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July 23, 2019

To: Senator Chuck Grassley, Chair, Senate Finance Committee  
Senator Ron Wyden, Ranking Member, Senate Finance Committee  
Senator Pat Toomey, Chair, Health Subcommittee  
Senator Debbie Stabenow, Ranking Member, Health Subcommittee  
All members of the Senate Finance Committee  
Finance Committee Staff Directors and Counsel

Dear Senator Grassley, Senator Wyden, Senator Toomey, Senator Stabenow, Members of the Senate Finance Committee, Staff Directors and Counsel,

VOR is a national non-profit organization comprised of families of individuals with intellectual and developmental disabilities (I/DD). Many of our loved ones are medically fragile, while others are prone to aggressive or self-injurious behaviors. This is an extremely diverse community, with a wide range of needs and aspirations. For 36 years, our organization has advocated for high quality care and human rights for *all* individuals with I/DD. We support a full range of residential service options which include family home, own home, intentional communities, and large and small, public and privately operated Intermediate Care Facilities (ICFs) and Skilled Nursing Facilities.

VOR requests that you consider changes to H.R.3253 - Empowering Beneficiaries, Ensuring Access, and Strengthening Accountability Act of 2019 – to address the concerns of our families and the needs of *all* members of the I/DD community.

H.R. 3253, which recently passed the House, consolidated several bills – a reauthorization of the Money Follows the Person Rebalancing Demonstration Program (MFP), The Excellence in Mental Health demonstration program and the spousal impoverishment program – into one. The new bill was introduced on June 13, 2019, and passed the House on the suspension calendar on June 18, 2019, without any committee deliberation. We believe that these bills should be considered separately. VOR supports several components of this consolidated bill, notably the sections that clarify authority to investigate and prosecute cases of Medicaid patient abuse and neglect in any setting, and the spousal impoverishment program. However, we have serious concerns about the Money Follows the Person provisions in this bill.

For the reasons stated below, **VOR urges you to request an audit of the MFP program and hold hearings before you take action.**

First, MFP funds are designed for a one-year term to cover transitioning services for an individual moving from an institutional setting, in most cases an ICF, to a smaller Home and Community Based Services (HCBS) waiver setting, in most cases a group home. We ask that an audit cover the following matters:

- Has the program been implemented properly? Families have reported that not all of the services promised had been successfully transitioned when the one-year mark for funds had passed.

- Do participants in the program fully understand that they are waiving their rights to a higher level of care, and that some of the services they have received will not “Follow the Person”?
- Are some necessary services dropped after one year because they are not included in the HCBS waiver?
- Have there been any mortality studies, to ensure that the individuals transitioned to this level of care are actually receiving the services and supports they require, or if the HCBS waiver settings have failed to meet the needs of the individuals in their care?

Second, proponents of MFP contend that it “rebalances” the system of services for people with intellectual and developmental disabilities (I/DD) against an institutional bias. This is simply not true. There is no institutional bias in services. Many states have closed their public Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICFs) or have closed them to new admissions and roughly  $\frac{3}{4}$  of federal dollars now go to community settings. If there is a bias, it is an *anti*-institutional bias.

Third, proponents of MFP contend that it promotes choice. But MFP only promotes *one* choice – to move from a congregate care facility like an ICF into a smaller Home and Community-Based (HCBS) waiver setting. If MFP offered true choice, it would support a full range of care options. By only offering one choice, to move from an ICF, this program further erodes the ICF option, which serves the 24-hour around-the-clock needs of people with the most severe I/DD needs.

Fourth, MFP has been used by states to incentivize the closing of ICFs, forcing individuals out of their ICF homes with no regard for the preferences of individuals and their families or guardians. Closing Medicaid-Certified ICFs hurts the most vulnerable, the severely impacted individuals who need the high level of care offered by these facilities.

