



## Vermont Developmental Disabilities Council

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TO: House Human Services Committee (Rep. Pugh, Chair; Rep. Haas, Vice Chair; Rep. Donahue, Ranking Member; Rep. Batchelor; Rep. Burditt; Rep. Frank; Rep. French; Rep. Krowinski, Clerk; Rep. McFaun; Rep. Mrowicki; and Rep. Trieber.)

FROM: Karen Schwartz, Executive Director

RE: Developmental Services System of Care ~ Why we need H.728 ~ Update

DATE: February 19, 2014

Thank you for your invitation to speak about House Bill H.728 and the developmental services system of care.

My experience with the system of care stems from my work with VTDDC starting in 2004, and as a parent who has benefitted from services for my son who is now a young man. I would say that we grew with the system, adding services and supports as needs changed and my son hit transition points. I would be glad to share more of those experiences with you when it makes sense.

I have come to know and admire the Vermont Developmental Disabilities Act. It starts off at §8721 with an admirable purpose:

It is the policy of the state of Vermont that each citizen with a developmental disability shall have the following opportunities:

- (1) To live in a safe environment with respect and dignity.
- (2) To live with family or in a home of his or her choice.
- (3) To make choices which affect his or her life.
- (4) To attend neighborhood schools, be employed and participate in activities, to the extent that this purpose is not construed to alter or extend rights or responsibilities of federal laws relating to special education.
- (5) To have access to the community support and services that are available to other citizens.

It lays out individual and family-centered Principles of Service at Section 8724 that support choice and self-determination. (See Page 4.)

It also assures individual and family input through an advisory council at §8733 and sets, as the number one duty of the Department of Disabilities, Aging & Independent Living, the duty to:

carry out all functions, powers and duties . . . by collaborating and consulting with people with developmental disabilities, their families, guardians, community resources, organizations and people who provide services throughout the state.

The Act set up Vermont's community-based system of care when Brandon Training School closed, and it served the State and its citizens well in its first decade or so. However, since 2000 the landscape has shifted, with challenges that were not anticipated twenty years ago. Demographic trends show more people entering the system each year, with more children surviving with complex disabilities, people living longer, and aging parent-caregivers developing their own support needs. Health care reform is challenging us to consider

developmental services as part of an increasingly complex service delivery system that in Vermont includes Choices for Care and Medicaid SIM Grant initiatives. In sum, after almost 20 years the Act is entering adulthood and some targeted changes are needed to address current realities.

### 1. Section 8725 System of Care Plan ~ Increase input and oversight of policymaking

As you have heard, the Act sets up a unique way to describe services and set policy. Rather than going through Rulemaking, the core is the System of Care Plan, written every 3 years. At §8725 the Act currently requires that:

(b) Each plan shall be based upon information obtained from people with developmental disabilities, their families, guardians and people who provide the services and shall include a comprehensive needs assessment, demographic information about people with developmental disabilities, information about existing services used by individuals and their families, characteristics of unserved and under served individuals and populations and the reasons for these gaps in service and the varying community needs and resources. The commissioner shall determine the priorities of the plan based on funds available to the department.

Over time this has been interpreted to provide authority for DAIL to set “funding priorities” i.e. to set out in the Plan which eligible people can receive funding for community-based services. The Plan also sets which services the system will provide, and at what level.

As budgets have become tighter and waiting lists for services grow this broad authority has resulted in a number of actions taken without legislative oversight, including:

1. Narrowing and eliminating funding “priorities”, for example ending services to eligible children unless they have had psychiatric hospitalizations, or to adults to prevent regression of adults and job loss. [See sample suspended priorities at page 5 and list at page 6
2. Eliminating flexible goods budgets
3. Capping the combination of community and job supports at 25 hours
4. Providing services in congregate day settings
5. Providing “wrap” services, in which a shared living provider also controls the budget for community, work and respite supports with minimal oversight.

