

### STATE OF VERMONT JOINT FISCAL OFFICE

#### **MEMORANDUM**

To:

James Reardon, Commissioner of Finance & Management

From:

Nathan Lavery, Fiscal Analyst

Date:

December 19, 2008

Subject:

JFO #2352, #2353, #2354, #2355, #2356, #2357, #2360, #2361, #2362,

#2363, #2364, #2365, #2366

At the December 19, 2008 meeting of the Joint Fiscal Committee, the following grant requests were approved:

JFO #2352 — \$807,500 grant from the U.S. Department of Health and Human Services to the Vermont Agency of Human Services - Department of Health.

**JFO** #2353 — \$9,000 grant from the U.S. Environmental Protection Agency to the Agency of Natural Resource – Environmental Conservation.

**JFO** #2354 — \$161,407 grant from the U.S. Department of Justice to the Department of Corrections.

JFO #2355 — \$20,000 grant from the State Justice Institute to the Judiciary – Vermont Supreme Court.

**JFO** #2356 — \$333,002 grant from the U.S. Department of Justice to the Judiciary — Court Administrator's Office.

JFO #2357 — \$212,408 grant from the U.S. Department of Justice to the Judiciary – Court Administrator's Office.

JFO #2360 — \$2,000,000 grant from Substance Abuse and Mental Health Services Administration to the Agency of Human Services – Department of Mental Health.

**JFO** #2361 — \$21,000 grant from the State Justice Institute to the Judiciary.

JFO #2362 — \$32,125 grant from the U.S. Department of Education to the Vermont Department of Education.

JFO #2363 — \$166,160 grant from the Center for Applied and Special Technology to the Vermont Department of Education.

JFO #2364 — \$12,000 grant from the National Governor's Association to the Agency of Human Services – Department of Children and Families. This grant was approved with the understanding that expenditure of the \$9,885 in state funds, as originally proposed, was no longer considered necessary and would not occur.

JFO #2365 — \$19,140 donation from the Vermont Veterinary Medical Association (VVMA) to the Agency of Agriculture, Food and Markets.

JFO #2366 — \$500,000 grant from the U.S. Department of Homeland Security to the Agency of Transportation – Department of Motor Vehicles.

In accordance with 32 V.S.A. §5, these grants were placed on the Joint Fiscal Committee agenda and subsequently approved by vote of the Committee. We ask that you inform the Secretary of Administration and your staff of this action.

cc: Robert Hofmann, Secretary
Wendy Davis, Commissioner
Michael Hartman, Commissioner
Stephen Dale, Commissioner
Andrew Pallito, Acting Commissioner
Armando Vilaseca, Commissioner
Lee Suskin, Court Administrator
Roger Allbee, Secretary
David Dill, Secretary
Bonnie Rutledge, Commissioner
George Crombie, Secretary
Laura Pelosi, Commissioner



#### MEMORANDUM

To:

Joint Fiscal Committee Members

From:

Nathan Lavery, Fiscal Analyst

Date:

November 26, 2008

Subject:

**Grant Request** 

Enclosed please find one (1) request which the Joint Fiscal Office recently received from the Administration:

JFO #2352 — \$807,500 grant from the U.S. Department of Health and Human Services to the Vermont Agency of Human Services - Department of Health. These grant funds will be used to improve access to quality, comprehensive, coordinated community-based systems of services for children and youths with special health care needs. [JFO received 12/24/08]

The Joint Fiscal Office has reviewed this submission and determined that all appropriate forms bearing the necessary approvals are in order.

In accordance with the procedures for processing such requests, we ask you to review the enclosed and notify the Joint Fiscal Office (Nathan Lavery at 802/828-1488; <a href="mailto:nlavery@leg.state.vt.us">nlavery@leg.state.vt.us</a> or Stephen Klein at 802/828-5769; <a href="mailto:sklein@leg.state.vt.us">sklein@leg.state.vt.us</a>) if you have questions or would like this item held for Joint Fiscal Committee review. Unless we hear from you to the contrary by <a href="mailto:December 10">December 10</a> we will assume that you agree to consider as final the Governor's acceptance of this request.

cc: James Reardon, Commissioner Robert Hoffman, Secretary PHONE: (802) 828-2295

FAX: (802) 828-2483



#### MEMORANDUM

To:

Representative Steven Maier

From:

Nathan Lavery

Date:

November 26, 2008

Subject:

JFO #2352 (Services for children with special health care needs)

Representatives Michael Obuchowski and Shap Smith asked that I forward to you a copy of the enclosed request and cover memo. They are requesting you provide them with your observations regarding the enclosed item.

cc: Rep. Michael Obuchowski

Rep. Shap Smith Stephen Klein



State of Vermont

Department of Finance & Management 109 State Street, Pavilion Building Montpelier, VT 05620-0401

Agency of Administration

[phone] 802-828-2376 [fax] 802-828-2428

F	INANCE				/ERMO Γ GRANT		EW FORM		
Grant Summary:			The Vermont Department of Health would like to accept a grant from the U.S. Department of Health and Human Services (Health Resources and Services Administration) for developing integrated community systems for children and youth with special health care needs.						
Date:	10/22/2008								
Department:		Health Department							
Legal Title of Grant:		State Implementation Grants for Integrated Community Systems for CSHCN							
Federal Catalog #:	6 D70MC09835-01-01 Award Number D70MC09835 Grant No								
Grant/Donor Name and Address:		U.S. Department of Health and Human Services, Health Resources and Services Administration, Rockville, MD							
Grant Period: From:		06/01/2008 <b>To:</b> 05/31/201		11 Grant	1 Grant Issue Date: 9/24/2008				
Grant/Donation		300,000/per year for 3 years			3 years				
Grant/Donation		SFY 1	00/ pcr	SFY 2			SFY 3	Comments	
Grant Amount:		07,500		\$300,00			\$300,000		
Position Information:	# Posi				/Comment	ts			
Additional Comments:		)			-				
Additional Comments.									
Department of Finance & M	<b>Janageme</b>	nt				R	1) 30/25/101	nitial)	
Secretary of Administration				RPN	10/28/08 (I	nitial)			
Sent To Joint Fiscal Office	AU					11/	) <u> 0 28 08</u> (I 4 08 <b>D</b>	ate	

RECEIVED



NOV 24 2008



**Agency of Human Services** 103 South Main Street Waterbury, VT 05671-3711

Agency of Human Services

Business Office

103 South Main Street
Waterbury, VT 05671-0204
[phone] 802-241-2949
[fax] 802-241-1200

#### **MEMORANDUM**

TO:

**Grant Reviewers** 

FROM: Jim Giffin, AHS CFO

DATE: September 30, 2008

RE: Vermont Department of Health HRSA Grant Award

VDH intends to assign existing staff to manage this grant. Therefore no new positions are requested in the AA-1. We anticipate no program impact for the reassigned staff since this work complements their existing work and work necessary within AHS to continue to streamline, quantify, and coordinate children's services across AHS.

