

**TESTIMONY  
OF  
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*Arkansas' parent-guardian association***

**March 22, 2012**

**U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON APPROPRIATIONS/  
Subcommittee on Commerce, Justice, Science & Related Agencies**

Re: U.S. Department of Justice/Civil Rights Division's Olmstead and ADA Enforcement

Chairman Wolf and Members of the Committee:

Thank you for the opportunity to testify regarding appropriations for the Department of Justice/Civil Rights Division. The Department is requesting additional personnel of 50 positions and resources of \$5.1 million to strengthen civil rights enforcement efforts that the Attorney General has identified as part of his Vulnerable People Priority Goal. My testimony today is limited to DOJ's activities under CRIPA (Civil Rights of Institutionalized Persons Act) and the ADA (Americans with Disabilities Act), which are included in this program area.

I represent the Arkansas statewide parent-guardian association, Families and Friends of Care Facility Residents ("FF/CFR"), a 501 (c) 3 organization. I am a volunteer advocate. My interest in the appropriations for the U.S. Department of Justice/ Civil Rights Division is that of mother and co-guardian of an adult son, aged 43, whose severe brain injuries occurred at birth. The Civil Rights Division's programs called "Enforcement of the Integration Mandate of the Americans with Disabilities Act (ADA) and Olmstead v. L.C." are aggressive legal actions against states which operate licensed, Medicaid-certified congregate care programs for individuals who have been adjudicated incompetent and whose continuous care is beyond their families' capacities. The Division's mission is to eliminate the option of state-operated congregate care for individuals with disabilities in the misguided notion that the Division knows what is best for my son and other individuals with severe and profound disabilities rather than their legal guardians who have made the residential decisions for their family members.

Our son, a middle aged man, has a medical diagnosis of profound mental retardation and autism. John functions on the level of a toddler. He is basically non-verbal, with occasional echolalia (he may repeat in short words or phrases what another says directly to him) and exhibits pica (an intense desire to consume inedibles). He has a toddler's sense of danger (without close supervision, he might walk into a busy street; and he would not recognize a toxic cleaning product as something harmful to ingest, for example).

John can be frightening to an untrained person. A large mobile man when he is frustrated or experiences discomfort, he might come too close to others, and in a full blown meltdown, he might howl and hit his face and chew on his right wrist. At such times, he is vulnerable to over-

reaction by un-trained, un-supported staff. Our son's care is beyond our family's capacities. All of his life, John and others similarly situated will rely on the humanity of others for health and safety. In particular, they will require residential programs with high standards when there are no living or active family members involved in their lives. For many years our son's safe home has been a state-operated congregate-care, Medicaid-certified intermediate care facility. Through costly litigation and arbitration, The Department of Justice Civil Rights Division is systematically dismantling the residential living facilities for these fragile persons, removing the most defenseless among us from their protected environment without respect for the wishes of guardians and with no clear underlying, peer-reviewed rationale. The Division's actions have caused and continue to cause enormous stress and anxiety for the families and guardians.

Federal tax dollars should not be spent in undermining and dismantling a system of care that is absolutely essential to many persons with disabilities. What is often overlooked, particularly by those in authority who are far away from the daily responsibilities of care and who are not responsible for providing the close care required, is that the population with disabilities involved in the Civil Rights Division's legal actions are extremely difficult to care for and to support, wherever they may live. It is our position (including those like my family who are parents and families of the critically disabled individuals at risk) that congregate care facilities, adequately funded, offer the most suitable settings and programs for a particular group of those suffering from some of the most severe forms of cognitive -developmental disabilities.

#### **Department of Justice/Civil Rights Cases in Arkansas and Similar Cases in the U.S.**

The Department policies, under the mask of "civil rights," were played out in a federal lawsuit in Arkansas (*USA v. State of Arkansas/Conway Human Development Center, Eastern District of Arkansas, Case No. 4:09-cf-00033-JLH (2011)*). The Justice Department began investigating the center in 2003 and spent millions of dollars with about 15 attorneys committed to the case (at trial) after an eight year investigation, and a six weeks federal trial challenging our State over one of its intermediate care facilities, which during the long years of investigation *was at all times in compliance with its federal Medicaid certification regulations*.

Arkansas defended its developmental center, and to our great relief, the substantive DOJ claims were denied and the case was dismissed (June, 2011).

