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The Honorable Jason Rapert, Chair
The Honorable Andy Davis, Chair
Arkansas Legislative Council - Joint Hospital and Medicaid Study Subcommittee
Arkansas State Legislature
Little Rock, Arkansas

Attn: Phil Price, Legislative Assistant to the Subcommittee, philp@blr.arkansas.gov

Dear Chairmen Rapert, Davis and Members of the Subcommittee,

Thank you for your efforts to consider so carefully the life-sustaining value of Arkansas' Human Development Centers. As Medicaid licensed Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID), Human Development Centers are truly your State's safety net for the most medically fragile and vulnerable citizens with intellectual and developmental disabilities (I/DD).

I appreciate very much this opportunity to share the perspective of VOR, a national organization advocating for high quality care and human rights for all people with I/DD.

VOR is the only national, non-profit, non-provider group that supports a full array of residential and support options to meet the vast array of needs of the disabled population. VOR supports quality facility-based care, such as Arkansas' Human Development Centers, *and* community residential options. Arkansas can and should have it both ways to adequately serve all its citizens with I/DD. One size does not fit all.

As shown below, legal, cost and quality arguments provide strong support for maintaining and expanding the role of Human Development Centers.

I. The Law Supports Individual and Family Residential Choice

Central to VOR's advocacy is the highest respect and deference to the individual choice – true person-centered planning – and where necessary, the input of families and legal guardians. Here, where the Subcommittee is considering the value of Arkansas' five Human Development Centers, the proper place to start is with the view of the families.

In the case of Human Development Center residents, the input of families and legal guardians is vital to ensuring good care decisions. Over 83% of the residents have severe (18%) or profound (65%) intellectual disabilities¹ and require the informed help of their families and legal guardians who know them best.

The law agrees. The U.S. Supreme Court expressly supported the importance of family involvement and input in its 1993 *Heller v. Doe* decision, where it stated, “close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person’s abilities and experiences and have valuable insights that should be considered during [placement decisions],” and observed that “allowing guardians and immediate family members to participate as parties in commitment proceedings increases the accuracy of those proceedings and implements the State’s interest in providing family members a voice in the proceedings.”²

Six years after the *Heller* decision, the Supreme Court further reinforced the importance of making placement decisions based on individual need and choice in its landmark *Olmstead* decision.³ In *Olmstead*, the Court *required* individual choice as one prerequisite to imposed community placement, and the further qualified its holding to ensure that its decision would not be used to force deinstitutionalization on any unwilling individual:

“We emphasize that nothing in the Americans with Disabilities Act or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings . . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not deserve it.”⁴

Federal courts have since recognized that individual choice is a key principle of the *Olmstead* decision.⁵

In Arkansas, upon dismissing a federal lawsuit by the U.S. Department of Justice relating to the Conway Human Developmental Center, U.S. District Court Judge J. Leon Holmes noted the sharp contrast between the claims of federal prosecutors and the perspective of the families/guardians:

Most lawsuits are brought by persons who believe their rights have been violated. Not this one....All or nearly all of those residents have parents or guardians who have the

¹ “What Legislators really need to know – Our loved ones depend on you!” Families & Friends of Care Facility Residents (January 2014).

² *Heller v. Doe*, 509 U.S. 312, 329-333 (1993).

³ *Olmstead v. L.C.*, 527 U.S. 581, 587 (1999) at <http://supreme.justia.com/cases/federal/us/527/581/case.html>; see also, *Olmstead Resources* (VOR) at <http://vor.net/olmstead-resources>.

⁴ *Olmstead*, 119 S. Ct. at 2187.

⁵ *Arc of Virginia v. Kaine* (December 17, 2009) (“Thus, the argument made by ARC and the United States [DOJ] regarding risk of institutionalization fails to account for a key principle in the *Olmstead* decision: personal choice. And here, where more residents desire to remain in institutional care than the new facility can provide for, there is little to no risk of institutionalization for those whose needs do not require it and who do not desire it”); and *Ligas, et al. v. Maram, et al.*, 05 C 4331 (N.D. Illinois, July 7, 2009) (denying proposed settlement and decertifying class on finding that the named plaintiffs failed to meet the criteria set forth in *Olmstead* because class definition was not restricted to individuals who were eligible for, and desired, community placement).

power to assert the legal rights of their children or wards. Those parents and guardians, so far as the record shows, oppose the claims of the United States. Thus the United States [Department of Justice] is in the odd position of asserting that certain persons' rights have been and are being violated while those persons – through their parents and guardians disagree.⁶

