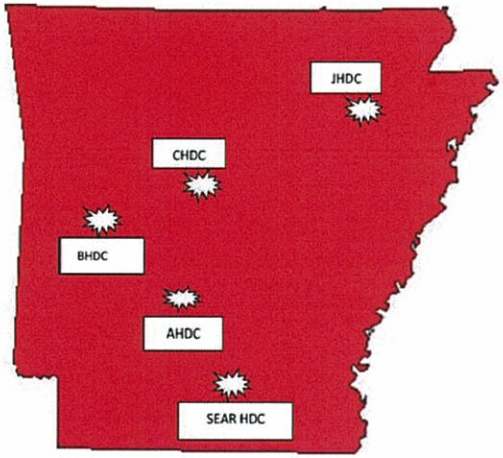
Arkansas' 5 Human Development Centers (HDCs)

HDCs serve over 900 residents from throughout the state. HDCs are foundational components of the Arkansas Developmental Disabilities Service System (DDS).



Arkadelphia HDC

Booneville HDC

Conway HDC

Jonesboro HDC

Southeast Arkansas HDC (Warren)

Families & Friends of Care Facility Residents (FF-CFR)

Presentation to

Arkansas Legislative Health Care Reform Task Force
September 16, 2015

Handout #9
Rec. 9-3

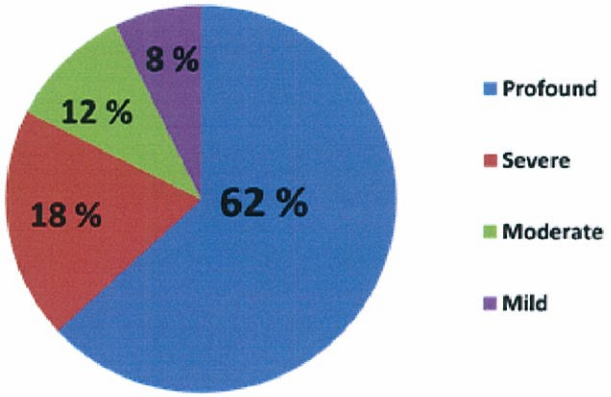
Families & Friends of Care Facility Residents (FF/CFR)

WHO WE ARE:

FF/CFR is a volunteer organization, comprised of families, guardians and friends of people with cognitive-developmental disabilities, most of whom live in one of Arkansas' five HDCs. We are a 501c3 non-profit corporation, and have no paid staff (we advocate at our own expense). We do not employ a lobbyist, and we are dedicated to securing, maintaining and improving services for Arkansans with all levels of intellectual developmental disabilities, particularly those with severe and profound cognitive deficits. We advocate for a full range of services and a full continuum of living arrangements with the understanding that one program will not eliminate any other program option.

We appreciate Governor Asa Hutchinson's support, and our Legislators' support of our loved ones' homes and communities. The HDCs are their life-lines!

HDC Residents



Total Residents 914		Ambulatory 619	Non- Ambulatory 295
Aggressive Destructive & Self-injurious 676		Hearing Impaired 109	Physician Ordered Modified Diets * 794
Health Fragile 424		Visually Impaired 342	Tube Fed 120

Data from DDS as of 1st Quarter 2015

** Due to dysphasia, choking, and swallowing issues.*

- ✓HDC residents are the most medically fragile and vulnerable of Arkansas' citizens with cognitive and other developmental disabilities.

Facts About the HDCs

- HDCs are long-term care facilities , which operate 24 hours a day, 365 days a year – they never close!
- The 5 HDCs serve over 900 individuals from counties throughout Arkansas providing specialized care required for their severe and complex conditions.
- 62% of HDC residents function in the profound range of cognition (IQ below 20), and another 18% function in the severe range of cognition (IQ 20 – 34).
- 87% - that is, 794 of the 914 HDC residents - are on physician ordered modified diets and are at high risk of choking.
- In addition to profound and severe intellectual disabilities, most HDC residents also have physical disabilities.
- 676 of 914 HDC residents exhibit aggressive, destructive and / or self-abusive behaviors.
- Arkansas HDCs have historically proven successful in providing quality services for Individuals with DD.
- HDCs are Patient-Centered Medical Homes & Health Homes.
- HDCs are Arkansas' Safety Net Programs. Many residents have lived at home with family, and have been unsuccessful in other programs. Over time, their situations and care-needs and that of their families have changed. Due to their mental incapacity, court appointed guardians have been secured to help make decisions about their required care including residential placement that is best for them. HDCs are a choice provided by our state to its vulnerable citizens with life-long developmental disabilities.
- HDCs provide training to professionals, and offer outreach services to non-residents and their families around the state.
- HDC's Seating Clinic and Orthotic Services provide assessments for proper body alignment and comfortable wheelchair seating to individuals statewide.
- HDCs provide Economy of Scale – It is more economically feasible to provide the required specialized services by trained professionals in a campus setting.

