

2024 VOR Report – State of Arkansas
by
Families & Friends of Care Facility Residents (FF-CFR)
Arkansas’ statewide parent-guardian association

June 20, 2024

I. Arkansas’ ICFs

- a. There are five state-operated intermediate care facilities (brief description below), which, in Arkansas, are called human development centers (HDCs).
- b. Arkansas has a policy of open ICF admissions, including admissions for eligible individuals under the age of eighteen to Conway HDC, the largest of our five public facilities. The school age program at CHDC offers specialized residential care for youth with autism.
- c. Each of the 5 public ICFs is licensed by CMS (Centers on Medicaid & Medicare Services) and includes annual unannounced state surveys; in addition, each center is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF), an independent, non-profit organization that provides accreditation services world-wide at the request of health and human services providers.

Following description of Arkansas HDCs is from a 2022 submission to a U.S. Senate committee:

Arkansas families of individuals with life-long profound disabilities will forever be grateful for the state’s intermediate care facilities. Most Arkansas ICF residents are non-verbal, or communicate with great difficulty, functioning in the profound range of cognition, with slight or little awareness of danger. The five state-operated human development centers (HDCs) are licensed intermediate care facilities (ICFs) and provide residential training and treatment for over 850 individuals with profound cognitive and developmental disabilities. The HDCs, located in Conway (Faulkner County), Booneville (Logan County), Arkadelphia (Clark County), Warren (Bradley County) and Jonesboro (Craighead County), provide irreplaceable services for vulnerable persons from throughout the state. The HDCs are foundational components of the state’s human service system. In addition to the public ICFs, there are twenty-seven private intermediate care facility (ICF) programs. If any of the ICFs were to be downsized or eliminated, our citizens, current and future, with life-long cognitive and other developmental disabilities would suffer. Further, any closures would be economically devastating to the areas in which the five public centers are located.

II. Arkansas’ parent-guardian association

Families & Friends of Care Facility Residents (FF-CFR) is Arkansas’ statewide parent-guardian association. Most, but not all, FF-CFR members have loved ones receiving residential treatment

services in the five HDCs. Serving on the FF-CFR board are two members whose disabled loved ones are no longer living, Darrell Pickney and Tim Zimmerman. Tim serves as our database coordinator, maintaining contact information for the membership and sending out Action Alerts when called upon. We advocate for human services policies which support a range of supports and services for individuals living with cognitive and developmental disabilities – home, community-based (HCBs), ICFs (large and small/public and private), competitive integrated employment and 14-c certificate work programs. In recent years, we have actively joined with two Arkansas private 14-c work programs in advocacy. All five HDCs operate the important 14-c programs, with a total of 392 participants.

III. Challenges.

1. Shortage of Nursing Staff at 3 of the 5 centers – As state agencies, our HDCs, at present, cannot offer competitive wages for nursing staff, and for almost a year the centers have had to hire contract nurses at higher costs and who may not be familiar with our residents. On April 30, 2024, three FF-CFR board members appeared before the Joint House and Senate Committee on Public Health, providing information about the HDCs, about the centers’ exemplary work during the COVID crisis, reporting the nursing shortage, and asking for their support for a solution. We were warmly received.

2. Policies of the Arkansas DD Act programs – In 2022 and 2023, FF-CFR representatives attended the Council on DD’s rally at the Arkansas Capitol, holding signs in support of the HDCs. Last year, we spoke with the executive director for the Arkansas Council on DD and with a sub-grantee of the protection and advocacy program, expressing our support for the HDCs, for the rights of legal guardians to represent their family members, and objecting to the groups’ messages. In 2023-2024, one of our members, Kimberly Dodd, attended a 9-month training program, Partners in Policy Making, which was funded by the AR Council on DD and organized by the AR P&A. Kimberly had opportunities to counter some of the program’s anti-institutional and inflammatory messages. Earlier this week, on June 17, 2024, three FF-CFR board members met with members of the Arkansas House and Senate and legislative staff to provide information about our experiences with Disability Rights Arkansas (DRA), the Arkansas P&A, and to propose legislation based on the Ohio and NC bills which would address the partisan activities of the state’s protection and advocacy system. Katrina Robertson initiated this project.

