most serious issues or those that might have a systemic impact. Assistance was also provided for clients wanting to return to work and clients needing sufficient supports to continue to live in the community; DRA prioritizes 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. 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 3rd District

Example 1: DRA represented a family trying to obtain an increase in private duty nursing services for their infant son. The use of a feeding tube and supplemental oxygen necessitated constant supervision 20 hours a day and made him eligible for private duty nursing services. The client’s father had recently become paralyzed and was undergoing rehabilitation, so he was not able to assist in the care of his child. The client’s mother was the sole wage-earner in the home, and worked 10 hours a day, five days a week. The Arkansas Department of Human Services (DHS) approved only eight hours a day of private duty nursing, due to its presupposition that it could “cap” service hours. Meanwhile, the mother was required to supervise the child’s feeding tube and oxygen the 14 hours a day she was not at work, since the approved hours were provided while she was at work. DRA attorneys filed an administrative appeal of the eight hours of services per day decision, and after three days of testimony the family was awarded 20 hours of private duty nursing, seven days per week. This decision allowed the mother to continue working and providing for her family, and potentially prevented the child from being placed in a residential facility to meet his complex medical needs.

Example 2: A family member of a man with an orthopedic impairment contacted DRA when the individual was transferred to a cashier position after working in maintenance for 18 years. In his previous role he worked on his knees for 50% of his shift, but as a cashier he was on his feet for the entire shift, which was causing him a lot of pain. He requested a stool so he could rest his foot periodically but was not provided one. A DRA attorney contacted the accommodations department to get the process started and then followed up when the stool was slow to be provided (the employer is a major retailer that sells stools in their stores), only to find that the

case had been closed without an accommodation being made. The attorney demanded the file be reopened, and the individual was immediately provided with the requested accommodation.

Example 3: An individual who uses a power wheelchair for mobility and works full-time in a clerical position at a factory requested the CAP's assistance when she was denied full funding for a vehicle modification that would allow her to travel independently to and from work. The CAP represented the client in an administrative review; upon receipt of the administrator's unfavorable decision, a request was filed for an impartial hearing. CAP attorneys negotiated with the Arkansas Rehabilitation Services (ARS) attorney and were able to achieve a resolution prior to the hearing date. The client was subsequently able to purchase a partially modified van, reducing the overall modification cost, and ARS agreed to pay all additional expenses to modify the vehicle to fit her needs.

Example 4: The mother of a deaf student whose Individualized Education Plan (IEP) specified a full-time American Sign Language (ASL) interpreter contacted DRA when the school district did not follow through with providing an interpreter full-time. The district did not have enough ASL interpreters for each of the students to always have someone available, so there were certain classes each day where students did not have an interpreter available to them. This led to extreme frustration for this student and resulted in behavior issues and declining grades. A DRA attorney filed a state complaint on the student's behalf, and the school district was told they must comply by giving this student a means to communicate throughout the entire day. The school hired more ASL interpreters to ensure that each student would have appropriate access to full-time interpreters. DRA's client also received the speech therapy services he needed and is now performing according to his ability because he can communicate and interact with his classmates and teacher all day at school.

Example 5: A student who requested brailled sheet music so he could participate in an All-Region and All-State choir and band tryouts was denied this accommodation; the organization in charge of the tryouts also refused to make any other accommodations. The student called DRA before the annual tryout and requested assistance in securing brailled sheet music. A DRA attorney contacted the organization in charge of the tryouts and advocated on behalf of the client, explaining to the organization its legal obligations to accommodate individuals with disabilities. The organization subsequently agreed to provide the student with brailled sheet music and extended time to read the music prior to his performing.

Example 6: A woman receiving ARS services requested assistance through the CAP program after her counselor, having agreed to pay for her licensed clinical social worker (LCSW) exam, reneged after her psychological evaluation came back with a recommendation by the examiner that she participate in mental health treatment. She did not want therapy services; she explained she practices self-care and takes a medication for pain and depression. Her ARS counselor stated he would not sign off on paying for the LCSW exam until the client complied with the examiner's recommendation and sought mental health counseling services. A DRA staff attorney filed for an administrative review, which was unsuccessful; the attorney then

obtained a letter from one of the client's treating physicians stating that he believed her mental health was fine, and DRA and ARS then settled the case without going to mediation.

Example 7: DRA assisted an advocate in Northwest Arkansas who was working with a student diagnosed with a mental illness who was presenting a significant elopement risk at school. The client's school district was seeking to place him in a psychiatric residential treatment facility (PRTF) because they determined they could not provide him with an appropriate educational setting. The client's treating psychiatrist stated that a PRTF is not a suitable environment for him, so DRA advised the advocate to press for mental health outpatient therapy as a viable alternative, and for a classroom aid, which should significantly mitigate the elopement risk. Ultimately, the client was able to remain in school, and with access to better mental health services and supports.

Example 8: A woman diagnosed with schizoaffective disorder who was placed under a guardianship during mental health crisis reached out to DRA after her ability to be self-reliant continued to be severely compromised post-crisis. A prospective employer informed her they could not hire her if she were under a guardianship, and she continued to live in a residential care facility in which her guardian had placed her, despite her ability to live independently. She had been stable for quite some time since the crisis and her treating psychiatric nurse practitioner was supportive of removing the guardianship. A DRA attorney filed a motion to terminate the guardianship and represented the client in a hearing on the matter. The judge required the parties to submit research supporting their positions post-hearing. DRA's attorney did so and, at the judge's request, prepared a proposed order terminating the guardianship. The judge signed the order removing the guardianship, and the client subsequently moved out of the RCF and into her own apartment.

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 DYS 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 DYS 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.

Contact information:

Tom Masseau, Executive Director
Disability Rights Arkansas, Inc.
400 West Capitol Avenue, Suite 1200
Little Rock, Arkansas 72201-3455
tmasseau@disabilityrightsar.org
501.296.1775
800.482.1174 Toll Free
501.296.1779 Fax
www.DisabilityRightsAR.org