Episode of care:
HDC residents have one life-long episode of care

- HDC residents' cognitive deficits & developmental disabilities cannot be cured with medication. Their level of cognition is not improved with medication.
- Cognitive deficits and other developmental disabilities cannot be cured. Through HDC training and structured predictable schedules, our family members can learn to tolerate a crowd, to sit with a group, to trust others, and to assist in their own care with the help of others.
- The majority of HDC residents are non-verbal; they are unable to express their hurts or needs or can only do so with limited ability.
- HDC residents require close supervision at all times. They have slight or little awareness of danger. If they wake in the night, an awake HDC staff member is present to assure their health and safety.
- HDC residents lack the cognitive ability to self-advocate or self-direct their services without the assistance of others.
- With support, a small percentage of HDC residents have employment off-grounds; the majority of HDC residents are unable to be gainfully employed.
- Most HDC residents take one or more medications for seizures, health and behavioral conditions. HDC residents are unable to safely store and administer these medications.

Services offered at HDCs:

- HDCs provide spacious, secure campuses where residents have easy access to comprehensive services.
  Residential Services (includes room & board)
- 24/7 Direct Care Awake Staff
- Interdisciplinary Teams with Person Centered Program Plans
- Case Management
- Health Care Management
- Bone Density – DEXA
- Total Drug Management
- Wheelchair & PTO Shop (utilized by others with DD around the state)
- Medical & Dental Clinics with Lab Services
- Dietary Management, Including Specialized Eating Equipment
- Alzheimer's Care
- Transportation
- Life Skills Habilitation & Job Training
- Professionals with Experience
- Recreation/Socialization Activities
- Occupational, Physical, Speech Therapies
- Psychiatric/Psychological Services
- Positive Behavior Support Services
- And so much more!

HDCs Accreditations & Licensure

- Arkansas Office of Long Term Care
- Certified by CMS (Centers for Medicare & Medicaid Services)
- CARF (Commission on Accreditation of Rehabilitation Facilities)
  - An International Commission on Accreditation

Myths and/or False Statements
That you will hear from time to time, and the *real truth*!

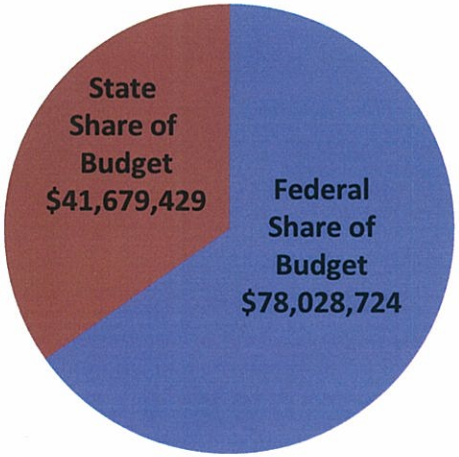
	Myths/False Statements:	Truth:
1	"Long Term Care Services are cheaper in the Community"	There is no cost savings if all "components of care" are factored in. For example, cost for housing, food, clothing, caregivers, transportation, recreational activities, medical needs, dental care, physical and/or occupational therapy, prescriptions, speech therapy, diapers, special equipment, close supervision.
2	"Least Restrictive Environment" is understood to mean services offered only in the "Community".	"Least Restrictive Environment" can be a Human Development Center.
3	HDC residents' constitutional rights are violated because they live in segregated settings.	HDC residents live in safe campus-based homes where they walk freely, without fear or danger; HDC homes are close to life-giving support services; numerous professionals, volunteers, career employees and visitors are part of their active lives.
4	Those living in institutions are "incarcerated" and are not offered the opportunity to be involved in their own communities, families, and friends.	In actuality, individuals in HDCs have many opportunities to be in their communities with family members, friends, shopping, eating in restaurants, movie theatres, county fairs, sporting events, church, horseback riding, fishing, and they have social interaction with their peers, staff, and volunteers.
5	"Institutions enforce an unnatural, isolated and regimented lifestyle that is not appropriate or necessary." The Arc Position Statement	Facility-based care is a "positive" long term care choice with the close individual professional care that is needed on a 24-hour basis.
6	U.S. Supreme Court decision: "Olmstead requires community integration." "Olmstead requires downsizing/eliminating the option of institutional care for persons with disabilities."	The Olmstead Decision supports facility-based (institutional care) for those individuals whose severe impairments require the close care found in such settings. Olmstead encourages a continuum of service options for disabled persons – home, community and institutional care.
7	"There is a need to rebalance the long term care current system. Overall about 60 percent of Medicaid long-term care dollars are still spent on institutional services, with about 40 percent going to home and community-based services (HCB)."	There is no need to "rebalance" the long term care system for persons living with the effects of cognitive -intellectual and developmental disabilities (ID/DD). Three times as many persons with ID/DD in Arkansas are served through Home & Community Based (HCB) programs than are served through licensed-facility-based programs (HDCs).
8	"A strong institutional bias remains in the provision of long term services and supports, both within Medicaid and in the private sector." Adapt.org	There is no "institutional bias" in Arkansas for individuals with cognitive-developmental disabilities. 74.2 % of Medicaid dollars are spent on Home and Community Based Waiver programs (for the DD population).

