



Vermont Developmental Disabilities Council

Mailing Address
103 S. Main St.
Waterbury, VT 05671-0206

Phone 802-828-1310
Toll Free 888-317-2006
FAX 802-828-1321
vtddc@state.vt.us
www.ddc.vermont.gov

Temporarily Located at 322 Industrial Lane Berlin VT

TO: Camille George, Director, DEVELOPMENTAL DISABILITIES SERVICES DIVISION

FROM: Karen Schwartz, Executive Director, with Kirsten Murphy, Policy Analyst & Planner

DATE: May 30, 2014

RE: Comments on System of Care Plan 2015-2017

Thank you for the opportunity to provide a response to the DRAFT System of Care Plan for FY 2015 – FY 2017 [Plan].

On behalf of the Vermont Council on Developmental Disabilities [VTDDC], we would like to commend the Developmental Disabilities Services Division [Division] on its efforts to expand sections of the Plan so that it can serve as a useful guide for people. In particular, revisions to *Section Two, Eligibility* will help to make this process more understandable. The suggestions in this memorandum reflect this same desire to make our complex system of care for individuals with Intellectual and Developmental Disabilities [I/DD] accessible and transparent, and to move towards the Rulemaking process for parts of the Plan, as required by H.728.

The System of Care Plan is a unique feature of our state's developmental services system that has evolved to provide (1) Set of funding guidelines to describe the scope of available supports for people with developmental disabilities and their families, both in terms of who will receive services and what types of services will be funded; (2) a system-wide improvement Plan, based on input from local agencies and groups like Green Mountain Self Advocates about their concerns and priorities; and (3) a description of existing agency and Division practices. As such, it is the one point of information that can help "people with developmental disabilities, their families, advocates, services providers, and policy makers understand how resources for individuals with developmental disabilities and their families are managed."¹ [Plan at page 3.]

In these comments we are conveying some over-arching concerns that we look forward to working on with you, along with a chart to help pinpoint and clarify specifics.

1. **Intake and eligibility:** While the description of the process is improved, there is still a lack of clarity about the process; what is available to those not meeting priorities, or funded "in part); and due process appeal rights. Also, although service management options are covered, the menu of services is not presented as part of the application process. (List set out in Attachment D.)
 2. **Choice, Autonomy and Independence:** Despite citing of the new Center for Medicare and Medicaid Rules, and input from self-advocates through the Consumer Survey and GMSA, there is little the Plan that directly fosters autonomy and independence, or promotes self and family-management.
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3. **Funding Priorities:** The new language providing for services for young adults is laudable. As detailed below, language changes could assure individuals and families that there are supports to help people get jobs, and also to make transition smoother by making decisions in advance of leaving school.

Of continuing concerns is that no rationale is set out for the priorities. While there was outreach, the Plan lacks an adequate objective needs assessment, and there was no apparent consideration of demographic trends, like aging parents, or the rise in autism incidence (to 1 in 68 i.e. 1.47%). Related to that, the waiting list section does not include details or adequately describe the State's responsibility.

The priorities continue to be predominantly crisis-driven. Yet the Plan does little to address crisis service needs outlined in local plans, and the Vermont Crisis Intervention Network is not described and its funding explained.

The priorities continue to confuse the doorway into services with access to specific services. It is not accurate to state that it is "only necessary to meet one", since services like home supports are not available under some priorities, and no wait list is kept about specific services requested. (See Intake on menu of services.)

Given the nature of intellectual disabilities, requiring psychiatric institutionalization for **children and youth** is no longer appropriate, and has caused inequities across the state. It is time to re-examine and re-define what is required for children to demonstrate the need for institutional level of care.

It is also important to restore language in the last Plan that described the continuing legal rights and safeguards for children and youth.

While changes have improved information on how funding committees work, concerns have not been addressed about using a public safety category for people who have not been adjudicated as committing an offense.

4. **Services and Supports:** While the Plan tackles a range of services under Funding Guidance, core concerns about current services and supports that include failure to meet or comply with the Developmental Disabilities Act Principles of Service, including:
- 25 hour cap on community and job support hour, which shifts burden to "respite" managed by families and shared living for bulk of care, without adequate oversight
 - Increase in congregate day services
 - Rise in "wrap services", which are not described.
 - Lack of state-wide standards or oversight of shared living providers and homes.
 - Lack of use of self & family-management option (Rewrite of Manual at Section 6 insufficient.)

The Plan's descriptions of services for eligible children, youth and adults who either do not meet a priority or only meet one "in part" are scattered; there is no clear mechanism that ensures that resources will be equitably distributed to people and families across the state, including Targeted Case Management

⇒ Targeted Case Management

⇒ Flexible Family Funding

⇒ Bridge Case Management Funding, which is mandatory EPSDT service that should not be capped

⇒ Family-managed respite for children and youth, which is a very welcome step, is not described

Also, while family support is mentioned, new language is stark in appearing to mandate family involvement, and the Plan does not include concrete help for families:

- Help for aging parents that was dropped after Fy2008-10 Plan, despite demographics
- There is no support for family peer organization.