They prorated the PS estimate for SFY09 as follows:

Salaries:

90,000/2 equals 45,000

Fringe: 31,500/2 equals 15,750

Indirects:

54,000/2 equals 27,000

Contracts:

10,000

Total:

45,000 + 15,750 + 27,000 + 10,000 = 97,750



#### FORM AA-1 (Rev. 11-05)

#### STATE OF VERMONT REQUEST FOR GRANT ACCEPTANCE

1. Agency:

**Human Services** 

2. Department:

Health

3. Program:

MCH-CSHN

- 4. Legal Title of Grant: State Implementation Grants for Integrated Community Systems for Children and Youth with Special Health Care Needs
- 5. Federal Catalog No.: 93.110
- 6. Grantor and Office Address: Health Resources and Services Administration, Rockville MD

7. Grant Period:

From: 6/1/08

To: 5/31/11

- 8. Purpose of Grant: To implement the President's New Freedom Initiative by improving access to quality, comprehensive, coordinated community-based systems of services for CYSHCN and their families that are family-centered, community-based and culturally competent. (see attached summary)
- 9. Impact of Existing Programs if Grant is not Accepted: None

10. Budget Information	(1st State FY) FY 2009	(2nd State FY) FY 2010	(3rd State FY) FY 2011
EXPENDITURES:			
Personal Services	\$ 97,750	\$185,500	\$185,500
Operating Expenses	\$ 4,750	\$ 9,500	\$ 9,500
Other (Grants)	\$105,000	\$105,000	\$105,000
TOTAL	\$207,500	\$300,000	\$300,000
REVENUES:			
State Funds:			
Cash	\$	\$	\$ \$
In-Kind	\$ \$	\$ \$	\$
Federal Funds:			
(Direct Costs)	\$180,500	\$257,400	\$257,400
(Statewide Indirect)		\$ 1,704	\$ 1,704
(Dept. Indirect)	\$ 26,148	\$ 52,296	\$ 52,296
Other funds:			
(source)	<u>\$</u>	\$	\$
TOTAL	\$207,500	\$300,000	\$300,000

Grant will be allocated to these appropriation expenditure accounts:

Appropriation Nos.	<u>Amounts</u>
3420010000	\$ 27,000
3420021000	\$180,500

[ ] Approved (not placed on Agenda in 30 days)

(Signature)

(Date)

[ ] Approved by JFC [ ] Rejected by JFC

[ ] Approved by Legislature

#### Request for Grant Acceptance Maternal Child Health – CSHN Summary July 29, 2008

The Department of Health was one of only eleven state organizations to be granted \$300,000 annually for three years to implement the *President's New Freedom Initiative (NFI)* from the Health Resources and Services Administration.

The Department proposes to transform the existing system of care for CYSHCN in Vermont into one that (1) serves the true population of children and families in need, (2) assures access to services that reflect evidence based, culturally effective practice, (3) supports a delivery system in which primary care services, including early and continuous developmental screening, are provided in accordance with the Bright Futures Guidelines for Health Supervision of Infants, Children and Adolescents (Third Edition, 2007) in Medical Homes with appropriate and effective linkages to the system of specialty care, (4) provides adequate and affordable health insurance, (5) operates within a community-based, coordinated, integrated system of care and (6) supports youth as they transition to adulthood.

Funds would be used for two main purposes:

- Personnel costs, including a Project Coordinator and approximately sixty
  percent of the work time of a Statistician. The Project Coordinator will be
  responsible for the day-to-day operations of the grant and will report directly
  to Steve Brooks, Vermont CSHN Director of Operations. The Statistician will
  augment the existing collaboration with BIN to support the goals of the
  CYSHCN Systems Integration grant.
- 2. To engage our community partners, especially *Vermont Child Health Improvement Program* (\$50,000) to provide technical assistance and evaluation, *Parent to Parent and the Vermont Parent Information Center* (\$55,000) to provide Needs Assessment, Family Collaboration and Parent Co-Coordinator through grants, and a *Third Party Consultation* (\$10,000) that will aid us in developing a Vermont specific gap assessment and to develop, in tandem with the central payors in Vermont to develop a model coverage plan and protocol.

The Health Department is hereby requesting acceptance of the \$207,500 in new Federal funds during State Fiscal Year 2009. A copy of the grant award document, the complete grant application, and the revised budget are attached. Continued Federal funding for this project will be included in future budget requests.

1. DATE ISSUED: 09/24/2008

2. PROGRAM CFDA: 93.110

3. SUPERCEDES AWARD NOTICE dated: 05/23/2008

ept that any additions or restrictions previously imposed remain in effect unless specifically rescinded

4a. AWARD NO.: 6 D70MC09835-01-01 D70MC09835

4b. GRANT NO.: 5. FORMER GRANT NO.:

6. PROJECT PERIOD:

FROM: 06/01/2008 THROUGH: 05/31/2011

7. BUDGET PERIOD:

FROM: 06/01/2008 THROUGH: 05/31/2011

DEPARTMENT OF HEALTH AND HUMAN SERVICES HEALTH RESOURCES AND SERVICES ADMINISTRATION



NOTICE OF GRANT AWARD AUTHORIZATION (Legislation/Regulation) Social Security Act, Title V, 42 U.S.C. 701 Social Security Act, Title V

Title V, Section 502 (a)(1) of the Social Security Act, as amended Social Security Act § 501(a)(2-3), 42 U.S.C. § 701(a)(2-3) Section 501(a)(2) of the Social Security Act

#### 9. GRANTEE NAME AND ADDRESS:

VERMONT STATE DEPARTMENT OF HEALTH

108 Cherry Street

Burlington, VT 05402-0070

10. DIRECTOR: (PROGRAM DIRECTOR/PRINCIPAL INVESTIGATOR)

Wendy Davis

VERMONT STATE DEPARTMENT OF HEALTH

108 Cherry St

#### 11. APPROVED BUDGET: (Excludes Direct Assistance)

[X] Grant Funds Only

[] Total project costs including grant funds and all other financial participation

a. Salaries and Wages:	\$ 90,000.00
b. Fringe Benefits:	\$ 31,500.00
c. Total Personnel Costs:	\$ 121,500.00
d. Consultant Costs:	\$ 0.00
e. Equipment:	\$ 0.00
f. Supplies:	\$ 1,100.00

f. Supplies: g. Travel: \$8,400.00 h. Construction/Alteration and Renovation: \$ 0.00 \$ 0.00 i. Other:

j. Consortium/Contractual Costs: \$ 115,000.00 k. Trainee Related Expenses: \$ 0.00

