

MINUTES OF MEETING
BOARD OF DEVELOPMENTAL DISABILITIES SERVICES
August 7, 2019
Conway Human Development Center
Conway, Arkansas

The regular meeting of the Board of Developmental Disabilities Services (DDS) was held August 7, 2019 at the Conway Human Development Center. The meeting convened at 10:30 a.m. pursuant to the call of the Board Chair.

MEMBERS PRESENT: Board Chair Darrell Pickney, Sally Hardin, Randy Laverty, Suzann McCommon, David Rosegrant and Artie Jones.

STAFF PRESENT: DDS Director Melissa Stone, Jeff Gonyea, Sarah Murphy, Johnathan Jones, Kerry Gambill, Diane Keith, Mark Wargo, Avis Lane, Tammy Benbrook, Dale Woodall, Thomas Tarpley, Simone Blagg, Jeff Williams and Hannah Knight.

OTHERS PRESENT: Jan Fortney, Rita Hoover, Conway HDC staff, parents and family members of HDC residents, Attorney General representatives Sarah Farris and Clayton Orr and Governor's Office representatives Brittney Roy and Jordan Burgess.

Mr. Pickney called the meeting to order, welcomed everyone in attendance and thanked the Conway HDC Superintendent, Sarah Murphy, for hosting the Board meeting.

Mr. Pickney called for a motion to approve the minutes from the May 1, 2019 regular meeting of the DDS Board. Ms. McCommon made a motion that the minutes be approved. Mr. Rosegrant seconded the motion which passed unanimously.

Mr. Pickney called for a motion to approve the minutes from the May 22, 2019 called meeting of the DDS Board. Mr. Laverty made a motion that the minutes be approved. Ms. McCommon seconded the motion which passed unanimously.

Mr. Pickney called for a motion to approve the minutes from the May 24, 2019 called meeting of the DDS Board. Mr. Rosegrant made a motion that the minutes be approved with the following amendments; the dollar amount to be paid to Coulson Oil be removed as the amount is yet to be confirmed and Attorney General Representative Sara Farris was not present for the meeting. Ms. McCommon seconded the motion which passed unanimously.

Ms. Hardin, chair of the Physical Management subcommittee, advised the Board that the subcommittee reviewed the Magazine Telephone Company two-year lease renewal. The lease involves a transmitter being placed on the Booneville HDC water tower. Booneville HDC benefits from this lease as the company provides computers for clients, internet service and fiber optic work. Ms. Hardin made a motion to approve the renewal. Mr. Rosegrant seconded the motion which passed unanimously.

Ms. Murphy presented the report for the Human Development Centers and shared items of interest about each center. Ms. Jones complimented Conway HDC for their service award recognition events. Ms. Hardin was pleased to note 49 new staff had been trained at Jonesboro HDC this quarter. Mr. Gonyea noted that the 3rd Annual Booneville HDC golf tournament is scheduled for August 10th with proceeds benefitting Special Olympics. He also advised that staff offered input on the design of the buildings to be constructed at Booneville HDC. The designs have been submitted to the architects with an estimated project completion date in 18 months.

DDS Director Melissa Stone began her report with an overview of direct care staffing issues and noted difficulties with recruitment and retention. A pilot plan involving 12 hour shifts with 3 and 4 day work weeks for direct care staff is currently being tested. The plan was implemented in 10 residences at Conway HDC and 4 residences at Jonesboro HDC. The plan's incentive allows staff to have two weekends off per month and an increase in pay as overtime is factored in. Since implementing the plan Conway HDC has experienced a higher retention rate in the month of July. Ms. Stone also noted that employees are often referred for HDC employment through word of mouth. Recent data, however, indicates the employment website indeed.com has produced positive results. Changes in shift differentials on the weekends are also being discussed. In response to concerns raised by Jan Fortney during the May 1st Board meeting, Ms. Stone advised the concerns had been addressed and improvements have been made. Retention plans at 3 of the 5 HDCs are currently in place. Jonesboro HDC's employment numbers have increased from the 80's to over 100 and the increase is due in part to the new pilot plan.

Ms. Stone announced a plan to move forward with professional certifications as suggested by Ms. Fortney. A pool of trained paraprofessionals will be beneficial to both the HDCs and the community programs. DDS is currently in the process of researching the certification and assessing the cost with plans to implement the program in July of 2020.

Ms. McCommon requested an update on the maintenance issues recently experienced at Arkadelphia HDC. Superintendent Kerry Gambill reported disasters occurring during the Spring and Summer left the HDC for periods of time without gas, electricity and water. She also noted how well Arkadelphia HDC staff faced the challenges and praised the resiliency of the clients. She added that surveys conducted during these events resulted in no deficiencies in client care. Ms. Gambill also thanked Conway HDC for assisting with laundry when they were without water. The Board commended Ms. Gambill and her staff for their efforts.

