# **ARKANSAS** Human Development Centers



## Families and Friends of Care Facility Residents (FF/CFR)

## Advocating for vulnerable Arkansans with life-long developmental disabilities

This material has been prepared and paid for with funds from Families & Friends of Care Facility Residents. Neither State funds, nor HDC funds were used in the printing of this material.

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

Advocating for vulnerable Arkansans with life-long developmental disabilities

## About Us:

We are members of Arkansas' statewide parent-guardian association, Families & Friends of Care Facility Residents (FF/CFR). For 20 years we have advocated for our loved ones.

FF/CFR is a volunteer organization, comprised of families, guardians and friends of people with cognitive/intellectual/developmental disabilities, most of whom live in one of Arkansas' five human development center programs;

FF/CFR is a 501©3 non-profit corporation registered in the State of Arkansas;

FF/CFR has no paid staff; we advocate at our own expense;

FF/CFR does not employ a lobbyist;

FF/CFR is dedicated to securing, maintaining and improving services for Arkansans with all levels of developmental disabilities. We advocate for a full range of services and a full continuum of living arrangements – home, community-based waiver and private and public ICF/MR programs (human development centers).

Thank you for your service to our state. Please let us know how we may assist you in your work. Our Board of Directors' contact information is found on the last page of this booklet.

Sincerely,

Families & Friends of Care Facility Residents



Level of Intellectual Disability of Residents at Arkansas HDCs

Class - Intellectual Disability	IQ
Profound	Below 20
Severe	20 - 34
Moderate	35 - 49
Mild	50 - 69

## **Arkansas Development Center Client Statistics – January 2016**

<u>Total Residents</u> 910	<u>Total Direct</u> <u>Care Staff</u> 1,044	<u>Ambulatory</u> 630	<u>Non-Ambulatory</u> 280
<u>Health Fragile</u>	Hearing Impaired	Physician Ordered Modified Diets	<u>Fed by Tube</u>
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## Facts About the HDCs Residents

- HDC residents' cognitive deficits and other developmental disabilities cannot be cured, not even with medication. Their level of cognition is not improved with medication. 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.

## Other Facts:

- 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

Stories

Family

& Letters

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#### April, 2016

#### Hello,

This is a photograph of our dear son John, the oldest of our three children, who was born 47 years ago. In still photographs, our son's disabilities are not apparent; you would need to meet him in person to have a sense of the realities attendant to his chronic and life-long disabilities.

Our son, whose severe brain injuries occurred at birth, functions on the level of a young toddler. He has a medical diagnosis of profound mental retardation and autism. A large middle-aged man, John is mobile, non-verbal and has little awareness of danger. At times, he exhibits mania, self-abusive behaviors and pica (eating inedibles). Although he can walk and feed himself, our son has never called us by name, cannot use a tissue to blow his nose, cannot shave himself, cannot report his hurts and needs. John can be frightening to an untrained person, especially when his behaviors spiral out of control.

### All of his life, John will rely on the humanity of others for his health and safety.

We are grateful for our great state's five publicly-owned and operated human development centers (HDCs). These Medicaid–certified facilities provide competent and compassionate care for over 900 at -risk citizens, including our son. When John was younger, Conway HDC provided our family respite care services for over 7 years – that predictable relief helped us care for him for almost 16 years. As our son grew to manhood, his care became beyond our capacities. For many years now our son's home has been the Arkadelphia HDC, where the close care and specialized services have met his intense care-needs.

Our family supports the great human development center staff system, which is absolutely necessary for the health, safety and welfare of some of Arkansas' most disabled citizens. Our legislature and our Governor support the human development center programs. They have a clear understanding of the challenging job which our state has in carrying out its responsibility in providing adequate care for our most difficult citizens to support, those

who through no fault of their own require close assistance 24 hours a day.

Please join with us in doing what is required – in humanity – to provide the assistance necessary for our state's most disabled citizens when the support required is beyond the capacities of their families.