I. Trainee Stipends: \$ 0.00 m. Trainee Tuition and Fees: \$ 0.00 \$ 0.00 n. Trainee Travel:

o. TOTAL DIRECT COSTS: \$ 246,000.00 p. INDIRECT COSTS: (Rate: % of S&W/TADC) \$ 54,000.00

q. TOTAL APPROVED BUDGET: \$ 300,000.00 i. Less Non-Federal Resources: \$ 0.00

Burlington , VT 05401-4295 12. AWARD COMPUTATION FOR FINANCIAL ASSISTANCE

a. Authorized Financial Assistance This Period \$ 300,000.00

b. Less Unobligated Balance from Prior Budget Periods

i. Additional Authority \$ 0.00 \$ 0.00 ii Offset c. Unawarded Balance of Current Year's Funds \$ 0.00

d. Less Cumulative Prior Award(s) This Budget

e. AMOUNT OF FINANCIAL ASSISTANCE THIS **ACTION** 

\$ 300,000.00 \$ 0.00

#### 13. RECOMMENDED FUTURE SUPPORT: (Subject to the availability of funds and satisfactory progress of project)

YEAR TOTAL COSTS Not Applicable

#### 14. APPROVED DIRECT ASSISTANCE BUDGET: (In lieu of cash)

a. Amount of Direct Assistance \$ 0.00 b. Less Unawarded Balance of Current Year's \$ 0.00 Funds \$ 0.00 c. Less Cumulative Prior Awards(s) This Budget

d. AMOUNT OF DIRECT ASSISTANCE THIS ACTION

\$ 0.00

15, PROGRAM INCOME SUBJECT TO 45 CFR Part 74.24 OR 45 CFR 92.25 SHALL BE USED IN ACCORD WITH ONE OF THE FOLLOWING **ALTERNATIVES:** 

\$ 300,000.00

A=Addition B=Deduction C=Cost Sharing or Matching D=Other

Estimated Program Income: \$ 0.00

ii. Federal Share:

[A]

#### 16. THIS AWARD IS BASED ON AN APPLICATION SUBMITTED TO, AND AS APPROVED BY HRSA, IS ON THE ABOVE TITLED PROJECT AND IS SUBJECT TO THE TERMS AND CONDITIONS INCORPORATED EITHER DIRECTLY OR BY REFERENCE IN THE FOLLOWING:

a. The grant program legislation cited above. b. The grant program regulation cited above. c. This award notice including terms and conditions, if any, noted below under REMARKS. d. 45 CFR Part 74 or 45 CFR Part 92 as applicable. In the event there are conflicting or otherwise inconsistent policies applicable to the grant, the above order of precedence shall prevail. Acceptance of the grant terms and conditions is acknowledged by the grantee when funds are drawn or otherwise obtained from the grant payment system.

REMARKS: (Other Terms and Conditions Attached [X] Yes [] No )

Electronically signed by Theda Duvall, Grants Management Officer on: 09/24/2008

<b>17. OBJ. CLASS:</b> 41.51 <b>18. CRS-EIN:</b> 1036000274A8			19. FUT	19. FUTURE RECOMMENDED FUNDING:				
FY-CAN	CFDA	DOCUMENT	NO.	AMT. FIN. ASST.	AMT. DIR. ASST.	SUBPROGRAM CODE		
08-3894150	93.110	D70MC0983	5A0	\$ 0.00	\$ 0.00	N/A		

Page 2 Date Issued: 09/24/2008
Award Number: 6 D70MC09835-01-01

#### HRSA Electronic Handbooks (EHBs) Registration Requirements

The Project Director of the grant (listed on this NGA) and the Authorizing Official of the grantee organization are required to register (if not already registered) within HRSA's Electronic Handbooks (EHBs). Registration within HRSA EHBs is required only once for each user for each organization they represent. To complete the registration quickly and efficiently we recommend that you note the 10-digit grant number from box 4b of this NGA. After you have completed the initial registration steps (i.e., created an individual account and associated it with the correct grantee organization record), be sure to add this grant to your portfolio. This registration in HRSA EHBs is required for submission of noncompeting continuation applications. In addition, you can also use HRSA EHBs to perform other activities such as updating addresses, updating email addresses and submitting certain deliverables electronically. Visit https://grants.hrsa.gov/webexternal/login.asp to use the system. Additional help is available online and/or from the HRSA Call Center at 1-877-464-4772.

#### **Terms and Conditions**

Failure to comply with the special remarks and condition(s) may result in a draw down restriction being placed on your Payment Management System account or denial of future funding.

#### **Grant Specific Terms:**

1. This revised Notice of Grant Award (NGA) accepts and approves the documentation sent via email 9/10/2008 regarding the condition of award; submission of revised budgets for all three years. The condition has been removed.

All prior terms and conditions remain in effect unless specifically removed.

#### Contacts:

Program Contact: For assistance on programmatic issues, please contact Lynda Honberg at:

HRSA/MCHB/DSCSHN

5600 Fishers Ln

Rockville, MD 20852-1750 Phone: (301)443-6314

Email: lhonberg@hrsa.gov

Division of Grants Management Operations: For assistance on grants administration issues, please contact Tammy

Jeffs at:

HRSA/OFAM/DGMO 5600 Fishers Ln Rockville, MD 20852-1750

Phone: (301)443-5419 Email: tjeffs@hrsa.gov Fax: (301)443-6686

Responses to reporting requirements, conditions, and requests for post award amendments must be mailed to the attention of the Office of Grants Management contact indicated above. All correspondence should include the Federal grant number (item 4 on the award document) and program title (item 8 on the award document). Failure to follow this quidance will result in a delay in responding to your request.

# <u>Vermont Department of Health Integrated Systems Grant for CYSHCN</u> <u>Budget Justification February 2008</u> Year One

Personnel \$ 90,000.00

Beth Cheng Tolmie, MSW, Ed.D. SIG Project Coordinator

FTE 100%

\$ 60,835.00

Dr. Tolmie acts as full-time coordinator for the grant. Beth's skills in organizational change and human services systems integration benefit the assessment, planning and implementation phases related to the integrated systems grant for CYSHCN. She will work internally and with external stakeholders to further plans for best addressing the three core outcomes associated with the grant: medical home; health insurance and financing; and community integrated services. With a Masters in Social Work, Beth is skilled in strengths based practices with children, individuals and families. Dr. Tolmie's term of service will be for the entire grant period.

Neil Augiar

BIN Coordinator / Statistician

FTE 60%

\$ 29,165.00

The CSHN program proposes to augment its existing collaboration with the Birth Information Network (BIN) to support the goals of the CYSHCN Systems Integration grant. The plan is to (1) expand the number of conditions we identify beyond birth defects to include other conditions within the broad definition of special healthcare needs and (2) expand from the focus on infants to include children and youth. These changes will result in an enhanced identification of children and youth with actual or potential special health care needs and will enable more thoroughly coordinated systems of care. In addition, BIN will create a system enabling the identification of the Medicaid participants who use the VDH CSHN programs. By accessing Medicaid claims data and, using certain pre-selected claims codes, the BIN will identify potential CYSHCN who may need follow up for resource referral or care management, and will issue regular reports for use by the CSHN program staff in follow-up up with families.

