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Statement on HB1382

Representative Jack Ladyman has sponsored HB1382, which requires state oversight of Disability Rights Arkansas (DRA), an independent, non-profit organization which receives no state funding. DRA opposes HB1382 for the following reasons:

1. Under this bill DRA will be required to submit biannual reports to the Hospital, Medicaid, and Developmental Disabilities Study Subcommittee of Legislative Council.
    a. DRA does not currently receive state funding. DRA is federally funded to perform our federally mandated duties. While DRA is more than willing to meet with any member of the legislature or other state official to discuss the work we do and the findings of any investigation we conduct, we are mandated by federal law to remain an independent organization.
2. This bill will also require DRA to: "Provide all information requested by the Hospital, Medicaid, and Developmental Disabilities Study Subcommittee of Legislative Council to the Hospital, Medicaid, and Developmental Disabilities Study Subcommittee of Legislative Council at the earliest opportunity but no later than the date designated by the Hospital, Medicaid, and Developmental Disabilities Study Subcommittee of Legislative Council."
    a. "Information" is not defined and thus, there are no parameters to what the subcommittee may request, including information protected under attorney-client privilege or federal privacy laws.
    b. The timeframe in which DRA must fulfil requests is not specified and could lead to unreasonable demands.
3. Members of Families and Friends of Care Facility Residents (FF-CFR) are working closely with Rep. Ladyman to investigate the activities of DRA due to our recent efforts to expose the failures of the state-run large Intermediate Care Facilities (ICFs) or Human Development

Centers (HDCs) to properly investigate abuse and neglect, and to implement policies and procedures that will prevent further abuse and neglect.

a. The FF-CFR are a group largely made up of the guardians of current or previous HDC residents. DRA respects this group of concerned guardians and advocates but feels that they fundamentally do not understand DRA's current goals.

   i. **DRA does not advocate for the closure of all HDCs or institutions.** In 2015, DRA advocated for the closure of Booneville HDC due to excessive use of restraint and the dilapidated condition of some buildings at the HDC at that time. Concluding that a particular facility is so unsafe and resistant to improvement that closure is in the best interest of residents, based on a thorough investigation and extended monitoring, is not the same as indiscriminately calling for the immediate closure of all facilities, as is being alleged. Booneville HDC did not close and is, in fact, currently expanding. Since the 2015 report DRA investigations have identified at least three deaths attributed to neglect, restraint, and medical neglect at Booneville HDC. In recent years, DRA has advocated for better conditions at the HDCs.

   ii. **DRA has never filed legal action against any of the HDCs**, as had been previously stated by the bill sponsor and FF-CFR. The Department of Justice filed legal action against Conway HDC in 2009. DRA had no part in this.

   iii. FF-CFR have publicly expressed concerns that DRA is not respecting guardian wishes, however guardians with concerns about our work have only contacted our agency directly a few times over the last several years. In contrast, **DRA has spoken to many guardians who have alleged maltreatment at the HDCs, which we thoroughly investigate, as federally mandated**. Due to the lack of community supports, most of these residents remain at the HDCs and thus, some guardians we have worked with are hesitant to "speak out against" the HDCs in fear that their children will be removed or retaliated against. DRA is also limited in what we can release due to federal regulations and privacy concerns.

4. DRA's abuse and neglect investigation activities have come under scrutiny by Rep. Ladyman and the FF-CFR. **DRA would like to shed light on some examples of what we are referring to when we talk about abuse and neglect, and the failures of state oversight when this abuse was reported to DHS officials. There are several stories just like this. We conducted 58 investigations into abuse and neglect at the HDCs in the past fiscal year alone. We have received permission from guardians to share the following information.**