Appropriately, Judge Holmes deferred to family/guardian support, also citing the residents' individual program plans and a survey of families and guardians in which 97% of respondents were satisfied or very satisfied with the services that their family receive at Conway Human Development Center, to find that residents were being served well in the least restrictive, most integrated placement according to individual needs.⁷

Congress has also spoken. Medicaid law and regulations have long required that beneficiaries be offered a choice between ICF/IID and Home and Community-Based Services (HCBS) services,⁸ and in 2000, Congress codified the individual and family choice requirement in its reauthorization and amendment of the Developmental Disabilities Assistance and Bill of Rights Act, which recognizes that individuals with developmental disabilities and their families are the "primary decisionmakers" of residential services, supports and policies.⁹

The law is clear and the views of Arkansas families, on behalf of their family members with profound developmental disabilities, are well known. They are vocal and effective advocates who are overwhelmingly supportive of the highly specialized, federally-licensed Human Development Center care received by their loved ones. Consistent with federal law, I urge you to begin your analysis with the perspectives of these families.

II. Cost Matters: Invest in Good Care, Invest in the Future

A. Human Development Center Care is Cost-Effective

Arkansas, like all states, must make difficult decisions regarding how to spread around a finite amount of public funding for its citizens with developmental disabilities. Although these decisions may seem complicated in light of competing views on the cost-effectiveness of the various service options, they need not be.

⁶ *U.S. v. Arkansas*, 794 F. Supp. 2d 935 (E.D. Ark. 2011)

⁷ *Id.* at 8.

⁸ *See*, 42 U.S.C. §1396n(c)(2)(C); 42 C.F.R. §441.302; and 42 C.F.R. §441.303 ("The [state] agency must furnish CMS with sufficient information to support the assurances required by §441.302, including . . .(d) A description of the agency's plan for informing eligible recipients of the feasible alternatives available under the waiver and allowing recipients to choose either institutional services or home and community-based services.")

⁹ Developmental Disabilities Assistance and Bill of Rights Act (DD Act) , 42 U.S.C. 15001(c)(3)(1993) (Findings, Purposes and Policies) ("Individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families.") Organizations like the Disability Rights Center of Arkansas and the Arkansas Governor's Developmental Disabilities Council are authorized via the DD Act to receive federal funding.

Common sense dictates if you begin with the premise that the State of Arkansas has no intention of cutting corners and will provide for high quality care based on individual need. **When you scatter highly specialized care, often medical care, around a community, delivering care to these scattered sites is more expensive than providing such care in a single location. That is economy of scale:** A hospital does not treat its patients in their homes because such dispersed care would be cost prohibitive and risky.

Samuel Bagenstos, a former Principal Deputy Assistant Attorney General in the Justice Department's Civil Rights Division and a key litigator in deinstitutionalization cases, recognized this fact in a 2012 law review article. Although he remains a staunch proponent of deinstitutionalization, he acknowledges in his article that the cost gap between facility-based and community-based supports only exists due to *underfunding* community systems, and that this cost gap will shrink, or even reverse, as people in the community receive necessary services.

Although studies of deinstitutionalization have found that people who move from institutions to the community can achieve better outcomes at lower cost, it is reasonable to expect that the cost gap will shrink [or reverse] as people in the community receive more services. This may be especially true because a significant part of the cost gap reflects differences in the wages paid to workers in institutional and community settings.¹⁰

This fact is one that VOR has pressed for our 30 years of advocacy, and one that is supported by peer-reviewed research.

In 2003, lead researcher Kevin Walsh, conducted a literature review of existing studies that compared the cost of care in small versus large residential settings for people intellectual disabilities. His results were peer-reviewed and published in the respected American Association of Intellectual and Developmental Disabilities' professional journal, then-titled *Mental Retardation*.¹¹

Dr. Walsh found that most cost comparison studies were flawed because "apples" were not compared to "apples," and did not account for all costs. Instead, Dr. Walsh wrote that his "[f]indings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified."

Dr. Walsh's study is particularly helpful to state lawmakers who must make informed funding decisions. Good care requires adequate investment. On this point, VOR and Bagenstos agree.

¹⁰ Samuel R. Bagenstos, *The Past and Future of Deinstitutionalization Litigation*, 34 *Cardozo L. Rev.* 1, 43 (2012) at <http://www.cardozolawreview.com/content/34-1/Bagenstos.34.1.pdf>.

¹¹ Kevin Walsh, et al, *Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research*, *Mental Retardation*, Vol. 41, No. 2: 103-122 (April 2003).

B. Investing in the Future: Support Capital Improvements

In the context of cost, Arkansas' five Human Development Centers are in urgent need of upgrades and replacement of buildings, particularly Booneville.¹² These upgrades are a necessary investment.