Neil is a Public Health Analyst III, Pay Grade 25. He will devote approximately .6FTE to this effort. In addition, other VDH Health Surveillance staff will contribute data retrieval and evaluation time.

Fringe Benefits: \$ 31,500.00

Fringe benefits are calculated at the standard percentage applied to all VDH staff at 35% of salary. Fringe benefits cover health insurance, life insurance, the retirement plan, taxes, and the dental plan.

Indirect Charges: \$ 54,000.00

We have applied the Cost Allocation formula to direct salary costs that is used across the Agency of Human Services. That is 60%. We have attached a July 12, 2007 letter from Robert Aaronson, Director, Division of Cost Allocation, Department of Health & Human Services, to Cynthia LaWare, Secretary of the Vermont Agency of Human Services, authorizing the agency to use its cost allocation formula to determine indirect costs.

#### Non Personnel

Travel: \$ 8,400.00

Travel costs reflect in-state travel for staff and families who will participate in this initiative. We anticipate twelve family advisory meetings in year one, with eight families in attendance at each meeting. Families will receive a modest stipend to help defray costs attributable to participation.

In-State Travel: \$ 6,691.50

Advisory meetings in the 12 regional areas of the state. Stipend Rate of \$50.00 per family will be paid for attendance at regional meetings x 8 families x 12 regions \$4,800.00

In addition, project staff will travel to statewide meetings, with primary and specialty care practices and other entities whose work is relevant to the project. In-state travel is based upon the current rate of \$.485/mile. We anticipate 3900 miles in year one. \$ 1,891.50

Out-of-State Travel:

\$ 1,708.50

Travel for project coordinator participation at year-one Grantee Meeting. Location TBD.

**Supplies:** \$ 1,100.00

Supplies to be purchased are strictly non-medical and consist of paper, pens, flip-charts, markers, other administrative and meeting supplies. As we move into the project, we will produce educational materials for families, advisory groups, and healthcare providers.

<u>Contractual:</u> \$115,000.00

We will enter into three contractual agreements as follows:

#### 1. Technical Assistance and Evaluation

\$ 50,000.00

<u>Vermont Child health Improvement Program (VCHIP)</u>, an affiliate of the University of Vermont and the College of Medicine. VCHIP has submitted its own documentation of capacity and qualification to participate.

#### 2. Needs Assessment, Family Collaboration

\$ 55,000.00

Parent to Parent of Vermont (P2P) and the Vermont Parent Information Center (VPIC). Vermont's Family Voices and Parent Information resource Center (PIRC) designees, respectively. These two long-standing partners with VDH/CSHN will work with us to bring families and family voices into every aspect of our work. In addition, we plan to have P2P provide a part-time parent co-coordinator for the project. This will clearly stamp our effort as family-centered. **Note**: effective July 1, 2008, P2P and VPIC will merge into a new entity, the Vermont Family Network (VFN), and will work with us through the remainder of the grant period. Our contract will reflect that change.

#### 3. Third Party Payer Consultation

\$ 10,000.00

<u>To be named</u>. In years one and two we will contract with a consultant to investigate in-state and national third-party coverage for special health care needs...through both public and private payors. This consultation will aid us in developing a Vermont-specific gap assessment and to develop, in tandem with the central payors in Vermont, to develop a model coverage plan and protocol. Contract will comply with all relevant administrative requirements for monitoring and evaluation.

Page 2 Date Issued: 05/23/2008
Award Number: 1 D70MC09835-01-00

#### HRSA Electronic Handbooks (EHBs) Registration Requirements

The Project Director of the grant (listed on this NGA) and the Authorizing Official of the grantee organization are required to register (if not already registered) within HRSA's Electronic Handbooks (EHBs). Registration within HRSA EHBs is required only once for each user for each organization they represent. To complete the registration quickly and efficiently we recommend that you note the 10-digit grant number from box 4b of this NGA. After you have completed the initial registration steps (i.e., created an individual account and associated it with the correct grantee organization record), be sure to add this grant to your portfolio. This registration in HRSA EHBs is required for submission of noncompeting continuation applications. In addition, you can also use HRSA EHBs to perform other activities such as updating addresses, updating email addresses and submitting certain deliverables electronically. Visit https://grants.hrsa.gov/webexternal/login.asp to use the system. Additional help is available online and/or from the HRSA Call Center at 1-877-464-4772.

#### **Terms and Conditions**

Failure to comply with the special remarks and condition(s) may result in a draw down restriction being placed on your Payment Management System account or denial of future funding.

#### **Grant Conditions:**

 Due Date: Within 30 days of Award Issue Date Submit a revised completed SF424A budget form for Year One the current 2008-2009 budget period; and the respective line item budget justification. In addition, submit separate budgets for the two and three years.

The budget narrative should explain the amounts requested for each line in the budget (i.e., personnel, fringe benefits, staff travel, equipment, supplies, contracts, other expenses). In particular, provide detailed justifications for all consultant, contract, and travel costs, providing name of consultants and hourly rates, clear descriptions of contractual costs, and detailed break-outs of all travel costs (number of trips, destination, cost per trip, etc.). The budget narrative must clearly describe each cost element and explain how each cost contributes to meeting the project's objectives/goals. Please show how each item in the "other" category is justified.

#### **Program Terms:**

1. On a regularly scheduled basis, HRSA grantees are required during their project period to participate in a performance review of their HRSA funded program(s) by a review team from HRSA's Office of Performance Review. If your organization has been selected for a performance review, you will be contacted at least twelve weeks before your performance review begins in order to provide you with additional information about the scope and process for your review, and to schedule the dates for the on-site phase. Upon completion of the performance review, grantees are expected to prepare an Action Plan that identifies key actions to improve program performance as well as addresses any identified program requirement issues.

#### Standard Terms:

1. All discretionary awards issued by HRSA on or after October 1, 2006, are subject to the HHS Grants Policy Statement (HHS GPS) unless otherwise noted in the Notice of Award (NoA). Parts I through III of the HHS GPS are currently available at ftp://ftp.hrsa.gov/grants/hhsgrantspolicystatement.pdf and it is anticipated that Part IV, HRSA program-specific guidance will be available at the website in the near future. In addition, HRSA-specific contacts will be appended to Part III of the GPS which identifies Department-wide points of contact.

Please note that the Terms and Conditions explicitly noted in the award and the HHS GPS are in effect. Once available, Part IV, HRSA program-specific guidance will take precedence over Parts I and II in situations where there are conflicting or otherwise inconsistent policies.