a. Above are photos of an HDC resident (Resident 1) who was hospitalized for malnourishment. Resident 1's parent contacted DRA for assistance at the end of 2023. Over the course of a year, Resident 1 lost 44 lbs. Despite being able to walk at baseline, Resident 1 increasingly required the use of a wheelchair due to suffering from frequent falls and lethargy (tiredness). Resident 1 was evaluated by medical professionals who were unable to pinpoint any condition contributing to weight loss. Following Resident 1's return to the facility from the hospital, DRA monitored Resident 1's mealtime and identified several issues: Resident 1's Diet Sheet located in the residence was outdated; Resident 1 was not provided a high sided divided plate as specified in their meal plan; staff rushed Resident 1 through meals, stating, "[Resident 1], I think you are done,"; and, dietary supplements were not served to any of the residents of their unit despite Diet Sheets for 12 residents stating that they should be provided a nutritional supplement at lunch. DRA reported these concerns immediately to the facility's dietician and reported the issues to the Office of Long-Term Care (OLTC) at DHS, the HDCs' oversight agency. Initially, the complaint submitted to OLTC was not investigated. DRA addressed this with OLTC, and the complaint was investigated 5 months after it was filed. By the time OLTC finally investigated the incident the facility had corrected the issues. The OLTC did not implement a corrective action plan addressing these issues. DRA has identified a total of 12 residents at this facility who have suffered from malnutrition, 8 of which were deaths.



b. Above, is a photo of the burns on Resident 2. Resident 2 suffered 2nd degree burns on their thigh and buttocks from hot water while being showered by direct care staff. The direct care staff described getting Resident 2 out of bed that morning and noting that they were covered in bowel movement "from [their] head to [their] feet." The direct care staff described "scrubbing" the bowel movement off in the shower in a witness statement. The direct care staff stated that their hand was in the water constantly during Resident 2's shower, and that the water was "not too hot." Resident 2 was the only client to sustain burns from the water despite a witness stating 15 other residents were bathed that day. The facility conducted an internal investigation and found no maltreatment, citing a hot water mixer malfunction. However, the Investigations & Accidents (I&A) department of the Division of Provider Services and Quality Assurance (DPQSA), found there was mistreatment by the direct care staff and referred them to the maltreatment registry, but this decision was appealed and overturned. The direct care staff was rehired and currently works at the facility. DRA has voiced their concerns to DPQSA, but DRA has no enforcement authority to prevent the staff from working at the facility, or to place the staff on the maltreatment registry. DRA can only advocate for this resident.



c. Above, is a photo of the x-ray of Resident 3's arm. Resident 3 has repeatedly stated that a direct care staff stepped on their arm, breaking it and requiring surgery. According to the direct care staff assigned to Resident 3 at the time, Resident 3 ran into the back hall and fell, causing an open fracture, a fracture where the bone comes through the skin creating an open wound. The direct care staff sat Resident 3 on the bed and called nursing staff. **Nursing staff did not arrive at the residence to evaluate Resident 3 for an hour, despite the severity of the injury.** EMS records obtained by DRA show that the **ambulance was not called for nearly 2 hours following the incident**. Due to the lack of camera footage at the facility, it is impossible to corroborate the direct care staff's account of events. The facility cleared the direct care staff of any abuse despite the allegations of the resident. DRA has tirelessly advocated for more camera coverage in community areas at the HDCs to aid investigations of abuse and neglect by not only our agency, but law enforcement and prosecutorial agencies as well. Resident 3 was removed from the facility by their guardians.

Conclusion

These stories are horrific, but we are not sharing them for shock value. It is important that if the legislature is going to make decisions which could have an impact on our ability to do the work that we do, that they get an unvarnished look at what we see in these facilities. We are not only investigating state-run facilities, we also monitor and conduct investigations into abuse, neglect, and exploitation in private facilities as well as home and community-based settings. We also work all over the state for people with disabilities in ways that have nothing to do with abuse or neglect, such as assisting parents with special education issues, helping people navigate the state's rehab services agency and obtain employment, and working to remove barriers to access across Arkansas.

DRA wants to engage in meaningful communication with policy makers. In the past we have provided information to legislators, DHS staff, and members of the Governor's staff. HB1382 is not just about sharing information on the work we do, it imposes duplicative and vague reporting requirements that would take away time and resources which we could be using to fulfill our mandate of advocating on behalf of all people with disabilities in Arkansas.