A.R. v. Dudek – Institution of Medically Complex Children

Florida has been home for approximately three thousand children with severe disabilities who require constant nursing care or supervision on a 24-hour per day basis to stay alive. These disabilities could be the result of a trauma, such as a shaken baby syndrome, near drowning, or an auto accident, or could be a condition with which the child was born. Many of these children have tracheotomies, gastrostomy tubes, or ventilators, and as a result of their conditions, most of these children have degrees of developmental or intellectual disabilities.

At least since 2010, it has been the policy of the State of Florida to rely on the parents and caregivers, including siblings, of these children to provide such life-sustaining nursing care to these children, despite the requirement of Medicaid to pay for as much nursing care as is medically necessary. These parents or caregivers are not medical professionals, yet they are entrusted with life sustaining care of their children. These parents are pushed into the position of placing their child in a nursing facility to obtain the medically-necessary services they could not receive in their own homes. As a result, the State of Florida pushed many of these children into institutionalized settings, such as residential geriatric nursing homes or 12-hour pediatric prescribed extended care centers. Due to their efforts, Florida saved over $ 25 million dollars by denying claims for nursing services for our most fragile children in 2011 to 2012 alone. For those children in foster care, nursing homes is the only option because of the lack of medical foster homes.

Disability Independence Group, Inc., the North Florida Center for Equal Justice, Inc. and the FSU College of Law Public Interest Law Center are representing these children to ensure that these families receive services in the most integrated setting with appropriate and necessary supports and services to allow these kids with disabilities to live at home. In the landmark United States Supreme Court case of *Olmstead v. L.C. ex rel. Zimring*, the Court recognized that the unjustified isolation of individuals with disabilities is discrimination under the Americans with Disabilities Act. In so concluding, the Olmstead Court found that "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." **ALL** children should be with a loving family and are worthy and capable of participating in community life. Unlike one's own family, medical foster home, or even a group home, such

restrictive, medically-based nursing facilities lack required integration with other persons, children, and the community.

This action seeks class-wide injunctive relief and requires the states and their agents to (1) provide all children with disabilities the opportunity to receive services in the most integrated settings; (2) make reasonable modifications to the Defendants' community service system to accommodate the needs of qualified children the opportunity to live in more integrated settings; (3) implement a professionally-adequate screening and assessment process of children in nursing facilities that will accurately identify children with developmental disabilities, including whether they can be appropriately served in the most integrated settings; and (4) for those children who are medically fragile or medically complex, to ensure that they receive adequate nursing care based upon their medical needs and not based on their parents or caretakers schedule, in the most integrated setting.

Every month, our website will update this matter and provide a description of a few of these children and the families that love their kids and care for them. Each of the families have fought for the care that they have and continuously fight for the lives of their kids.