## Thank you.

Carole and Bill Sherman 450 Midland Street Little Rock, AR 72205 carolelsherman@sbcglobal.net



## Who Is Most Precious To You??

## Who needs your protection from those who would do them harm? It could be your elderly parents, your spouse, or your children. You would do everything to help them and protect them!

Our daughter, Kim, is that precious someone for us. She needs our every effort to make sure that her life is safe and full.

Kim is "multi-handicapped". She has cerebral palsy, profound intellectual disabilities, is physically impaired, and does not know how to defend herself from harm. She is trusting of everyone, requires "round-the-clock" personal care, and does not know how to express hurts. Kim must have someone feed her, clothe and bathe her, and is incontinent. She says about 21-words. Kim requires 24 hours

a day/7 days a week care, with awake care staff.

Kim's life at the Conway Human Development Center is very full. She loves her home, and all of the activity. Kim is busy everyday with training classes, recreational swimming, speech therapy, trips to the mall, movies, the zoo, restaurants, bowling, church, and even horseback riding from time to time. Her care givers love her and want what is best for her, too! We are thankful for them! We remain very much a part of Kim's life!



As her parents, we want to make sure that her life continues to be safe and have quality to each day! Please do everything you can (and would do if she were yours) to help keep her home available to her and the other individuals that need these services.







Alan & Jan Fortney \*

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#### June 2016

I am the mother and legal guardian of Timothy Hoover, a resident of the Conway Human Development Center ("CHDC"). My only child, the love of my life, is 39, soon to be 40. Tim was born with a medical diagnosis of intellectual and developmental disabilities. He is non-verbal, non-ambulatory, and incontinent. He has contractures, suffers from seizures, has chronic dysphasia (aspiration) and suffers severe behavior issues. He functions as a 2 year old. Tim depends on others for feeding, toileting, ambulation, and lifesaving medications. He is total care. He will <u>always</u> rely upon others for his basic health and safety needs.

This being said does not describe the curly red haired, blue-eyed, deep dimpled, huge smiling, funny "Tim Bo Jessie" the staff at CHDC has come to know and love. Tim joined the HDC system 16 years ago at age 24. When moving to Conway Human Development Center 9 ½ years ago, Tim had severe behavior issues. During behavior meltdowns, Tim would self-injure by slamming his head into the nearest hard object or person or he would flip over his wheelchair causing many trips to the emergency room. On one ER visit, the doctor thought Tim had



crushed his facial bones. Not one time since moving to Conway HDC has Tim flipped over his wheelchair. Within a couple of years, the trained staff at CHDC, working together as a team, gained control of those terrible behavior meltdowns. Tim's outbursts are rarely seen now. He is happy in his home. He is happy in his daily routine.

I visit his home several times a week assisting with his meals by feeding him and giving him fluids; I watch music videos with him in his room; and sometimes I take him on a walk around campus. Tim is fully integrated into his community that meets his needs, from direct care, to health care, to friendships, to recreation. He is an active member in his community of care at CHDC and is known and loved by many people, with and without



disabilities. He is safe and he feels safe. Tim lives as independently as possible. He enjoys on-campus living; medical and dental clinics, chapel, daily living classes, the aquatic center, social and recreational events. Our HDC campuses help people with intellectual and developmental disabilities lead meaningful lives. They serve families who want the best for their loved ones, yet cannot provide it at home. I like to call them "Community of Care Campuses."

Many, many, many thanks to the great folks in the wheelchair clinic at CHDC who build wheelchairs from the ground up to specifically fit each individual. Many, many, many thanks to the teams who meet regularly evaluating and re-evaluating each and every person for their specialized care. Arkansas' Human Development Centers are communities of care.

Rita Hoover 110 Apple Blossom Loop Maumelle, AR 72113 rhoover@fridayfirm.com



How can anyone write a few words and accurately reflect a lifetime of attention to the care and wellbeing of their child with a disability? Harder still, if you are blessed and fortunate enough to never have had to deal with this challenge, how can you possibly understand and absorb what it means?