IV. Some items which have worked well for Arkansas families.

1. Active statewide parent-guardianship association.

In response to a class action lawsuit, the late Bill Sherman and other parents formed a statewide parent-guardianship association in 1991, which continues to be the framework for our advocacy, both state and federal. The FF-CFR executive committee is comprised of four officers, the presidents of each of the five centers and other members at large. Twenty-five individuals serve on the FF-CFR Board of Directors. At present, one of the five centers is without an active family association.

Led by President Terry Johnson, the FF-CFR Board strives to meet quarterly by phone. FF-CFR held its general membership meeting – the first since COVID – in October, 2023 at CHDC. Through e-mails and an annual hard copy newsletter, we strive to keep the general membership informed, and, as a result, we have raised sufficient funds to print and distribute informational materials and to send two representatives to the 2024 VOR initiative.

The FF-CFR Executive Committee maintains an active e-mail conversation about state and federal issues which affect our family members with disabilities.

2. Advocacy work – state and national.

In our individual advocacy work, FF-CFR members advocate for: the intermediate care facility (ICF) system (the five HDCs), rather than solely for our family members' individual ICF/HDC. We advocate for all eligible individuals (present and future) for ICF programs, rather than for our individual family members. FF-CFR creates and updates informational booklets to use as “leave-behinds” in our meetings with policy makers. The most popular section contains the one-page family story-sheets with photographs of members' loved ones with disabilities. We are indebted to former FF-CFR secretary Jan Fortney for creating the “model” for the booklets, and to FF-CFR current secretary, Kimberly Dodd, for her work in updating and printing our booklets.

Annually, since 2012, FF-CFR has submitted requests to the U.S. House and Senate Committees on Appropriations seeking relief from the anti-institutional policies of the DD Act programs and from the Office of Civil Rights Division in the Department of Justice. We strive to have working relationships with the health LAs for the Arkansas delegation.

3. Actions to assist all the centers.

The FF-CFR Board has worked to strengthen all centers by attending their parent-guardian meetings and by advocating for the centers before their communities' leaders and before state legislative members from the areas. We worked steadily over 10 years for capital improvement funds for one of the oldest centers, BHDC, and, on May 18, 2022, we attended the ribbon-cutting ceremony of two new living quarters on the BHDC campus. Previously, BHDC had been targeted by the protection and advocacy system (Disability Rights Arkansas) for closure. In the most recent legislative session, funds were ear marked for extensive capital improvements to a second HDC (JHDC). Long-range plans to address the other centers' larger capital improvement projects are in place. A new medical facility at CHDC, our state's largest center (450+ residents) is sorely needed. Other centers' medically fragile individuals are offered a transfer to CHDC for specialty medical care when changes occur in HDC residents' health.

4. Up-to-date Contact information.

We continue the important work of collecting e-mail addresses from the five centers' families. FF-CFR Database Coordinator, Tim Zimmerman, maintains the e-list, which we use in emergency advocacy efforts and to keep members informed. Currently, there are over 503 addresses in the database. We are indebted to former FF-CFR board members Jan Fortney and Alan Fortney for their early organizational work in maintaining the FF-CFR e-lists.

5. Contacts with the Arkansas General Assembly and the Administration.

FF-CFR strives to attend meetings of and to meet with leaders of key legislative committees, House and Senate, which are most likely to address HDC issues. We strive to stay connected with the Governor's DHS liaison to the legislature. The Arkansas Division of Developmental Disabilities Services (DDS) is one of many divisions under the Department of Human Services (DHS) and is governed by a Governor-appointed board. FF-CFR strives to have representatives at quarterly DDS Board meetings.

6. Awareness of State Policies.

We work to keep informed about division policies which might affect the viability of the centers. These policies include (1) steady capital improvement funds for all five centers; (2) open admissions to qualified individuals, including persons under the age of 18; (3) adequate pay for staff; and (4) properly funded operational budgets.

Respectfully submitted,

ON BEHALF OF FAMILIES & FRIENDS OF CARE FACILITY RESIDENTS

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