



Vermont Developmental Disabilities Council

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TO: Senate Health and Welfare Committee (Sen. Ayer, Chair; Sen. Lyons, Vice Chair; Sen. Pollina, Clerk; Sen. McCormack; and Sen. Cummings)

FROM: Karen Schwartz, Executive Director

RE: Developmental Services System of Care ~ H.728

DATE: April 17, 2014

Thank you for this opportunity to testify and to submit written comments about H.728 and alternative proposals. I speak as a parent with a son who is served by the system, as well as for a coalition of organizations that try to help individuals with developmental disabilities and family members have a voice.

First, I would like to clarify what people are seeking. We are not seeking an opportunity for more input at the Department of Disabilities, Aging & Independent Living [DAIL]. What we are seeking is a more formal structure for input that goes beyond the Department, and sets up an external check and balance so that there is increased oversight of decision-making about who gets served and the services that are provided.

The original Bill at §8725 went a long way towards achieving increased external oversight through:

- ⇒ Identifying key policy items in the System of Care Plan that trigger Rulemaking
Rulemaking safeguards include a statement of reasons and impact on people, multiple points to give input, and final review and hearing at LCAR that would be guided by the Principles of Service.
- ⇒ For the first time, describing the process and timeline for annual updates.

Over time Vermont's Developmental Disabilities Act has been interpreted to allow broad discretion by the Department to make policy decisions without legislative oversight, including:

1. Narrowing and eliminating funding "priorities". Examples are ending services to eligible children unless they have psychiatric hospitalizations, or to adults to prevent regression of adults and job loss. Page 4.
2. Creating a public safety category of people.
3. Capping the combination of community and job supports at 25 hour.
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.

Once priorities are eliminated they basically evaporate. Currently data on the unmet needs they represent is not collected, and those unmet needs are not included in the annual reporting.

The current process for changing the System of Care Plan is not guided by regulations or formal policy. It is determined solely by the Department, and the Plan can and has been changed at any time. An example is the suspension of funding priorities that went into effect on December 1, 2001, a scant five months after the 2002-4 System Care Plan went into effect. (See page 3.) Part of the negative reaction of individuals and families this past summer was to a change to the Plan that appeared to allow for future changes to be made within the Department without any process at all.

With all due respect, the proposal to present the new 3 year Plan and the Task Force results to the Health Care Oversight Committee for hearing does not address ongoing structural problems in how policy decisions are made.

H.728 as passed by the House was a compromise, intended to cut through the current lack of legislative review and oversight by:

- ⇒ For the first time, including legislators, to lead a time-limited group, with Legislative Council support.
- ⇒ Targeting its charge to include issues NOT covered by other groups or studies.
 - (1) How AHS programs – like Reach-up -- prioritize which eligible people are served.
 - (2) What the legislature’s participation should be.
- ⇒ Identifying the key items not in the current Annual Report to present to committees of jurisdiction, including the extent to which the principles of service have been met, and unmet needs.

In closing I ask that you review the original Bill that provides for Rulemaking, and also take a look at Version 2.2, which sets out a two-step process for setting priorities and looking at available resources. That version also clarified the needs assessment requirement for development of the System of Care Plan that has not been followed in recent cycles.

Thank you for your consideration.

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>
- H.728 Version 2.2
<http://www2.leg.state.vt.us/CommitteeDocs/House%20Human%20Services/Bills/H.728/Bills,%20Amendments%20and%20Summaries/2-19-2014~Katie%20McLinn~H.728~French%20Draft%20No.%202.2,%202-19-2014.pdf>

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 physically⁵. **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.).⁶ **12/01/01 SUSPENDED**⁷
- ☞ 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 caregiver⁸.
- ☞ 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 others⁹.
- ☞ 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).

⁵ 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.)

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

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

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

⁹ 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)