Page 3 | Date Issued: 05/23/2008 |
Award Number: 1 D70MC09835-01-00

2. The HHS Appropriations Act requires that when issuing statements, press releases, requests for proposals, bid solicitations, and other documents describing projects or programs funded in whole or in part with Federal money, all grantees receiving Federal funds, including but not limited to State and local governments, shall clearly state the percentage of the total costs of the program or project which will be financed with Federal money, the dollar amount of Federal funds for the project or program, and percentage and a dollar amount of the total costs of the project or program that will be financed by nongovernmental sources.

- 3. Recipients and sub-recipients of Federal funds are subject to the strictures of the Medicare and Medicaid anti-kickback statute (42 U.S.C. 1320a 7b(b) and should be cognizant of the risk of criminal and administrative liability under this statute, specifically under 42 U.S.C. 1320 7b(b) Illegal remunerations which states, in part, that whoever knowingly and willfully:
  - (A) Solicits or receives (or offers or pays) any remuneration (including kickback, bribe, or rebate) directly or indirectly, overtly or covertly, in cash or in kind, in return for referring (or to induce such person to refer) an individual to a person for the furnishing or arranging for the furnishing of any item or service, OR
  - (B) In return for purchasing, leasing, ordering, or recommending purchasing, leasing, or ordering, or to purchase, lease, or order, any goods, facility, services, or item
  - ....For which payment may be made in whole or in part under subchapter XIII of this chapter or a State health care program, shall be guilty of a felony and upon conviction thereof, shall be fined not more than \$25,000 or imprisoned for not more than five years, or both.
- 4. The HHS Appropriations Act requires that to the greatest extent practicable, all equipment and products purchased with funds made available under this award should be American-made.
- 5. Items that require prior approval from the awarding office as indicated in 45 CFR Part 74.25 [Note: 74.25 (d) HRSA has not waived cost-related or administrative prior approvals for recipients unless specifically stated on this Notice of Grant Award] or 45 CFR Part 92.30 must be submitted in writing to the Grants Management Officer (GMO). Only responses to prior approval requests signed by the GMO are considered valid. Grantees who take action on the basis of responses from other officials do so at their own risk. Such responses will not be considered binding by or upon the HRSA.

In addition to the prior approval requirements identified in Part 74.25, HRSA requires grantees to seek prior approval for significant rebudgeting of project costs. Significant rebudgeting occurs when, under a grant where the Federal share exceeds \$100,000, cumulative transfers among direct cost budget categories for the current budget period exceed 25 percent of the total approved budget (inclusive of direct and indirect costs and Federal funds and required matching or cost sharing) for that budget period or \$250,000, whichever is less. For example, under a grant in which the Federal share for a budget period is \$200,000, if the total approved budget is \$300,000, cumulative changes within that budget period exceeding \$75,000 would require prior approval). For recipients subject to 45 CFR Part 92, this requirement is in lieu of that in 45 CFR 92.30(c)(1)(ii) which permits an agency to require prior approval for specified cumulative transfers within a grantee's approved budget. [Note, even if a grantee's proposed rebudgeting of costs falls below the significant rebudgeting threshold identified above, grantees are still required to request prior approval, if some or all of the rebudgeting reflects either a change in scope, a proposed purchase of a unit of equipment exceeding \$25,000 (if not included in the approved application) or other prior approval action identified in Parts 74.25 and 92.30 unless HRSA has specifically exempted the grantee from the requirement(s).]

- Payments under this award will be made available through the DHHS Payment Management System (PMS). PMS is administered by the Division of Payment Management, Financial Management Services, Program Support Center, which will forward instructions for obtaining payments. Inquiries regarding payment should be directed to: Payment Management, DHHS, P.O. Box 6021, Rockville, MD 20852, http://www.dpm.psc.gov/ or Telephone Number: 1-877-614-5533.
- 7. The DHHS Inspector General maintains a toll-free hotline for receiving information concerning fraud, waste, or abuse under grants and cooperative agreements. Such reports are kept confidential and callers may decline to give their names if they choose to remain anonymous. Contact: Office of Inspector General, Department of Health and Human Services, Attention: HOTLINE, 330 Independence Avenue Southwest, Cohen Building, Room 5140, Washington, D. C. 20201, Email: Htips@os.dhhs.gov or Telephone: 1-800-447-8477 (1-800-HHS-TIPS).

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 Award Number: 1 D70MC09835-01-00

- 8. Submit audits, if required, in accordance with OMB Circular A-133, to: Federal Audit Clearinghouse Bureau of the Census 1201 East 10th Street Jefferson, IN 47132 PHONE: (310) 457-1551, (800)253-0696 toll free http://harvester.census.gov/sac/facconta.htm
- 9. EO 13166, August 11, 2000, requires recipients receiving Federal financial assistance to take steps to ensure that people with limited English proficiency can meaningfully access health and social services. A program of language assistance should provide for effective communication between the service provider and the person with limited English proficiency to facilitate participation in, and meaningful access to, services. The obligations of recipients are explained on the OCR website at http://www.hhs.gov/ocr/lep/revisedlep.html.
- 10. This award is subject to the requirements of Section 106 (g) of the Trafficking Victims Protection Act of 2000,as amended (22 U.S.C. 7104). For the full text of the award term, go to http://www.hrsa.gov/grants/trafficking.htm. If you are unable to access this link, please contact the Grants Management Specialist identified in this Notice of Grant Award to obtain a copy of the Term.

#### Reporting Requirements:

Due Date: Within 90 days of Budget End Date
 The grantee must submit a Financial Status Report SF-269A/Short Form (http://www.psc.gov/forms/sf) within 90 days
 after the budget period end date. This report should NOT reflect cumulative reporting from budget period to budget
 period and must be submitted to the HRSA, Division of Grants Management Operations, 5600 Fishers Lane, Room
 11A-02, Rockville, MD 20857-0001.

Failure to comply with these reporting requirements will result in deferral or additional restrictions of future funding decisions.

#### Contacts:

Program Contact: For assistance on programmatic issues, please contact Lynda Honberg at: HRSA/MCHB/DSCSHN

5600 Fishers Ln Rockville, MD 20852-1750 Phone: (301)443-6314 Email: lhonberg@hrsa.gov

Division of Grants Management Operations: For assistance on grants administration issues, please contact Tammy

Jeffs at:

HRSA/OFAM/DGMO 5600 Fishers Ln Rockville, MD 20852-1750 Phone: (301)443-5419

Email: tjeffs@hrsa.gov Fax: (301)443-6686

Responses to reporting requirements, conditions, and requests for post award amendments must be mailed to the attention of the Office of Grants Management contact indicated above. All correspondence should include the Federal grant number (item 4 on the award document) and program title (item 8 on the award document). Failure to follow this guidance will result in a delay in responding to your request.