While the goals of the MFP program may be to help individuals with I/DD, in our members’ experience, it has served to limit options, deny choice, and promote a bias against facilities that offer a higher level of care and oversight. Therefore, before the Senate takes any action to extend and reauthorize the MFP, we urge you to secure an audit of state programs and then hold hearings to hear from the public.

We appreciate your consideration of these concerns,

Hugo Dwyer  
Executive Director, VOR

Darrell Pickney,  
President, VOR

**The following organizations, families and guardians have signed in support of this letter:**

**Organizations**

Association for Individuals with Intellectual Disabilities (New Jersey) - Joanne St. Amand, President  
Bellefontaine Habilitation Center Parents' Association (MO) – Mary Vitale, President  
COFAR (MA) - Colleen M. Lutkevich, Executive Director  
Disability Advocacy Alliance (Ohio) – Caroline Lahrmann, President  
Family and Friends Association of Green Brook Regional Center (New Jersey)  
Family and Friends of the Arizona Training Program In Coolidge (ATPC) – Blinda Mills, President  
Friends of Ann Kiley Center (Illinois) - Henrietta Reder, President  
Friends of Choate (Choate Developmental Center, Anna, Illinois) - Rita Burke, President  
Friends of Wyoming Life Resource Center - Shawn Humberson, President  
Gracewood Family Council, GA - Ann Knighton, President  
Home and School Association of the Southbury Training School (CT) – Martha Dwyer, President  
Homes for Life (Delaware) – Micki Edelsohn, President  
KIIDS - Keeping Individuals with Intellectual Disabilities Safe (PA) – Susan Jennings, President  
Mabley Family Association, Inc. (Illinois) - Barbara Cozzone-Achino, President  
Murray Parents' Association (Warren G. Murray Developmental Center, Centralia, Illinois) – Rita Winkeler, President  
Pinecrest Parents Association (Pinecrest, LA) - Terry Lafleur, President  
PROOF (Parent-Relative Organization of Oakwood Families), Oakwood, KY  
Save NJ Developmental Centers  
The Friends of the Shapiro Developmental Center, Kankakee, IL - Joan Janzon, President  
Autism Pennsylvania Policy Work Group - Dan Torisky, Chair (President Emeritus & Founder, Autism Society of Pittsburgh, Past President, Autism Society of America)  
Parents and Friends of Dorothy Ludeman Center, Park Forest, IL - John Haley, President

**Families and Guardians**

Cynthia J. Allen, Mother and Guardian of Nicholas Aquilino, Woodbine Developmental Center, NJ  
Joanne St. Amand, sister and guardian of Rosemary Sciarrillo  
Marilyn Straw, mother and guardian of Bob Straw  
Marty & Hugo Dwyer, sibling co-guardians of Tom Dwyer  
Terry Lafleur, father and guardian of Jaime Lafleur  
Deborah and Gary Cates, Parents and Conservator of Michael Jameson  
Frank & Lynn Waddy, Parents and Guardian of James Waddy (deceased); Grandparents of Michael Jameson  
Jill Barker, editor and author of The DD News Blog <https://theddnewsblog.blogspot.com/>  
Mother and guardian of two sons with autism, Ian and Danny  
Bill Ryerson – Brother and co-guardian  
Peter Kinzler – Father and co-guardian of Jason Kinzler  
Jane Anthony – Mother and co-guardian of Jason Kinzler  
Harris and Fran Capps, parents and guardians of Matthew Capps  
Jennifer Viox – Twin sister of Matthew Capps  
Daniel Capps – Brother of Matthew Capps  
Randall Laverty, Advocate for persons with Special Needs  
Mary Jane Beck, guardian of brother with I/DD  
Karen House, sister and guardian

Connie Bowen, sister and guardian of Mike Lee  
Sybil Finken, mother and guardian of Seth Finken  
Rebecca Japko, Texas  
Mary Kay Cowen, siser and guardian of Tommy Cowen  
Leonard I. Nieland – Guardian of Jimmy L.