Individuals with disabilities and family members provided moving testimony this summer on a recent proposed change to the Plan that would allow the Commissioner to make all future changes. They described a crisis-driven system that prioritizes funding over all, and has shifted away from its core values and focus on individuals and families.

### **H.728 proposes to re-balance the system of care. Revisions at §8725 changes would:**

- ⇒ **Identify key policy items in the Plan that trigger increased oversight via the Administrative Procedure Act, including statement of impact on people; opportunities for stakeholder input; and review based on §8724 Principles of Service**
- ⇒ **Clarify that priorities must be based on needs assessment, including unmet needs, before considering available resources.**
- ⇒ **For the first time describe the process for annual updates**
- ⇒ **Specify the deadline; committees of jurisdiction; and contents for the Annual Report which has been skipped and late in recent years (avoiding sunset under 2 V.S.A. 20).**

## 2. Section 8723 ~ Strengthening Accountability and Quality Assurance Duties

Over the last ten years quality assurance efforts in developmental services have lagged despite the budget climbing to \$170 million and an increase in the number of people served. In addition, there have been increasing calls for results based accountability, by both the Centers for Medicaid and Medicare and the Vermont Legislature, and in health care reform efforts. Based on available data,

- Quality assurance staff for the developmental service system decreased from 12 to 5
- Individual reviews have decreased to 24 per agency every 2 years i.e. once in 20 years unless there is a crisis
- State inspects a shared living home only when the first person moves in, or there is a change in use

### **The Bill proposes to strengthen accountability at §8723 by**

- ⇒ **Adding proactive requirement to monitor services state-wide**
- ⇒ **Specifying fiscal oversight and state contracting**
- ⇒ **Expanding quality assurance and linking to the Principles of Service**

## 3. Additional changes to consider, so that the Act is consistent with federal and state law.

As Vermont moves forward to use respectful language to describe people in all of its legislation, Act updates are needed to ensure that people with developmental disabilities are treated with the dignity and respect that is their right. Specifically:

- ⇒ At § 8721 add that equal opportunity is a matter of right, consistent with the federal Developmental Disabilities Act, in which Congress found that: "...disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities" [42 U.S.C. § 15001].
- ⇒ Remove references to "available" resources and funds in §§ 87223 and 8725 that are assumed for any program funded.

We appreciate the support you have shown over the years. The work is not done, and we ask that you consider these carefully crafted updates to the Act so that we can continue to make progress on welcoming Vermonters with developmental disabilities as part of our communities.

Thank you.

### RESOURCE LINKS

- 18 VSA 8721 On-line <http://www.leg.state.vt.us/statutes/sections.cfm?Title=18&Chapter=204A>
- System of Care Plan <http://www.ddas.vermont.gov/ddas-programs/programs-dds/socp-2014-update>



## ... AND TODAY



Adults make decisions for themselves



Adults can live in typical homes



Adults contribute as citizens in the communities in which they live

## Principles of Service 18 V.S.A. § 8724, *abbreviated*

**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 in the communities in which they live.

**Children's services.** Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment.

**Individualized support.** To be effective and efficient, services must be individualized to the capacities, needs, and values of each individual.

**Full information.** People with developmental disabilities and their families need complete information about the availability, choices, and costs of services, how the decision making process works, and how to participate in that process.

**Family support.** Effective family support services shall be designed and provided with respect and responsiveness to the unique needs, strengths, and cultural values of each family and the family's expertise regarding its own needs.

**Meaningful choices.** Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values, and needs and assure that each recipient is directly involved in decisions that affect their life.

**Community participation.** When people with disabilities are segregated from community life, all Vermonters are diminished.

**Employment.** The goal of job support is to obtain and maintain paid employment in regular employment settings.

**Health and safety.** The safety and health of people with developmental disabilities is of paramount concern.

**Accessibility.** Services must be geographically available.

**Trained staff.** All individuals who provide services to people with developmental disabilities and their families must receive training as required by § 8731 of this title.

