

Testimony on H.728
House Human Services

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, which has reviewed the proposed changes to the DD Act identified in H.728.

The developmental services budget has been under significant pressure over the past few years, because of the growing demand for new caseload which has ranged from about \$7.5 million to about \$9.5 million. As a result, 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).

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 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 most significant changes in H.728 are the additions of legislative involvement in the system of care planning process and the removal of the language directing the Commissioner to determine priorities based on funds available. 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 that would have included individual budgets. Budgets are created by following a needs assessment, meeting a system of care funding priority and from months of planning meetings with the individual and their team. 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 were only going to be two meeting sites via VT interactive TV, neither of them being in the south. 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. Oversight and transparency are key components in having a healthy system of care for our most vulnerable citizens.

H. 728 proposes Administrative Rules process for determining 1) the priorities for continuation of existing programs or development of new programs; 2) criteria for receiving services or funding; 3) type of services provided; and 4) a process for evaluating and assessing the success of programs in the State System of Care Plan process. These are all areas for which it is important to assure necessary resources/funding.

This language is critical because in the past inadequate funding has led to : the narrowing of funding priorities; reduced services for people already being served; congregate care and diminished capacity of the designated provider network to meet changing needs.

In Section 8723, strengthening accountability and quality assurance data, 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.

There have been significant staffing cuts to the Designated Agency system over the past 5 years. Increasing quality service staff without corresponding ability of agencies to implement internal quality assurances will not produce new results.

It is unclear how H.728 will ensure adequate funds to prevent 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 directly 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 necessary services based on a reasonable criteria?

Finally, we also recommend that future changes to the system of care plan and funding are made on a timely bases to avoid mid-year rescissions, whenever possible.

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.