In spite of all the challenges and tough decisions that have been made along the way, I wouldn't trade my life with my son Danny for anything else in the world. Most parents probably feel the same way. Sure, the bad times were pretty brutal, but the good times...oh man...provide us with the best

feelings this planet can dish up.

I would say some of the toughest times were when Danny finally was "on his own", meaning beyond the legal age of his K-12 years in public school. Once a disabled person reaches this age, they seem to be standing on the edge of an abyss with no clear path forward. And the pressure falls onto us parents, who now have to make life altering choices for another adult person! No stress there!

It was my experience to give just about everything a try. Over about 10 years, Danny belonged to FOUR different "Community based" Medicaid Waiver programs, and we even built and ran our own Group House. Although these programs work well for some, they were nightmares for Danny and our family. By definition, these programs assign a single care-giver to a single client, usually



going through 3 shifts of care-givers every 24 hour period. This creates a one-on-one situation that produces extreme tension and responsibility for care-givers that by financial default, are not trained professionals. Most are retirees or College kids making some extra money. Again, fine for some, but a formula for disaster for many, like my son, who are complicated and demanding to say the very least. The administration of tightly controlled medicines...the proper and safe handling of extreme behavioral episodes....not to mention the day to day personal hygiene requirements of an adult, are just too much to lay on a single care-giver, regardless of training.

The answer? For us it was finally finding the Jonesboro Human Development Center. There are about 100 Medicaid Waiver programs in Arkansas, but only FIVE HDC's. An HDC provides a real Community atmosphere, right there on campus. Sure, Danny takes trips all over town for special activities, dances, haircuts, McDonalds and what have you...but the HDC serves as his "College", complete with a wealth of friends, classroom learning, baseball teams and workshops. And instead of just one care-giver per client, at any time, there are at least 3-4 staff within verbal distance of Danny. He loves the structure and daily routines and faces. He has genuinely thrived in this environment. He loves his "College".

What is the future looking like? Well, none of us are sure. There are several misguided organizations who are constantly trying to defund our HDC's and redirect those funds to their "alternative" care models such as the



Community based Waiver Programs. And of course our own Federal Government has several groups preaching "least restrictive environment" laws that have little to no knowledge of the damage they would cause if they actually won what they believe they are fighting for.

I hope...and pray...that all those in authority within our society's leadership will understand and take the time to fully appreciate the human value that our HDC's provide to those of us who depend on them.

Respectfully,

Terry Johnson (Danny's Dad) terry.johnson@clearpointe.com

Work Phone: 479-845-3695

May 2016



## Chris

These are photographs of our youngest son Christopher (Chris). He is 42 years old and functions as a three year old. After numerous trips to doctors in Arkansas and Tennessee, he was diagnosed at the age of two and one-half with a chromosome translocation. Because the doctors had no knowledge of anyone with this same translocation, we had no idea how this would affect Chris in the future. We now know he has profound intellectual disabilities. At the age of thirteen, the school he was attending could no longer accommodate individuals under the age of eighteen. He resided at Easter Seals for a year then another community based facility before Jonesboro Human Development Center had an opening. JHDC is one of five Medicaid certified facilities in Arkansas. JHDC has been a blessing to Chris as well as our family. He is mobile only with help, non-verbal, often incontinent, and cannot bathe or shave himself. He can help dress himself, but is unable to put his shoes on and when he is sick, he can only point to what hurts. At JHDC he gets to participate in numerous activities such as swimming, bowling, Miracle League ball program, trips in the community, eating at restaurants, picnics, rodeos, and his job is shredding paper. He has an infectious smile and never meets a stranger.

