VOR
Speaking out for people with intellectual & developmental disabilities

VOR
Main Office
836 S. Arlington Heights Rd. #351
Elk Grove Village, IL 60007
Toll Free: 877.399.4867
http://www.vor.net

Executive Director
Hugo Dwyer
72 Carmine St.
New York, NY 10014
646.387.2267
hdwyer@vor.net

President
Caroline Lahrmann
2359 Coventry Road
Columbus OH 43221
(614) 359-9323
calnwal@aol.com

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012
410.757.1867
LarryInnis@aol.com

July 26, 2017

Mr. Robert T. Gonzales, Esquire
Chairman
ABA Commission on Disability RIghts
Law Offices of Hylton & Gonzales
201 N. Charles Street, Suite 2200
Baltimore, MD 21201-4126

Dear Mr. Gonzales,

VOR is a national non-profit organization that works to protect high quality care and the human rights of individuals with intellectual and developmental disabilities. As many of our members serve as guardians for their loved ones, we write to express our concerns with the American Bar Association's (ABA) resolution in support of amending guardianship laws to require Supported Decision-Making (SDM) before guardianship.

Supported Decision-Making (SDM) is a controversial and unproven method of supporting individuals with disabilities in making decisions for themselves, and therefore, VOR has serious concerns with its use as an alternative to court ordered and monitored guardianship. It is based on an ideology that presumes that everyone with a disability, without exception, can make decisions for themselves, including those with severe and profound cognitive disabilities or severe behaviors that impede their ability to make rational decisions.

ABA's resolution and report to the House of Delegates speaks of the intrusions of guardianship and regards it only in the pejorative sense of "removing rights." It gives no credit to the vast majority of guardians who are parents, close family members or friends who voluntarily and lovingly take on the responsibilities of guardianship to assure that their loved one's rights are protected.

Lack of protection of person's rights under SDM is evident in an ABA response to a VOR member who attended a recent SDM webinar. ABA Senior Attorney David Godfrey of the Commission on Law and Aging confirmed that there is no oversight with SDM stating, "there is no outside oversight of supported decision-making" and that "a supported decision making arrangement will not spot or prevent abuse or exploitation."

As guardians of individuals with severe and profound needs, we find that SDM is an unacceptable risk to take, especially given that traditional guardianship offers a time-tested solution to protect individuals with intellectual disabilities that includes third-party oversight – the probate court. These protections are further enhanced when guardianship is undertaken by parents and family members guided by their unconditional love and devotion.

The recent case of the disabled British infant, Charlie Gard, (https://www.theguardian.com/uk-news/2017/jul/13/charlie-gards-parents-walk-out-of-court-hearing) should give pause to all involved in the issue of guardianship in our country and across the world. Charlie's case is about the right of parents to make medical decisions for their own children and demonstrates a guardianship system run amok. It is a system that promotes the wishes of detached judges, professional guardians, lawyers, and officials over and above the powerful bond of parental love. This took place in a country that ratified the UN Convention on the Rights of Persons with

Disabilities (CRPD), including Article 12, which has been interpreted to endorse SDM. The ABA House of Delegates passed a resolution urging the U.S. "to ratify and implement" the CRPD. As family members and guardians, we believe the CRPD is tragically flawed in its disregard for parental rights.

Charlie's parents explored every alternative to save their son's life and demonstrated their undying dedication to his best interests. Yet, this was not enough for a court-appointed guardian and a court system determined to end Charlie's life over the objections of his parents before all options had been exhausted. There was no indication that the parents did anything wrong other than to disagree with the medical advice given them by the hospital. The ABA states in its resolution that "guardianship intrudes substantially on a person's liberty, self-determination, and autonomy." One cannot imagine what could possibly be more intrusive than a state-guardian and a court-system set on ending your child's life. It is these type of conflicts VOR members worry about when policies like SDM are given precedence over family bonds.

The draft law supported by the ABA to promote the concept of the "least restrictive alternative" in decision-making is the Uniform Law Commission's *Guardianship, Conservatorship and Other Protected Persons Act.* In this proposed model law, family guardians are given the lowest priority in guardian appointments, behind technology, SDM, state guardians, attorneys and agents. The radical nature of such a proposal is evident by the outpouring of support for Charlie Gard's family from political and religious leaders and citizens in the United States and around the globe.

VOR is deeply concerned that the promotion of SDM is being used to discourage parents and family members from taking on the responsibilities of guardianship and to diminish their role in their intellectually disabled family members' lives. As such, we have attached our comments to ULC's draft law.

We urge you to oppose model law which supplants guardianship with SDM and to stand in favor of the time-tested role of family members as guardians in their vulnerable loved ones' lives.

We look forward to your response.

Sincerely,

Caroline Lahrmann
VOR, President

CC: Ms. Amy Allbright, Director, ABA Commission on Disability Rights