

Testimony on H.728
April 2, 2014

My name is Julie Cunningham and I am the Executive Director of Families First, based in Wilmington VT. Families First is a single service agency serving children and adults with developmental disabilities. I am a member of the Vermont Council of Developmental and Mental Health Services which has reviewed and supports the proposed changes to the Developmental Disabilities Act identified in H.728.

Developmental services in Vermont have been under significant pressure over the past several years, and our system is now at a cross roads. Children with disabilities are surviving into adulthood, adults with disabilities are living longer and aging caregivers have their own support needs. From FY2009 through FY2014, the DS system has experienced almost \$14 million in budget cuts and the System of Care funding priorities have been narrowed.

The current priorities are:

- **Health and Safety:** Ongoing, direct supports and/or supervision are needed to prevent imminent risk to the individual's personal health and safety (applies to adults age 18 and over).
- **Public Safety:** Ongoing, direct supports and/or supervision are needed to prevent an adult who poses a risk to public safety from endangering others (applies to adults age 18 and over).
- **Preventing Institutionalization – Nursing Facilities:** Ongoing, direct supports and/or supervision needed to prevent or end institutionalization in nursing facilities when deemed appropriate by Pre-Admission Screening and Resident Review (PASRR) (these are legally mandated services for children and adults).
- **Preventing Institutionalization – Psychiatric Hospitals and ICF/DD:** Ongoing, direct supports and/or supervision needed to prevent or end long term stays in inpatient public or private psychiatric hospitals or end institutionalization in an ICF/DD (applies to children and adults).
- **Employment for High School Graduates:** Ongoing, direct supports and/or supervision needed for a high school graduate to maintain employment upon graduation (applies to graduates age 19 and over).
- **Parenting:** Ongoing, direct supports and/or supervision needed for a parent with developmental disabilities to provide training in parenting skills to help keep a child under the age of 18 at home. Services may not substitute for regular role and expenses of parenting; maximum amount is \$7,800 per person per year (applies to adults age 18 and over).

Six funding priorities have been suspended, eliminated or changed between 2000 to 2010. (see attachment). Comprehensive services for children on the Developmental Services waiver are now only available to prevent institutionalization or children in DCF custody. 298 children and families were receiving comprehensive supports in FY2009 compared to 103 in FY2011. Adults also must be in more dire situations to access services. For example, unless they are a recent

graduate, they are unable to access employment supports unless they also meet the strict criteria for health and safety.

These changes have impacted our ability to ensure that individuals and families receive services that adhere to the DD Act principles such as:

- **Children's services.** Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment. The quality of life of children with developmental disabilities, their families and communities is enhanced by caring for children within their own homes. Children with disabilities benefit by growing up in their own families; families benefit by staying together; and communities benefit from the diversity that is provided when people with varying abilities are included.
- **Adult services.** Adults, regardless of the severity of their disability, can make decisions for themselves, can live in typical homes and can contribute as citizens to the communities where they live.
- **Employment.** The goal of job support is to obtain and maintain paid employment in regular employment settings.

The original version of H.728 added legislative oversight of the system of care plan, including who is served and the services provided. This past summer, there was fast moving potential policy changes to the System of Care which would have allowed the Commissioner to make all future changes as deemed necessary without limits.. Parents from Families First and around the State expressed their disappointment and fears about a system that has been driven by self-determination and civil rights would become a top-down hierarchy. Initially there was only going to be one hearing during the day. After pressure an evening hearing was scheduled but with only 2 sites via VT interactive TV, neither of them being in the south. After further advocacy, this was corrected at the last minute, but it has been extremely challenging for advocates from Brattleboro, Bennington and surrounding towns to have stakeholder input of any kind. This clearly illustrated that their needs to be more safeguards in place that create a forum for information and input. Oversight and transparency are key components in having a healthy system of care for our most vulnerable citizens.

H. 728's changes would help to address the concerns voiced this past summer. It is encouraging that legislators want to understand and improve the processes for developing and changing the System of Care plan. People with intellectual disabilities and their families should have the same safeguards as those offered in other AHS programs.

It is important to note that Developmental Services are happening in the rapidly changing context of health care reform. Long-term care is often invisible or an afterthought in these policy discussions. It is essential that outcome measures are connected to the principles of the Vermont Development Disabilities Act. Quality assurance and improvement would be strengthened by Section 8723, and has the potential to help instruct policy with the Accountable Care Organizations.

Also, since more community support workers are hired by the Developmental Home Provider, not the agency, it has been increasingly difficult to direct outcomes. As an agency, I can ask that the home provider offer training to their staff, but I don't have direct control as they are not my employee. This has been happening more and more around the State and has raised many questions about quality assurance.

Finally, the annual reporting requirements in Section 8723 (g) ensures that reports are grounded in the principles of service, and that they get to legislators needed information in a timely way on unmet needs for this population.

It is unclear how H. 728 will address the further narrowing of funding priorities and budget cuts. A preferred approach would be to have parity with other health conditions funded through the global commitment waiver, without caps. Although this issue is not addressed in the proposed legislation, it raises a critical question. How can we, as a State, best meet the commitments of the DD Act and ensure that people with developmental disabilities receive the quality of services they deserve?

Thank you for your time in taking testimony on this important issue, and your well demonstrated commitment to community based supports for people with disabilities.