**Fiscal integrity.** The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities.

To learn more about the Campaign,  
please contact the  
VT Developmental Disabilities Council:



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## NEW CASELOAD FUNDING

### Health & Safety

- ☞ Support needed to prevent an adult from being abused, neglected or exploited, or otherwise having his or her health and safety jeopardized.
- ☞ Support needed to prevent an adult or child from regressing mentally or physically<sup>5</sup>. **12/01/01 SUSPENDED**

### Security

- ☞ Support needed to keep a child under 18 with his or her natural or adoptive family. Services may not replace the regular role and expenses of parenting (e.g., childcare, transportation, household bills, etc.).<sup>6</sup> **12/01/01 SUSPENDED**<sup>7</sup>
- ☞ Support needed for parents with developmental disabilities to provide training in parenting skills to help keep a child under 18 at home. Services may not substitute for the parent and may not replace the regular role and expenses of parenting (e.g., childcare, transportation, household bills, etc.).  
**12/01/01 LIMIT TO 2 HOURS/WEEK SERVICES COORDINATION OR \$5,000/YEAR**
- ☞ Support needed to prevent an adult from becoming homeless.
- ☞ Support needed by an adult who is experiencing the death or loss of a caregiver<sup>8</sup>.
- ☞ Support needed to prevent or end institutionalization (i.e., VSH, psychiatric hospitals, ICF/MRs, nursing homes) or residential school placements.  
**12/01/01 SUSPEND NURSING HOMES FOR MEDICALLY ELIGIBLE & RESIDENTIAL SCHOOLS**

### Independence

- ☞ Support needed to keep a person from losing a job. **12/01/01 SUSPENDED**
- ☞ Support needed to assist an adult to be independent from DDS-funded services, or to move to "minimal services," within 2 years. **12/01/01 SUSPENDED**

### Legally Mandated Services & Community Safety

- ☞ Support needed by an adult who has been committed to the custody of the Commissioner of DDMHS pursuant to Act 248.
- ☞ Support needed to prevent an adult who poses a risk of public safety from endangering others<sup>9</sup>.
- ☞ Support needed by a person in a nursing home for specialized services or community placement under the requirements of federal law (i.e., OBRA '87).

<sup>5</sup> This includes equipment and modifications that may be needed to prevent an adult or child from regressing. This is not intended to substitute for other responsible public services (e.g., public education, child welfare, health insurance, etc.)

<sup>6</sup> Services can cover extraordinary costs as a result of the child's developmental disability.

<sup>7</sup> Families are eligible for Flexible Family Funding in accordance with the *Flexible Family Funding Program Guidelines*.

<sup>8</sup> Caregiver means an unpaid or minimally paid (e.g., a residential care home) caregiver.

<sup>9</sup> Based upon past known behavior (e.g., arrested for serious offense, substantiated sexual abuse, under restraining order because of dangerous conduct, etc.). Not intended to substitute for or replace Corrections supervision for people who have committed and been convicted of a crime.

## Developmental Services System of Care ~ Changes to Funding Priorities 2000 to 2010

The following funding priorities have been suspended, eliminated, or changed:

- Support to prevent an adult or child from regressing mentally or physically (suspended 2002; eliminated 2005)
- Support to keep a child under 18 with his or her natural or adoptive family (suspended 2002; eliminated 2005)
- Support to assist an adult to be independent from DD-funded services, or to move to “minimal services’ within 2 years (suspended 2002; eliminated 2005)
- Support for a young adult aging out of SRS custody who is eligible for and requires ongoing services (eliminated 2003)
- Support to keep a person from losing a job (suspended 2002; limited to “support needed for a high school graduate to maintain paid employment” in 2005; changed qualifying age from 18 to 19 in 2006.)
- Prevent risk to health or safety (changed qualifying age from 18 to 19 in 2006)

**FROM Developmental Disabilities Services ~ FACT SHEET #2, To Help Inform System of Care Planning Input ~ Funding DAIL, Division of Disabilities & Aging Services (2010)**