## Implementation Grant for Integrated Community Systems for Children and Youth with Special Healthcare Needs

### Vermont Department of Health February 1, 2008

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#### I. INTRODUCTION:

The overarching goal of Vermont's State Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs is to transform the existing system of care for CYSHCN in Vermont into one that (1) serves the true population of children and families in need, (2) assures access to services that reflect evidence based, culturally effective practice, (3) supports a delivery system in which primary care services, including early and continuous developmental screening, are provided in accordance with the Bright Futures Guidelines for Health Supervision of Infants, Children and Adolescents (Third Edition, 2007) in Medical Homes with appropriate and effective linkages to the system of specialty care, (4) provides adequate and affordable health insurance, (5) operates within a community-based, coordinated, integrated system of care and (6) supports youth as they transition to adulthood. While our intent is to address all six components identified by MCHB in framing such a comprehensive, community-based system, we will focus on the following three core outcomes: (1) Medical home, (2) Health insurance and financing, and (3) Community integrated services. In addition, the theme of Family Professional Partnerships/Cultural Competence is infused throughout our vision for planning and implementation. In completing this application, we have looked for every opportunity to create respectful partnerships among our CYSHCN, their families, and the professional representative of our community-based system of care.

#### Challenges To Be Addressed

Vermont's small, rural nature (2006 population is 632,908) presents the issue of scattered, sparse populations trying to obtain ready access to resources and services. As such, we face major challenges in transforming its system of care for CYSHCN, especially in the areas selected for focus in this grant:

Medical Home: Although data from the 2005-6 National Survey of Children's Health-CSHCN indicate that 51.5% of Vermont families report that their child with special health needs received care in a Medical Home, parents reported the following concerns when queried as part of Vermont's 2003

Medical Home (HRSA-funded) project: (undue) delay in diagnosis (with negative impact); parents' concerns disputed/ignored by the primary care provider (PCP); confusing/incomplete communication of information; inadequate information specifically from PCP's; PCP's without central role in overall care of child; little/no care coordination by PCP's; parents desire increased control over/responsibility for care decisions. Tracking of Medicaid claims data (the only payer in Vermont who reimburses for such plans, and only on a limited basis) indicated that less than 15% of PCP's in Vermont submitted care plans for patients with SSI.

Health Insurance and Financing: While Vermont's Title V CSHN program (VDH/CSHN) has taken its responsibility as a payer of services for CYSHCN very seriously, the range of services covered (constrained by patient, service or provider eligibility) translates into what is, at best, a selective safety net with severe limitations for a selective group of children. VDH/CSHN bears the cost of limitations created by other payers who place inappropriate limits on frequency/duration of coverage, restrict access to specific providers, apply strict definitions of "medical necessity" and "evidence based practice," and exclude certain services altogether.

Community Integrated Services: In a survey conducted by Parent to Parent of Vermont, 55% of parents reported being dissatisfied or very dissatisfied with how services are organized in Vermont; 20% indicated that the system was impossible to understand and hard to navigate (and that there was no one designated to help them with such navigation). Vermont's Agency of Human Services (AHS) has attempted to address the perception that the system of care and supports for families of CYSHCN, especially those with the most complex needs, is silo-bound, uncoordinated, and duplicative. Although a departmental reorganization was undertaken in 2003-2004 to address these concerns, significant concerns persisted regarding the Agency's categorical departmental structure, duplication of administrative functions, and fragmentation of services for individuals and families.

#### Strengths and Opportunities

Vermont's small, rural nature also provides an opportunity to effect systems change by enabling collaboration and commitment to shared MCH goals and objectives. The 2005 Title V Strengths and Needs Assessment described a statewide community coalition that works "beautifully," garnering resources to support new initiatives and showing interest in these initiatives. In considering whether or not to apply for this Integrated Community Systems grant, we recognized a number of current activities which led to a consensus that the time is absolutely right for Vermont to implement major systems change. Many internal and external initiatives have created a climate that is ripe for true systems change. The following represent key elements of such initiatives:

Realignment at the Vermont Department of Health: The mission of the Vermont Department of Health is to "lead our state and communities in the development of systematic approaches to health promotion, safety, and disease prevention." In the spring of 2007, the Department participated in a realignment process, the guiding principles for which included leading and advocating for the health of the public, integrating behavioral health and physical health, and meeting today's needs and preparing for the future. Prior to undertaking this process, many programs serving children and families, including

those serving CYSHCN, existed in multiple divisions throughout the Department, operating in a collaborative manner, but without centralized management. During the assessment phase of this process, a team assembled to evaluate programs related to Maternal and Child Health (MCH) identified and conducted key informant interviews with a broad range of internal and external stakeholders; reviewed themes identified through the 2005 Title V Strengths and Needs Assessment; created an inventory of laws, regulations, policies and procedures affecting MCH programs; reviewed and revised program goals and measurable objectives that had been entered into the Department's Asset Management Inventory System. As a result of the realignment process, a number of related programs (CSHN Clinical and Developmental Programs, Newborn Population-Based Programs, Title V/MCH Block Grant, Title X/Family Planning Grant, EPSDT, WIC, School Health, and other (general) MCH programs,) were reorganized under a newly-(re)formed Division of Maternal and Child Health. The team that has come together under this umbrella is committed to using the work of the MCH realignment team as a springboard to continued strategic planning and implementation. Strengths and challenges within the existing system were aptly summarized in the aim articulated as the foundation for our development of a family-centered system of care: beginning with families' own identification of service needs, identify system strengths that require enhancement and system gaps that need addressing; develop and implement strategies to meet the needs directly, where appropriate, and advocate within the larger health care and human services system for higher-level strategies for the children with special health care needs population.

Health Care Reform: Vermont's health care reform was created from a realization by many policy makers that the fundamental goals of health care reform are inter-related: (1)

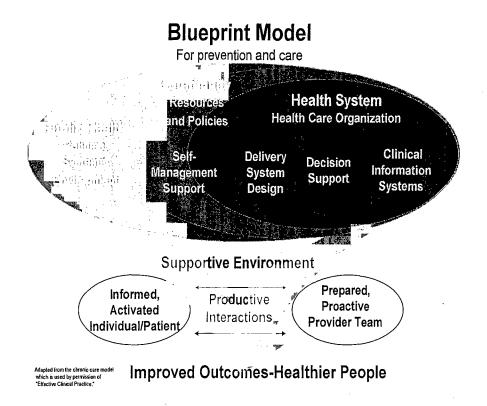
Covering the uninsured will help to lower uncompensated care costs, which affect premiums paid by the insured; (2) Unless health care costs can be brought to within a more manageable rate of growth, Vermont will not be able to afford to cover the uninsured; and (3) Public health initiatives and appropriate attention to healthy lifestyles and disease prevention are essential elements of an effective health care reform strategy. More than thirty-five separate initiatives contained in the legislation provide the framework for Vermont's Health Care Reform of 2006.