In 2013, **Wyoming** faced a very similar situation. The Wyoming Life Resource Center, like Arkansas's Human Development Centers, is a Medicaid-licensed ICF/IID that provides residential care and support services to residents with profound disabilities. The Wyoming Department of Health (WDH) was directed by the Legislature to conduct a study of "the most effective and efficient means of providing care to clients of the Wyoming Life Resource Center."¹³ WDH concluded that the Center "provides appropriate and needed care to a group of high-need people in the State of Wyoming," is a "necessary safety net," and expressly recommended against "forced transition of clients from the WLRC." In response to this report, and the State's 2013 State Facilities Plan, the Governor's proposed budget adequately funds the Wyoming Life Resource Center *and seeks capital improvement funds* to address health and safety upgrades due to aging equipment and buildings.

Likewise, several years ago, **Delaware** opted to invest in the future of the state-operated Stockley Center by renovating, not closing, Stockley, and just this past October released a State-Community Partnership Task Force report that recommends maintaining a residential component for people with developmental disabilities, while also repurposing the facility.¹⁴ The future vision allows for greater public use through farmers' markets, mixed use residential and office space, access to the therapeutic pool; and greater service to disabled and low income citizens by establishing a medical residency program. Rita Landgraf, the Secretary of Delaware's Department of Health and Social Services, calls the Stockley Center one of "Delaware's gems" which she wants to share with the public and adamantly will not close.

Finally, a **California** Health and Human Services Agency-created Task Force last month released its proposed "Plan for the Future of Developmental Centers in California."¹⁵ The Task Force, comprised of consumers, family members, workers, and state employees, did not recommend the closure of developmental centers, but instead recommends repurposing these centers, recognizing the ongoing role of the State to operate "safety-net crisis and residential services

¹² Families & Friends of Care Facility Residents, supra note 1 ("Currently, adequate funds for upgrades and replacement of buildings at the five HDCs are urgently needed. Particularly the Booneville HDC is in urgent need of attention.")

¹³ "Wyoming Life Resource Center Study: Final Report," Wyoming Department of Health (November 1, 2013) (in reaching these conclusions, the Department considered community provider capacity, the many years most residents have lived at WLRC, and the strong family support for the care received at WLRC) at <http://www.health.wyo.gov/Media.aspx?mediaId=14664>

¹⁴ "Report and Recommendations of the Stockley Initiative Task Force" (October 15, 2013) at http://dhss.delaware.gov/dhss/admin/files/stockley_finaldraft101513.pdf.

¹⁵ Plan for the Future of Developmental Centers in California, December 2013 at <http://www.chhs.ca.gov/CWCDOC/DC%20Task%20Force%20Plan%20DRAFT%2012-12-13.pdf>

coupled with specialized health care resource centers," secure treatment programs, and public/private partnerships.¹⁶

Arkansas Legislators have the unenviable task of divvying up finite funds for the benefit all deserving Arkansans with developmental disabilities. Just as a hospital will spend more on its ICU patients in comparison to its outpatients, so should Arkansas invest in the cost-effective, high quality supports needed by Human Development Center residents. **Invest in the future of these necessary centers.** Please support for funding for necessary capital renovations for residents, and consider repurposing these Centers to allow for greater access by non-residents.

III. Human Development Centers (ICFs/IID): Unmatched Quality

Adequate investments, no matter the setting, lead to good quality care for the people served. As noted above, Sam Bagenstos acknowledged that the failure to make adequate investments in community-based systems has led to less-than-robust (VOR would argue dangerous) community situations for many individuals who have been forced from facility-based care, or never allowed access in the first place.

VOR has collected an extensive bibliography of 148 investigative media articles, state audits and peer-reviewed studies from 1997 through current, representing 12 national reports and 34 states, detailing *systemic* abuse, neglect and death in over-stressed, under-funded, community settings.¹⁷ Some of the more recent entries are from states that have experienced total deinstitutionalization, such as Oregon, Minnesota, Michigan, Indiana, and the District of Columbia; other entries are from states that have been aggressively downsizing and/or are closing their state-operated centers, such as Georgia, New York, and New Jersey.¹⁸

In March 2013, U.S. Senator Chris Murphy (D-CT) called the situation "alarming" and "not without warning signs" calling on the U.S. Department of Health and Human Services' Office of Inspector General to undertake an immediate investigation into the "alarming number of deaths and cases of abuse of developmentally disabled individuals in group homes," focusing in particular on "prevalence of preventable deaths at privately run group homes across this nation and the widespread privatization of our delivery system."