As the parties prepared for trial, Department of Justice filed a second law suit against Arkansas, naming all of the state's licensed facilities, including my son's home, alleging ADA violations. The Department's ADA case against all of the centers was dismissed, and the federal trial by DOJ against the Conway Human Development Center proceeded in early September, 2010. I was a spectator and observer through most of the 6-weeks trial in Little Rock, Arkansas. Not one family from the over 400 Conway center residents supported the Department's claims that their family members' rights were violated; not one medical provider or hospital representative familiar with the center's residents and their complex medical needs testified to support the Department's claims of poor care.

The Court dismissed the Justice Department's lawsuit against the Arkansas Center (June 8, 2011). In an eighty-five page decision, the Court began its findings as follows:

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 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. See Case decision, 1st para., p. 1

In the Arkansas case, Department Of Justice was assessed \$150,585.01 in court costs to be paid to the State, but the Department was not required to pay the over \$4.3 million in attorney's fees and litigation costs Arkansas spent for defending the center. These fees were not reimbursed and they came from several places including the sale of timber on board - owned properties and donations and bequests accumulated in over 50 years to the Conway center for the purpose of enhancing services for the center's vulnerable residents.

States across the nation have been confronted with the Department of Justice's misguided ADA/Olmstead Enforcement policies. The latest example is in the State of Virginia. Simultaneously, with no opportunity for public review, the Department of Justice filed both a Complaint and a Settlement Agreement in January of this year. We know from hard experiences in other states, that the Department of Justice objectives to close state-operated centers are usually not identified clearly in the documentation of an investigation of a case, but the intentions become clearer as implementation of the settlement agreements is carried out. A settlement in Texas, for example, requires the state's centers to undergo additional reviews by DOJ approved court monitors. None of the Texas centers is likely to achieve the goals set by the monitors. In a recent editorial, a Texas newspaper commented that based on its first-hand knowledge of a center, the complex population it serves and the staff, "the demands are not reachable." (Lufkin Daily News, 2/26/2012).

In a settlement agreement with the State of Georgia, which was entered contemporaneously with filing of the lawsuit and without public review, all persons with developmental disabilities in the developmental centers are required to move from their licensed facilities. The Assistant Attorney General for Civil Rights Division described the Georgia Settlement Agreement as a "template for our enforcement efforts across the country." In a teleconference, he described his role in the settlement which included going directly to the Governor of Georgia to press for an agreement rather than costly litigation.

### **Conclusion**

It is not in the public interest for a federally funded entity through power of its office and out of the public view to coerce a state to cease operating programs which have historically proven successful in assuring the health and safety of persons with lifelong, severe cognitive disabilities. It is deeply offensive to me, my family and many others that our federal government through the U.S. Department of Justice is empowered to intimidate state authorities into unfair settlement agreements resulting in closures of our children's safe homes. It is especially egregious that this activity continues when the Department's legal claims have been found so

weak in federal court and the outcomes are so dangerous to the health and safety of the most vulnerable among us.

The Department of Justice does not reference the Arkansas case on its website; however, it does have a document entitled “Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.” This document omits the federal laws which recognize that individuals with developmental disabilities and their families are the primary decision makers in placement choices; it omits the Medicaid rule which provides that eligible persons may choose between home and community based care and institutional care. The DOJ statement presents an incomplete interpretation of the Olmstead decision and ignores critical parts, for example: In the Olmstead majority opinion, Justice Ginsberg wrote that “[w]e recognize....the State’s need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, ....” 527 U.S. 597. The Court further held that “[w]e emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.” 527 U.S. 601.

Justice Kennedy, joined by Justice Breyer, wrote in his concurring opinion, joining the majority of four: “it would be unreasonable, it would be a tragic event, then, were the Americans 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 into settings with too little assistance and supervision. 527 U.S. 610. Justice Kennedy’s prognostic fear is a present day reality.

DOJ should re-examine its programs under Olmstead, which the Department calls an “integration mandate,” and answer for the very serious consequences of its actions. Most important, how many former residents of congregate care facilities have died from preventable causes since being displaced from their ICF/MR (Intermediate Care Facilities for persons with Mental Retardation) - homes? What are the actual facts on quality of care and comparative costs?

### **Request**

The comprehensive and devastating reach of the Civil Rights Division agenda on the most vulnerable among us requires active, vigilant Congressional oversight. We respectfully request this subcommittee’s review and action by: 1) halting the misguided mission of the Civil Rights Division of the Department of Justice, as described above; 2) discontinuing to fund the de-institutionalization programs of the of the Civil Rights Division of the Department of Justice; 3) placing restrictions on the Civil Rights Division’s programs, limiting its funds to bring actions that drive states out of their roles in providing care for our most severely impaired developmentally disabled citizens, all under the mask of “civil rights.”