Mr. Laverty asked for clarification of the terms mechanical and chemical restraints and respite. He was advised that a mechanical restraint refers to a papoose board or other physical restraints while a chemical restraint refers to medication. Respite care refers to a client who is not fully admitted but housed at an HDC temporarily for any number of reasons.

Deborah Rainwater introduced herself to the Board as the new President of the Conway HDC Parent Association and FFCFR Board member. Ms. Rainwater's son, Kirk, is a client of Conway HDC.

Rita Hoover, VOR National Board member, commended Ms. Stone for her presentation at the national conference in June and noted it is available on YouTube. Mr. Pickney, National VOR

President, also attended. He was able to share information with Congressional Delegates and provide them with gifts from The Blue Umbrella Store. Ms. Hoover provided an article (attachment 1) written by Susan Jennings who works with families affected by autism. She also wanted the Board to be aware of VOR's opposition of the Disability Integration Act as it would lead to the closure of ICFs. Mr. Lavery noted the conference was very informative and VOR members from other states would like services provided in Arkansas to be available in their state. Ms. McCommon and Mr. Pickney shared similar sentiments of the Arkansas's ability to maintain these services.

There being no further business Mr. Pickney called for a motion for the meeting to be adjourned. Ms. Hardin made the motion. Mr. Rosegrant seconded the motion which passed unanimously. The meeting adjourned at 11:22 a.m.

ATTEST:

Executive Secretary

Darrell Pickney
Mr. Darrell Pickney, Chair, Board of DDS

Susan Jennings

July 23, 2019

**IACC Workshop – Addressing the Housing Needs in Autism
Making the Case for the Vital Need for Public Intermediate Care Facilities**

I would like to thank the members of the IACC Committee for giving me an opportunity to speak to you today.

My name is Susan Jennings – I am the mother of severely autistic and behaviorally challenged young man named Joey and a founding member of KIIDS – Keeping Individuals with Intellectual Disabilities Safe, a Pennsylvania grassroots organization of parents, friends and families of the profoundly and severely disabled who advocate for residential housing models that meet the intensive needs of our loved ones.

We were successful in launching a petition drive in support of our treasured Pennsylvania State Developmental Centers, public intermediate care facilities (ICF) where my son and many others live and thrive. We recently expressed the necessity for ICF care for our loved ones on April 30 in a hearing before the Pennsylvania House of Representatives, Human Services Committee, entitled “Open the Doors to Dignity”.

The statistics are grim as I am sure you know better than anyone. In 2018 according to the CDC, the autism rate is now 1 in 59 births, 500,000 of these children will enter adulthood in the next decade and roughly 40% will be moderately to severely impaired, like my son. Approximately 424,000 are waiting for services now. The need for adequate residential services is urgent.

This is my son Joey while he resided in the group home waiver houses in the community. In the space of 4 short years, he was discharged by 3 different providers, (6 different group homes) and Section 302'd into 6 different psychiatric wards by the providers, who simply could not manage his challenging behaviors under their community residential business model. At one point, he languished in a psychiatric ward for 6 months, simply because he had no place to go, a now common phenomena for young autistic adults, called “Psychiatric Boarding” – a direct result of Deinstitutionalization. In the group homes, he suffered a broken eye socket, multiple mysterious bruises, was exposed to pornography, slept on a bare mattress in his street clothes, went unbathed for days, was forced on multiple powerful psychotropics (popping a pill is cheaper than providing a stable, therapeutic environment) that made his challenging behaviors worse and left with neurological damage – secondary Parkinsonian tremors in his hands, female breasts, intractable insomnia, excessive weight gain and psychotic breaks with reality.

My son is not an anomaly and he is not alone. The HCBS waiver group housing system has amassed a record of abuse, neglect, injury and death as grim as the psychiatric institutions of a generation before. I have to agree with Dr. David Mandell, ScD. Director of Health the Center for Mental Policy and Services Research at the University of Pennsylvania when he says that small, dispersed settings are often not up to the task of caring for individuals with more profound impairments.” I also agree with Supreme Court Justice Kennedy prophetic words in *Olmstead* “*It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some*

incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.”

That is exactly what happened to my son, he was in need of medical care and treatment and driven into a setting with too little assistance and supervision in the community. Joey was rescued by a public Intermediate Care Facility, a reformed and modernized institution, where he now lives and thrives after a costly battle with state bureaucrats in the Pennsylvania court system to gain admission to the State Developmental Center. My son was never in danger of being “institutionalized”, he was in danger of being “integrated to death.” This is the situation that we, as the autism community, desperately need to prevent for the generation of autistic children coming of age that we love.