The Secretary of Administration is responsible for overall coordination of health care reform.

Each initiative is assigned to lead entity/entities within state government with the expertise and ability to work collaboratively with the stakeholders to ensure its success. The 2006 Health Care Reform Five-Year Implementation Plan presents a description of the individual health care

reform initiatives.

Vermont's Blueprint for Health: The goal of this initiative is to establish in Vermont a comprehensive, proactive system of care that improves the quality of life for people with or at risk for chronic conditions. It represents a new, collaborative approach that involves major changes in the health care system based around the needs of patients. Information systems, effective patient self-management tools and community supports are examples of changes being developed as part of this effort. The vision for the Blueprint includes the following elements: (1) utilize the Chronic Care Model as the framework for the required system changes; (2) utilize a public-private partnership to facilitate and assure sustainability of the new system of care; and (3) coordinate with other statewide initiatives to assure alignment of health care reform efforts. The Chronic Care Model (see figure below), a national model for collaborative care and quality improvement, includes an active role for individuals, communities, the health care and public health systems, and provider practices. There are several major areas of overlap between the Blueprint goals for adults living with chronic disease and goals of the CYSHN integrated services grant. The following concepts are integral to both programs: access to a quality advanced medical home, community-based and coordinated integrated models of care, community support for families and individuals, partnerships between activated and informed individuals and their families and prepared, proactive health care teams, and the central role patients play in making health-related decisions and following through with the necessary actions. In both cases, the entire system is supported and enhanced by efficient information systems and public health infrastructure. Although at present the Blueprint is concentrating on adult with chronic illness, its leaders understand that children who live with chronic disease or disability will age into adulthood and become users of the Blueprint resources and programs. In addition, as the Blueprint expands its statewide health system coordination, its leaders are very willing to work with CSHN leadership to insure that the two systems are complementary and mutually supportive. Thus, as the Blueprint expands its target population to include children and also children with special health care needs, the planning as funded by the SIG grant will have enabled complementary systems that will be able to smoothly interact on all elements.



Examples of specific projects that will enable a collaborative approach in melding VDH/CSHN systems of care with Blueprint adult care systems are as follows: 1) Promotion of Bright Futures developmental screening process in all pediatric/ family practice setting, 2) Use of educational tools for informing families. Those developed by VDH/CSHN and its partners (such as VFN) will be able to be used by Blueprint staff for PCP's who see CYSHCN, 3) Blueprint Information System is a web-based clinical tracking system with a central data repository. PCP patient data is electronically gathered, centralized, "cleaned" and managed for confidentiality and accuracy of information. Data reports are them produced for both patient case management by PCP and also generalized reports for Blueprint program evaluation and public health planning. Using the capacity from the Integrated Systems grant, VDH/CSHN programs within VDH will investigate the use of this data system within its own clinical practice systems and tracking systems.

Global Commitment Waiver—As part of the State Fiscal Year 2006 budget proposal process, the administration of Governor James Douglas presented this Plan for Saving the Vermont Medicaid System. With this long-term strategy Vermont proposed to replace its

existing section 1115a waiver, the Vermont Health Access Plan (VHAP). The replacement is the Global Commitment to Health. With the federal approval of this proposal, certain federal Medicaid requirements found in Title 19 of the Social Security Act are waived. The result is that the Global Commitment to Health includes the tools necessary for the state, in partnership with the federal government, to address future needs in a holistic, global manner.

Integrating services for children with disabilities—The AHS Secretary has recently (January, 2008) charged a group of program leaders with collectively designing a plan to fully integrate services for children with disabilities across the entire Agency. This work will encompass an existing initiative, Children's Integrated Services (CIS—an effort to integrate 3 specific programs: early developmental screening and referral through the Family and Infant Toddler Program/FITP; the Healthy Babies, Kids and Families (HBKF) home visiting program; and Children's Upstream Services/CUPS, or Early Childhood Family Mental Health).

Building Bright Futures To address overlap and fragmentation of early childhood services, the state of Vermont received technical assistance in 2002 to explore how North Carolina's Smart Start model could be used to establish a unified early childhood system and to support a formal planning process, which included a strategic plan and timetable for implementation. This strategic planning process resulted in Vermont's <a href="Early Childhood System Plan">Early Childhood System Plan</a>. With the ultimate goal of ensuring that all Vermont children are healthy and successful, the Plan resulted in the formation of Vermont's Building Bright Futures, an innovative public-private partnership that coordinates and oversees Vermont's early childhood care, health and education system.

MOVE (Modernization of Vermont's Enterprise: Vermont is changing its Medicaid IT world) Project—The goal of this project is to create information systems for Vermont Medicaid that are modern, flexible, responsive and interoperable, so that the key implementation drivers are our health care vision, optimal customer service, and program needs, not the constraints of the supporting technology. The MOVE Project encompasses planning, designing and implementing systems which meet the current and future needs of Vermont's Medicaid program. ACCESS (Vermont's integrated eligibility system dating to 1983) and the MMIS (Medicaid Management Information Systems) will receive in-depth attention. Other systems which support Medicaid business processes will also be evaluated.

Reorganization of our partner agency, Parent to Parent of Vermont—In 2007, the Board of Directors of Vermont Parent Information Center (VPIC) and Parent to Parent of

Vermont (P2P) voted to merge. As of June 30, 2008, they will be known as the Vermont Family Network. This merger is viewed as an exciting opportunity to provide a continuum of support to families that is family-centered, comprehensive, and easy to access. By merging, P2P and VPIC combine their talents and expertise in partnering with families and professionals to achieve better outcomes for children and adults with special needs, including the activities established when P2P was awarded the MCHB grant to function as a Family to Family Health Information Center.

In and of themselves, each of the aforementioned initiatives represent some of state government's best thinking about how to strengthen Vermont's health care delivery system. But examined collectively, they also represent some of the challenges identified in the needs assessment portion of this application: activities evolving in silos, without any central coordination. We know from prior needs assessment and strategic planning activities that the lack of coordination is central to the perception of VDH/CSHN services as patients and families come into our system: many well-intentioned staff and programs operating on their behalf, but in a confusing/at times bewildering manner. And in the end, desired/needed services are still not easily recognizable and accessible.