Because of his gait, he is prone to falls and therefore can never be on his feet without someone holding on to the gait belt he has to wear. He thrives in the structure of JHDC, and the medical staff is excellent. It seems that in recent years the Federal Government has decided that community based programs are the perfect choice for everyone. NOT TRUE! Community based programs are great placement for some individuals because their disabilities are not as severe as those like Chris. The HDC's are the perfect placement for those who require the constant monitoring and intense care that Chris requires. There is no such place as a one-size fits all program for individuals. We need the HDC's as well as community based programs. Please realize that assistance is absolutely necessary for those disabled citizens who require close assistance twenty-four hours a day and whose support is way beyond those of aging families.

Thanks so much, Charles and Gloria Holden, 607 Lakeshore Drive, Newport, AR 72112 gh@holdenscorner.com



Darlene Pickney, my first of three lovely daughters, was born December 12, 1965 in Garden Grove California. Shortly after her birth we learned that she was severally mentally retarded and we have spent the last 45 years trying to provide her with the best life possible in an environment that is best suited to meet her special needs.

During Darlene's first year of life we moved back home to Hoxie, Arkansas determined to raise our baby to the very best of our ability. We were successful in caring for her until she reached school age at which time we enrolled her in a special school in Jonesboro known as Helen Dudley. She was completely unable to function in that environment and we were forced to move her to the Cottage of Hope, a facility providing basically daycare for the severe mentally retarded. At age nine her mother graduated college and began teaching in the Trumann public school system and Darlene was enrolled in special education classes there. Even though we were striving to do what was best for our daughter, this was a big mistake. Darlene was unable to function in the public school system and that experience culminated in a complete emotional and mental breakdown for her.

Shortly after the public school fiasco, we were successful in getting her placed in a 24-hour facility that was then known at the Children's Colony in Conway, Arkansas, a school and home that later became the flagship facility of the Arkansas Human Development Centers. She lived there until age 14 and functioned wonderfully during her five years in Conway.

By this point in her life her mother had relocated to Harrison, Arkansas and had a strong desire for Darlene to lead a more "normal" life in a less restrictive living environment. She moved her into her home in Harrison and enrolled her in school at the Boone County Learning Center, a facility for students with special needs, and operated by the state. Darlene functioned fairly well in Boone County but had to disrupt her life a year later when her mother's work necessitated her relocation to Little Rock. With no suitable facility in the Little Rock area, Darlene was placed in the Jackson County Learning Center, a privately operated facility in Newport, Arkansas. Without going into detail I will just say that her two years spent in Newport was the biggest mistake we ever made in Darlene's life and she still has damages from her experiences at that facility.

At age 17 we were, through an emergency enrollment, able to get Darlene out of Newport and transferred back into the state system with placement in the Human Development Center in Warren. She lived there until 1985 at which time our request for closer placement was honored with her move to the Jonesboro Human Development Center.

For the past 25 years the Jonesboro Human Development Center is the place that Darlene proudly calls her home. Every year during her annual plan review I witness a scene that is both heartwarming and truly amazing. Even though her severe mental condition prevents her from providing substantial plan input toward her daily needs and wishes, when asked where she wants to live she loudly and proudly exclaims, "At my home in the Human Development Center".

Our desire has always been to have Darlene living in the least restrictive environment that can best meet her needs. Based on 45 years of trying to achieve this goal, there is no doubt in my mind today that place is the Jonesboro Human Development Center, 1100 Liberty Circle, Jonesboro, Arkansas.

#### Sincerely,

Darrell D. Pickney Father and co-guardian of Darlene L. Pickney <u>ddpickney@yahoo.com</u>

Darlene (left) and my youngest daughter, Heather (right) taken at JHDC Family Day



#### Hello,

This is a photograph of my eldest brother, Leonard (he is called Lanny to all that know him). Lanny is the eldest of 6 children to our mother Jane Richardson, she passed away in 2002. Our father also passed away in 2000. Since my mother's death I have been Lanny's guardian.