5. **Quality Assurance and Improvement:** New initiative to do individual sampling is a positive step. However recent quality issues are glossed over, including the challenge of providing oversight to services increasingly based on independent contracts.
6. **Funding Types and Streams:** While efforts were made to better describe various developmental service funds and other funding resource streams, there remains a lack of clear descriptions of what the various funds are; how they are allocated; who they are managed by; and when they are available to meet people's needs. That includes base funding, returned and "reallocated" funding; new caseload, and its allocation between people already receiving services and new people; and special and specialized service funds.)

Please see attached chart for details.

Thank you for your consideration.

2015-17 System of Care Plan ~ VTDDC Specific Comments

Positive	Pages	Area of Concern
OVERARCHING		
Effort to explain more, including <ul style="list-style-type: none"> ○ Intake ○ Eligibility 	Section 2 Page 7-	Still lack of clarity about intake and eligibility process <ul style="list-style-type: none"> ⇒ If do not meet priority, or meet “in part ⇒ Appeal rights ⇒ Explaining menu of services, not just service management options (list in Attachment D)
Inclusion CMS Rule language on choice, access to community, etc.	Section One at page 2; Section 6 at page 52.	Despite CMS Rule and new language <ul style="list-style-type: none"> ⇒ Choice narrowed by wording change from provider to SSA. Section 4B at page 36. ⇒ Other than transportation plan and using public transit, no specifics to address limited autonomy reflected in Consumer & other surveys. E.g. Access to phone, computer, house key, etc. Does not adequately address making lack of use of self and family-management, making a more viable option. [Section 6 action to create manual inadequate.]
Effort to reorganize information on funding, other resources.	Section 3 A at page 15- et seq. Section 3B at page 19 Section 3C at page 22, page 26 Section 4B at page 35	Lack of adequate explanation of what funds are available to meet people’s needs and how funds work <ul style="list-style-type: none"> ⇒ Continuing confusion base, and split between new people and new ⇒ One-time funds ⇒ Returned caseload ⇒ Reallocating caseload ⇒ Special Funds ⇒ Specialized Services
	Section 2D; Section 3A at page 13;	Due process rights not explained. <ul style="list-style-type: none"> ⇒ Deleted from Section 3A Funding Authority Overview. Lost where moved, to 4B page 35 ⇒ Minimal information is provided on page 11 about decisions.
New quality assurance item reviews individual samples	Section 3B at page 16 Section 6 at 6.3e to g	Plan does not directly and adequately address quality assurance. Examples <ul style="list-style-type: none"> ⇒ Section 6 systems development item focuses on format and filing of critical incident reports, and not analyzing them to improve how services are delivered. ⇒ Recent quality issues glossed over. Example is provisional status of one agency.

FUNDING PRIORITY ISSUES		
Employment Priority & Community Support Conversion	Section 3B Page 30 Section 3E Page 27	New priority for young adults, Transition & Waivers ⇒ For those out of school without waiver, what help will they have to get job to trigger “priority”? ⇒ Language change appears to exacerbate situation voiced by families that not knowing about services until leave school causes anxiety, etc. Support Conversion unclear – Weren’t all agencies required to help people get jobs already? Need more information on what the barriers have been, including the impact of recent cuts, and how many are expected to be helped by conversion as a percentage of the total who could be working.
Budget to consider trends Section 3B at 16	Section 3B Page 30 Section 4 D Page 42	No rationale for priorities; reflect Inadequate needs assessment reflecting demographics and recent trends. Examples ⇒ Do not address aging parents, caregivers ⇒ Autism figures are not based on most recent CDC estimated prevalence of 1 in 68 (1.47%). Waiting list not adequately explained, or State’s role related to list. ⇒ Wait list has no specificity about services people waiting for Example is people whose needs re “met in part”. Example is living at home with aging parents who need housing, but there is no crisis. ⇒ Agency notice that someone is on wait list has no link to decision of denial of
	Section 3B Pages 29-30	Priorities remain confusing. ⇒ Door in, or trigger to certain services? ⇒ Not accurate to say “only necessary to meet one”, because some do not give access to full range of services. ⇒ Needs link to application, list of what services can tap (Attachment) ⇒ <i>** Priority for children remains prevention psychiatric institutionalization. Does not recognize current realities.</i> ⇒ <i>Key statement that addressed rights of children and youth has been deleted.</i>
	Section 3B	Issues about Public Safety as category not tackled. ⇒ Use of legal term “evidence” at page 20 number 4.e. is misleading ; implies adjudication ⇒ Item Number 4.f. dense and confusing; inappropriate to use “offense” for actions not adjudicated.
	Attachment H	Priorities remain crisis-driven, yet crisis issues inadequately addressed. ➤ Need for more crisis beds raised in 4 local plans, but not addressed ➤ Information lacking on VT Crisis Intervention Network and how it is funded. ➤ The actions taken in previous System Development Plan did not solve the identified problem.

