



Toll free
877-399-4867
www.vor.net

Executive Director
Julie M. Huso
836 S. Arlington Heights Rd, #351
Elk Grove Village, IL 60007
605-370-4652 Voice
605-271-0445 Fax
Jhuso@vor.net

Dir. of Govt. Relations & Advocacy
Tarnie Hopp
PO Box 1208
Rapid City, SD 57709
605-399-1624 Voice
605-399-1631 Fax
Thopp@vor.net

Washington, D.C.
Larry Innis
529 Bay Dale Court
Arnold, MD 21012-2312
410-757-1867 Voice/Fax
LarryInnis@aol.com

January 30, 2014

Jeff Rosen, Chairman
National Council on Disability
1331 F Street, NW, Suite 850
Washington, DC 20004

Dear Chairman Rosen,

Over the past few months, the National Council on Disability (NCD) has received communications from over 350 families of individuals with profound intellectual and developmental disabilities (I/DD) from around the country urging NCD to reject **forced** deinstitutionalization and embrace individual choice.

The vast majority of these families have family members with profound I/DD who also experience medical, physical and/or behavioral challenges so extreme that highly specialized, licensed facility-based care is necessary for survival. All of these families support residential choice to accommodate the vast array of human need, from small to facility-based homes.

- **We call on NCD to listen to these families/guardians and represent *all* individuals with I/DD, regardless of where they call home, by adopting a position in support of providing each individual with I/DD all necessary services and supports, based on individual need and choice, regardless of setting.**
- **We call on NCD to expressly reject forced deinstitutionalization.**
- **We call on NCD to include as stakeholders the families/guardians of individuals with profound I/DD – individuals whose lives are directly impacted by NCD actions but who require their families who know them best, to be their advocates and their voice.**

Most individuals with disabilities are capable of determining job opportunities, leisure activities, and housing options, and have the right to exercise individual choice, with any necessary supports. Other individuals experience profound I/DD or other serious I/DD and medical and/or behavioral disabilities and require highly specialized care and the support of their families and legal guardians to ensure that their choices for housing, employment, and services are safe, comfortable and responsive to their needs.

As an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities, NCD has a special responsibility to be accountable to, and represent, *all* citizens with disabilities by adopting policies and positions that are person-centered and reflective of all individual needs and choices. NCD must reject "broad brush," ideologically-motivated positions that apply to most, but not all, individuals and the residential supports they need. An "all or nothing" approach places our most fragile individuals at great risk and compromises NCD's responsibility to advocate for all people with disabilities. As you stated in response to a debate involving the Apache ASL Trails, a housing complex for seniors with hearing disabilities, "we're having a more involved conversation that includes living the way we choose. That's the type of evolution we're talking about, and it is not unique to deaf people." (*New York Times*, April 28, 2013)

The hundreds of families and legal guardians who have written to NCD in support of person-centered living in settings of their choice deserve a response. **Will NCD support choice, reject forced deinstitutionalization, and include families/guardians as stakeholders?** We look forward to your response.

Sincerely,

Ann S. Knighton
President

Jill Barker
First Vice President / Chair, Issues Oversight Committee