Our story is different than most you will hear. Lanny is our half-brother. Our mother became pregnant with him as a teenager and her mother forced her to give him up for adoption. My siblings and I were raised knowing we had a brother who our mother loved very much, and had been searching for since she became an adult. When I was 9 years old, my mother found Lanny. He was in Beverly Hills, California. The day my mother contacted the adoptive parents is the day she found out that the son she had been searching for all these years had severe mental retardation and was in an institution. My mother asked to come meet him and she went immediately to California. While in California she fell in love with that precious 19 year old boy and asked to have him back regardless of his handicap. She was granted her wish and she brought him straight from institutionalization to our small home in Arkansas.

When I was 16, my parents decided that they could no longer keep Lanny at home. They were exhausted and the strain on my mother was evident. He needed constant supervision. He's mental age of a toddler, he could feed himself, bathe himself (with supervision) but became easily frustrated with simple tasks and would often hurt himself by hitting himself or banging his head. He would have frequent verbal outburst, and frustration needing redirection to keep him from self-harm. They visited different Human Development Centers, and decided upon the one in Booneville, Arkansas, 2 ½ hours from their home in Jacksonville. They felt this facility was the best fit for Lanny.



Donna J. Richardson 1740 Drury Lane, Conway, AR 72034 501-416-8564 Lanny is now 60 and has been at the Booneville HDC for approximately 33 years. My parents were always pleased with the excellent care he received there. I am now Lanny's guardian, I am a registered nurse and a project manager at UAMS Center for Distance Health. I am very involved in Lanny's plan of care and attend an annual meeting with his caregivers. I am notified by email or phone of any and all events in his life. I am very pleased with the well-rounded care he receives.

He is well adjusted and at home there. He has a daily schedule that keeps him busy. He goes to 'work' where he tears magazines, he goes to exercise and rides a stationary bike and he loves to sit by the window outside his dorm room and drink a cup of decaf coffee and look out the window for any dog or cat strolling by. When he comes to my home for a visit it only takes a few days for him to asks to 'pack suitcase' and head back home to Booneville. He keeps his room very neat with all his prized dog statues and a well-made bed. Every foot of wall space is filled with family pictures and posters of all the animals he loves. Lanny laughs frequently and loves to talk about dogs. Lanny cannot tie his shoes, does not know his colors or how to read or write. But he knows he is loved by his siblings and his family at Booneville HDC.

My son, Andy, has been at the Human Development Center, in Conway, AR, for 36 years; at care centers in earlier life in Kansas and in Wyoming. (whenever we moved, we took him with us) Had to have help when he got bigger than me (all my children are bigger than me and I am 5'9"). He has diagnosis of Lennox-Gastaut syndrome, which is the direct result of a forceps delivery. It is a generalized myoclonic astatic epilepsy in children with mental retardation, resulting from various cerebral afflictions, such as perinatal hypoxia, cerebral hemorrhage, encephalitis, maldevelopment or metabolic disorders of the brain: characterized by multiple seizure types (generalized tonic, atonic, myoclonic, tonic-clonic, and atypical absence) and background slowing and low spike and wave pattern on EEG: patients are usually mentally retarded or developmentally delayed (definition

taken from Stedman's Medical Dictionary for the Health Professions and Nursing, Fourth Edition 2001).

Andy knows his family and talks to us with his eyes, has never been verbal, except for squeals of happiness or unwanted procedures. He recognizes our voice on the phone and tries to talk to us and becomes frustrated when not able to do it. He can only walk if two people are with him, one in front and one behind, due to his seizure status. He is tall and the people walking him must be taller than him and someone he trusts. Therefore he is wheelchair bound. In his younger years, while living at home, and his first cottages, he walked all over the house with a seizure helmet on his head. He loved to get into a double swing set and swing himself, but that soon became a danger to him. He is in a cottage with other boys and they are his "friends" and the caretakers all have a relationship with him. He can feed himself finger food, but makes a mess, so usually the staff feed him and he will eat almost anything you offer. He is total care. Conway Human Development Center has been



the perfect place for his 'home'. I live 45 minutes from him and make frequent visits. If his seizure status is down, he is very happy to see me, otherwise, he cannot interact with me.