SPECIFIC SERVICE ISSUES		
	Section 3C at pages 25 Section 4B at page 36 Section 4D, page 42 on wait list	Does not address or inadequate explanation about what is available for people not served by waive; how resources will be equitably distributed across the state; and relation to wait list <ul style="list-style-type: none"> ⇒ Targeted Case Management ⇒ Flexible Family Funding ⇒ Bridge Case Management Funding, which is mandatory Early Periodic Screening, Diagnosis and Treatment [EPSDT] service, which should not be capped People whose “needs are met in part” i.e. on wait list for some services.
Section 2C Page 9 Clarifies that shared living providers is an agency, not shared management option.	Section 3C; 4B; etc.	Does not address concerns about service “models” <ul style="list-style-type: none"> ➤ Cap on hours – Shifts burden to ”respite” managed by families and shared living for bulk of care, without adequate oversight ➤ Does not address increase in congregate day services ➤ Does not explain or address rise in “wrap services” ➤ Lack of state-wide standards, oversight of shared living providers and homes. ➤ Lack of use of self & family-management option – Section 6 rewrite of Manual not adequate responses
Family support	Section 3 Page 13	While mentioned, no concrete help for families <ul style="list-style-type: none"> ⇒ Help to aging parents was dropped from System Development Plan , although still identified as a need. ⇒ No support for family peer organization ⇒ New language is stark in appearing to mandate family involvement, vs. supportive.
Family Managed Respite	Section 3C Page 25	Lack of information on how to access, who qualifies, whether family is responsible for finding provider and if the provider is an employee of the family or of the designated agency.
Children’s Services -- expand and clarify	Section 3 Pages24-25	<ul style="list-style-type: none"> ⇒ How is Bridge Program different from Targeted Case Management [TCM]? ⇒ Integrated Family Services [IFS] is confusing: Which regions have/will have IFS? What can families request if their region does not have IFS? NB: Local System of Care Plans cite need for more information about IFS (e.g. Rutland). ⇒ Funding priority #4: children with I/DD are poorly served in psychiatric hospitals and emphasis must be on prevention.

OTHER		
Reworked section on funding committees; added Transition II for self/family management	Section 3B Page 17-20	Funding Committee structure still loose <ul style="list-style-type: none"> ➤ Numbers are not specified, majority ➤ Appointment of individuals and families is not open, objective process. Page 18 ➤ No individual, family on Public Safety Page 19
	Section 3C Section 4 B Especially 34-40	Organization, lack of groupings and explanation of content, create lack of clarity about services and supports <ul style="list-style-type: none"> ⇒ Section 3C Other Resources mixes Medicaid State Plan services, waiver-funded items; and non-waiver services without clearly differentiating. ⇒ Other categories of funding that are administered by the Designated Agencies: Children’s Personal Care, High Tech Home Care, EPSDT therapeutic services including Applied Behavior Analysis, and the Vermont Crisis Intervention Network. ⇒ Care coordination for kids (Bridge or TCM) cannot be capped, per EPSDT. ⇒ Section 4B 3 Administrative Guidance has 14 items by alphabet letter ⇒ Section 4B 4 Limitations on Funding has 12 items by alphabet letter.
	Section 3 C Page 41	Section on options when “budget pressures” is skewed towards region and agency-specific solutions and agency needs, rather than state-wide equity for people.
	Section 6 Page 51	Systems Development Plan [SDP] – Predominantly focused on department tasks to get done. ** Does not meet basic tenets of Results Based Accountability [RBA] – to focus on quality of life: whether people are “better off”. Ideas ** Does not appear to be tied to “Special Initiatives”; only 2 of 6 are included in the SDP. ** Four of seven goals are not based on the Plan Development process but rather are taken directly for the AHS strategic plan. <ul style="list-style-type: none"> ⇒ Increase in hours worked – voiced in Consumer Survey etc. ⇒ Increase in use Self-Family Management ⇒ Analyze data from critical incident reports to improve quality of care (not just reduce!)
Revisions needed	Attachment H	Activity #5 is misleading: (1) Despite \$90,000 investment (action taken), did not achieve goal for increasing Board Certified Behavior Analysts as many left Vermont after training, per recent testimony in House Health Care Committee. (2) VTDDC grant to VFN is not designated for autism-related information.