The question is why? Why does my son and others like him thrive “in a modern institution” and suffer “in the community.” The word institution has been successfully demonized. When a parent says to me, with self-righteous arrogance “I would never “institutionalize” my child!” I ask them “Would you deny your child medical care? A hospital is an institution. Would you deny your child higher education? A university is an institution.” Olmstead recognized the need for institutional care for some disabled individuals and clearly states “. . . *institutional settings are needed and must remain available.*”

It is a fallacy that individuals residing in modern long-term Intermediate Care Facilities cannot eat what they want, wear what they want or go where they want. My son has all this freedom in his modern ICF and more, he has opportunities to socialize, parties, barbecues, dances, events and outings in the greater community.

It is a fallacy that all disabled individuals can be safely served in “community” settings. There are systemic shortcomings to the HCBS Waiver system for the severely disabled that no amount of money can remediate. ICFs provide superior care to severely autistic individuals because allegedly inclusive settings like small dispersed group houses and apartments can be the most isolated and segregated for all those with challenging behaviors who require more structure and support than can be provided by these environments.

- ICFs must meet rigorous standards to achieve and maintain certification with CMS – Appendix J is 257 pages long. There is no such requirement for HCBS settings.
- ICFs are required to provide **Active Treatment**. There is no such requirement to provide Active Treatment for HCBS waiver houses and they seldom do.
- ICF provide a level of service HCBS waiver services almost universally lack – on-site nursing, clinicians, highly trained staff, behaviorists, supervisors, therapy rooms and pools, nutritional services, developmental training
- ICFs are required to report all critical incidents of abuse and neglect to the state, HCBS providers self-report.
- Frontline caregivers, Direct Support Personnel (DSP) in HCBS waiver group homes are not justly compensated or provided with a supportive, caring team to aide them in handling the daily

emergencies and critical issues presented by behaviorally challenging and medically fragile clients. 2 out of 5 DSP workers leave the job every year and 20% of job vacancies remain unfilled.

All the trauma and injury my son suffered in the "community" waiver system was not cheap. The provider was paid \$369,000 per year and that did not include room and board which is paid by a different agency. The taxpayer and the legislators footed the \$345,000 bill to Section 302 Joey into 6 different psychiatric wards and the additional thousands of dollars for emergency calls from the group home to 911, police intervention, court costs, ambulance transportation to emergency rooms and medical care for staff.

Psychiatrist Christine Montross expressed the situation best when she wrote: *Neither my chronically psychotic nor my mentally disabled patients can safely care for themselves on their own. They deserve the relief modern institutionalization would provide. Naysayers cite the expense as prohibitive. But we are spending far more on escalating prison and court costs and inpatient hospitalizations. More important, we are doing nothing about the chaos and suffering in patients lives.*

Large institutions are less expensive than community residences for challenging populations because there is cost savings in consolidation and they can take advantage of the Economy of Scale. Fewer professionals are needed to treat more patients, and there are more people on the campus to share resources and fixed costs. This is a financial efficiency utilized as a matter of course by private corporations.

No one is seriously suggesting that we go back to the bad old days of Willowbrook, with a 40 residents to 1 staff ratio. Why does society have to lurch from one extreme unworkable system for the disabled (overcrowded, understaffed institutions) to another extreme, unworkable system (scattered, costly dispersed little community houses)?

Why public Intermediate Care Facilities like State Centers? Because public ICF's do not have to make or show a profit. The services cost what they cost. And public ICF's have to serve the challenging individuals that nobody else wants, so they are a valuable safety net for our society.

There is a cruel movement afoot to eliminate all out-of-home residential services for disabled adults. Group homes are now classified as "mini-institutions" and inclusion zealots claim the root of all abuse and neglect is the evil of "paid staff." This elimination movement is paraded as a crusade for disability civil rights and freedom, but when the virtue-signaling smoke is cleared away, society is left with a system of anemic and inadequate "in-home supports" for the family to care for their adult disabled family member until they die and the adult foster care system for those without family. If aging parents do not have the facilities, resources and strength to safely manage big, strong, tantrumming adults who are kicking out van windows, breaking up furniture, detaching their own retinas and eloping into traffic, how will adult foster care families fare any better? Who would willingly sign up for that? So there would be long waiting lists for whatever inadequate services are made available and how will the unserved disabled population live? In Jails? In Psych Wards? On the Streets? Truly, this is a prescription for societal suffering on a massive scale and a return to the Dark Ages.

Why can't we utilize the already donated resources at our fingertips – open the state's reformed public ICF's to admissions! Having the choice of the modern congregate care residential model as well as community services is compassionate, fiscally responsible and the way of the future for the autism community. The United States is great enough and big enough to offer a full range of choices in residential care for the disabled.

Sincerely,

Susan Jennings

Mansfield, Pennsylvania

Mother/Co-guardian of Joey, White Haven State Center

KIIDS – Keeping Individuals with Intellectual Disabilities

Safe www.thekiids.org

Facebook: <https://www.facebook.com/grassrootsKIIDS/>

VOR- A Voice of Reason, Pennsylvania State Coordinator and Board

Member www.vor.net