Earline H. Stoddard, RN BSN Guardian of Andrew Stoddard at CHDC, Conway, AR

> Bryant, AR 72022 Cell: 501-416-8279 earlinehallam@sbcglobal.net

#### June 2016

I am the mother of two children. My youngest child is Melanie and she is 40 years old. She was born with microcephaly. She lived with me until she was 8 years old. She went to two day service centers when she was younger until her medical problems became greater. Melanie has a seizure disorder, is hypothermic, severely and profoundly intellectually disabled and is tube fed. Melanie has no self - help skills and is totally dependent for her care.

Conway Human Development Center became her home and lifeline. It saved her life. They have a loving staff who genuinely care for the residents and have given her a wonderful home with her residence family. Melanie lifts my spirits when I am with her there and lights up a room with her smile. It is her best skill. She enjoys music and I rarely visit without singing some songs I have sung to her from when she was a baby. Before she was too big to carry, she was known as "the Dancing Queen" as we waltzed around the room. Today Melanie enjoys music still and finds it both fun and soothing.

When she was school age they provided training that helped her even today be cooperative when she is groomed daily - bathing, brushing teeth, brushing her hair. Melanie is seen by physicians at the center and outside as needed. She enjoys the social activities, tractor rides, and other opportunities that CHDC provides

So what does the future look like? There are some misguided groups who think community providers are the answer for everyone. They would be wrong. Their efforts to close centers and take funding to move it to community providers is wrong.

I not only pray each day for Melanie but for her HDC family and staff. I urge our leadership to understand the value of the HDCs and what they provide to our family members.

Peggy Nabors Little Rock, AR 501-221-1476 (Home)

501-658-6911 (Cell)

pnabors6975@att.net







February 1, 2016

Governor Asa Hutchinson State Capitol Room 250 500 Woodlane Ave. Little Rock, AR 72201

Dear Governor Hutchinson:

This letter is in response to the recent report released by Disability Rights Arkansas regarding the tragic death of a young woman at Booneville Human Development Center which occurred a year ago. My daughter Stephanie is a client at the Booneville Human Development Center. In 1981 my husband and I adopted four-year-old Stephanie and her brother through Arkansas DHS. Stephanie has been quite a challenge with her dual diagnoses of an intellectual disability and a mental illness, disabilities that have increased in severity as she has gotten older. We tried many of the services in the state that provide community-based support for individuals like her. In the last one that Stephanie participated in, she was found wandering the streets in northwest Arkansas after putting herself in significant danger and was sent to jail to keep her safe. It then became quite evident to us that she absolutely could not function in the community. She was then moved into a human development center.

Finally, at BHDC we have found a group of individuals truly committed to working with this population of dually diagnosed clients. Stephanie is very difficult to manage and unpredictable. At times she is one of those who requires personal or mechanical restraints for her safety and for the safety of those around her. I totally understand that. We receive copies of any behavioral reports that she has as well as any documentation regarding restraints, and it is obvious to me that decisions about restraints are not made without a lot of training and contemplation about what would be best for all involved. We also receive immediate calls about any injuries sustained at any time.

I strongly request your support in doing whatever is in your power to do to keep facilities like the BHDC open and to help provide them with the finances that they need to improve. BHDC provides a safe living environment for a group of individuals that our society does not provide adequate care for anywhere else. I do not understand why Disability Rights Center, a federally funded organization, would be advocating for closing the human development centers in the state. They are definitely NOT fighting for the rights of my child. Without a human development center, she would probably be in jail or dead. I am not being overly dramatic. She is simply not capable of living in the community as was proven in her previous placement.

If there are any questions that I can answer for you, do not hesitate to contact me.

Sincerely,

Julia Frost

Julia Frost, Director Jones Learning Center 479-979-8963



Stephanie

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

Advocating for vulnerable Arkansans with life-long developmental disabilities

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## ARKANSAS' Human Development Centers



June 2016