¹⁶ Consistent with the Families & Friends of Care Facility Residents' request of this Subcommittee, some California Task Force members are also calling for greater transparency in the state's human services policies and programs, as well as for access to outcome data – better information on how people are doing in the aftermath of past developmental center closures in California.

¹⁷ "Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities: Media coverage highlighting the increasing need for more effective federal and state protections in the ever-expanding community system of care for people with intellectual disabilities," VOR (rev. November 2013) at <http://vor.net/images/stories/pdf/AbuseandNeglect.pdf>

¹⁸ Georgia is particularly alarming. Since October 2010, the State has been working to implement a Justice Department-imposed timeline of mental health and developmental disability hospital closures. High mortality rates, along with other alarming incidents of abuse, incarceration, and hospitalizations, have been reported. In September, the Federal Court Independent Reviewer imposed a temporary moratorium on the transfer of individuals with developmental disabilities.

These articles and reports point to a broken system, not anecdotal tragedies, that offer significant lessons learned for states like Arkansas that are considering the value of its Human Development Centers now and in the future.

These lessons learned are reason enough for families to overwhelmingly support continued high quality care at Arkansas Human Development Centers. As the Families & Friends of Care Facility Residents (FF/CFR) shared, HDC services are exceptionally robust and appropriate to the high needs of those being served.¹⁹ As Medicaid licensed ICFs/IID and independently accredited by the Commission on Accreditation of Rehabilitation Facilities, oversight and adherence to high standards and requirements is required and consistent, and highly specialized, high quality care is ensured.²⁰

IV. Conclusion: Doing More with More

Over the past several decades, many high quality ICF/IID homes have been closed and thousands of fragile people with I/DD have been displaced. What began as a well-meaning trend decades ago is now causing great harm to our nation's most disabled citizens. Early justification for deinstitutionalization – hiding away individuals with disabilities for no good reason other than that they were different - is long behind us. Facility *homes* are now federally-licensed and subject to significant oversight to ensure consistently high quality, highly specialized care. Admissions are closed or nearly closed in all states so the resident population is aging and by vast majority has severe or profound intellectual disabilities, with other physical, medical and/or behavioral disabilities.

You will be told about a national trend to close ICFs/IID and urged to follow the crowd. However, **37 states still offer state-operated ICFs/IID.**²¹ That is a significant majority of states that, like Arkansas, see the value in providing an array of service options to meet a spectrum of care needs. Furthermore, as reported above, the increasing reports of abuse, neglect and death in community-settings serving people with developmental disabilities suggest that aggressive deinstitutionalization is unwise and harmful to those affected. Instead, recent reports from Wyoming, Delaware and California, hint at an emerging new trend of states reimagining their Human Development Centers to allow for the continued exceptional residential care and supports that they have long provided to high needs individuals, while also using Centers to bring desperately needed services to people with disabilities and others who are now without.

That's "doing more with more." There are people in need in Arkansas. According to one resource, there are more than 2,000 people in Arkansas waiting for residential services.²² Would some of these individuals benefit from Human Development Center admission? Could some of

¹⁹ Families & Friends of Care Facility Residents, *supra* note 11 (“[S]ervices include residential, habilitation, rehabilitation, medical, dental, prescription drugs, transportation, oversight and monitoring, social work, occupational, physical, and speech therapies, psychology, and community development and outreach services.”)

²⁰ *Id.*

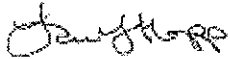
²¹ “Residential Services for Persons with Intellectual and Developmental Disabilities: Status and Trends Through Fiscal Year 2011,” University of Minnesota, Research & Training Center on Community Living, Institute on Community Integration (UCEDD), at page 20 (Table 1.11) (2013) at <http://rtc3.umn.edu/risp/docs/risp2011.pdf>.

²² *Id.* at 45 (Table 2. 5).

these individuals be adequately served in home and community-based settings if they were able to access health care, therapies and other specialized services at Human Development Centers? It makes perfect sense for states to invest in expanded community options,²³ but not at the expense of human development center residents. Eliminating services for the highest need, difficult-to-serve population will create more problems than it solves at a greater cost.

On behalf of VOR's members in Arkansas and across the country, thank you again for your thoughtful and informed consideration of the value of Arkansas' Human Development Centers. I welcome any questions you may have.

Sincerely,



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cc:

**Mr. Darrell Pickney, President, Arkansas Families and Friends of Care Facilities Residents; and
VOR Arkansas State Coordinator**

²³ Arkansas already dedicates 51% of its funding to serves 73% of its population of people with intellectual and developmental disabilities in home and community-based settings ("*The Case for Inclusion*," United Cerebral Palsy (2013) at <http://www.ucp.org/the-case-for-inclusion/2013/>)