• Sources of Funding –

Medicaid (70% Federal Match for 30% State Dollars)

Medicare

HDC Provider/Bed Tax



HDC Budget Numbers for FY 15				
HDC	Total Budget for FY 15	Federal Share	State Share	Number of Residents
Conway	$ 63,704,720	$ 41,438,336	$ 22,266,384	481
Arkadelphia	$ 15,155,680	$ 9,971,926	$ 5,183,754	119
Jonesboro	$ 12,603,419	$ 8,173,194	$ 4,430,225	105
Booneville	$ 15,989,376	$ 10,432,278	$ 5,557,098	129
Warren	$ 12,254,958	$ 8,012,990	$ 4,241,968	90
TOTAL	$ 119,708,153	$ 78,028,724	$ 41,679,429	924

We **oppose** the use of Managed Care Organizations for the residents of the Human Development Centers

- ***Managed Care will result in the elimination of the model which historically has been successful in serving our family members and Arkansas' most vulnerable persons.***
- ***Privatization of Safety Net programs in other states have resulted in increased deaths.***

  Nebraska, Washington, D.C., Georgia & California
- ***MCOs will provide less than what our loved ones require to live! To provide less than they require is unacceptable!***

We recommend Strengthening Program Integrity & Infrastructure

In Conclusion -

FF-CFR opposes privatization of state human development center programs. HDC care is safer for those disabled individuals found to benefit most from state-operated congregate care facilities. The close care residents receive in our HDC programs is essential to their health and safety. HDC residential care is not suitable for everyone; many individuals with disabilities thrive in other models of care. We see a need for a range of care options, which reflect the realities of the individual with disabilities and their family.

FF-CFR opposes the use of Managed Care Organizations (MCOs) for the residents of the Human Development Centers. MCOs' position is that cost savings will result when they are given the business of caring for people with disabilities.

Contracting with one or more Managed Care organizations for the Arkansas developmental disabilities population would likely result in the elimination of the model (state-operated residential long-term care programs at the five human development centers), which historically has been successful in serving our family members and Arkansas' most vulnerable citizens. Elimination of centers would not happen overnight but would occur over time.

Deflecting admissions from, downsizing, closing/privatization of public Safety Net Programs in other states have resulted in increased deaths for persons with developmental disabilities. See e.g.: 1,000 deaths in Georgia (2013-2014) following closure of state centers required in a settlement agreement with U.S. Department of Justice. See also states of Nebraska, California and Washington D.C.

A developmental disabilities service system operated by one or more Managed Care Organization(s) will add additional layers of administrative costs to the Arkansas DDS system which in turn will result in a decrease in available funds for adequate services to vulnerable persons who rely on others for their survival.

FF/CFR strongly supports the maintenance of infrastructure at the human development centers with planned and adequately funded improvements.

Thank you for giving us the opportunity to speak in behalf of HDC residents today, and thank you for your public service.