**Proposed Interventions** (Refer to Section IV: Workplan for related Goals and Objectives)

#### Medical Home:

- Establish Medical Home advisory group with strong, statewide family representation
- Update inventory of current Medical Home capacity and practice operations (new: assess capacity of FQHC's and rural health clinics to provide primary care for CYSHCN)
- Clarify and promote sound Medicaid billing practices, including those for care planning and coordination activities
- Update strengths and needs assessment re: communication; organize and disseminate existing tools and, where necessary, develop new tools to address communication issues
- Provide statewide leadership for interagency initiatives, especially in the areas of family involvement and medical home
- Establish and lead a work group of Medicaid staff, AAP-VT, AAFP-VT, and family representatives to establish protocols for assessment, referral and treatment and monitor improvements in service delivery
- Continue strategic planning and implementation regarding VDH/CSHN's Child Development Clinic (assist PCP's with standardized primary screening; operationalize our unique role in secondary screening and treatment planning, in order to assure coordinated early and continuous screening)
- Conduct regional trainings with Medical Home providers and staff, families, and community representatives to promote the use of Bright Futures Guidelines for Health Supervision of Infants, Children and Adolescents (Third Edition, 2007)

#### Health Insurance and Financing

- Assess ideal components of coverage for CYSHCN and gaps in current public and private financing mechanisms
- Evaluate VDH/CSHN's *payer of last resort* policies and practices, and redesign support systems for assuring that all potential payment mechanisms are appropriately utilized
- Provide statewide leadership on behalf of CYSHCN in Vermont's Care Coordination and Chronic Care Management Programs
- Reconfigure financial support to families (e.g., direct services vs. care coordination)
- In implementing systems which meet the current and future needs of Vermont's Medicaid program. ACCESS (Vermont's integrated eligibility system dating to 1983) and the MMIS (Medicaid Management Information Systems) will receive in-depth attention. Other systems which support Medicaid business processes will also be evaluated

#### **Community Integrated Services**

- Provide collaborative oversight (by The Medical Home Advisory Group and Parent to Parent of Vermont) to achieve full integration of existing local Children's Integrated Services and Building Bright Futures teams, including family and primary health care provider representation in *every* region throughout the state
- Provide statewide leadership in the AHS initiative to integrate services for children with disabilities across the entire Agency

#### **Anticipated Benefit**

Upon implementation of these interventions, Vermont will have a sustainable system of care for CYSHCN that is patient- and family-centered, integrated, and community-based. Entry will be seamless, the services provided will be culturally competent, evidence-based and of high quality, and communication will be effective and transparent to all engaged parties. Patients and providers will understand and utilize appropriate and effective payment mechanisms, with the best assurance possible of financial support for health services for CYSHCN. And throughout the period of grant activity, and onward into the future, we will continuously measure and improve public and private health practice in order to optimize the health of Vermont's children and youth with special health care needs.

#### II. STRENGTHS AND NEEDS ASSESSMENT

#### Family/professional partnership at all levels of decision-making

There can be no system of care for CYSHCN without their families in leadership. The system must work—and change—to deserve the privilege of the relationship to CYSHCN and trust the trust of their families. Our proposal includes families in each goal and objective. Families must inform the system, must shape the system, must motivate the system—and must change the system if it has slipped from its proper service to children and families.

The NS-CSHCN 2005-6 reports that somewhat more parents in Vermont, than nationally

or regionally, feel that they are partners in decision-making at all levels, and who are satisfied with the services they receive (VT: 59.8%; Region I: 58.3%; US: 57.4%). P2P reports that 85% of families responding to a recent survey felt that "they were satisfied or very satisfied with their ability to partner and team in their child's care." We rely very greatly on our collaborative relationship with P2P to help us understand the needs and preferences of families with CYSHCN--especially families who do not receive services from our programs. Since 1987 we have provided a substantial annual infrastructure grant to support P2P's unique activities and resources for families, to extend their support to families statewide and to create and maintain a database of inquiries and needs of families whom they serve

In 2003, as an activity associated with VT's HRSA grant-funded medical home project, 57 parents of 73 CSHCN. Parents were adamant that they "want and expects total control and full responsibility over all care decisions" for their children, and want information to guide their decisions, and support and resources in fulfilling their responsibilities. But "inclusion" and "participation" do not describe sufficiently the power and depth of the parent centrality in the care of their children and in the system of care "Parent partnership" includes both the essential role of leader of one's own child's care team and the leadership in policy and practice affecting the care of other children.

The demographics of Vermont are overwhelmingly non-Hispanic white; yet, there are still very great contrasts from urban, suburban, rural, remote, from areas whose unemployment rates are double those of other regions, whose children are the first to finish high school. Refugee and immigrant families hail from Africa, South Asia, and Eastern/Balkan Europe. Migrant families labor in Vermont orchards in summer, and year-round in dairy farms. Native American Abenaki have recently renewed their cultural and political voice. Our clinical presumptions—identify the developmental deficit as early as possible, diagnose why, and apply interventions as quickly and intensely as tolerable—make little sense to the parents whose culture does not think of childhood as a series of milestones to be achieved. We understand the need for translation of written and spoken materials, but we understand little about how to explain the future—in America--of the child with autism.

#### Access to comprehensive health and related services through the medical home

The American Academy of Pediatrics, Medical Home Initiative for CSHCN committee articulated the AAP Policy Statement on "The Medical Home" (*Pediatrics*, July 2002; 110; 184-

186) makes it clear that Medical Homes are for "All Children." The concept and practices acknowledge that family-centered care, clear and unbiased information, comprehensive care including screening, continuous access to care, care throughout childhood and coordinated across the lifespan, collaboration with subspecialty providers, collaboration with community providers, care coordination and comprehensive care planning, a comprehensive record, and developmentally appropriate and culturally competent planning for transition to adult services—are valuable for all children and families. The National Survey of CSHCN (2001, 2005-6) has documented how very large a portion of the childhood population (13.9 % nationally, 16.4% in Region I, and 15.0 % in Vermont) is comprised of CYSHCN. These numbers alone would argue for a system of care which is comprehensive and flexible—not one built upon categories, limited eligibility criteria, and thresholds for qualifying for receiving appropriate quality care.

Unfortunately, the reality of limitations in resources has always driven systems of care to create barriers to services and supports, in order to conserve resources for those who meet the threshold criteria of need--such as "medical necessity." Criteria which are developed independently by different parts of the "system"—health care payers, education entitlements, providers themselves—all quite unintentionally create a system of care that poorly achieves the six desired outcomes of the President's New Freedom Initiative and the characteristics of medical home care: accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

The NS-CSHCN 2005-6 survey found that a slightly greater percentage—but still only one-half--of VT families felt that their child with special health needs received care within a medical home (51.5% in VT; 47.9% in HRSA Region I; and, 47.1% nationally). P2P reported that 100% of responding families had a PCP. In their survey associated with the first Title V needs assessment 58% of 404 VT parents that they had a medical home. However, only 17% of 169 parents participating in regional dinner forums, when asked the same question during group discussion, responded that they had a medical home. There is a high level of satisfaction with PCP care, but less when compared to the expectations of the medical home.

In 2003, as an activity associated with VT's HRSA grant-funded medical home project, 57 parents of 73 CSHCN, from three areas of VT, participated in focus group discussions. More specific questions were asked about the PCP's knowledge of the child's special condition, the level of communication with the parent, and the coordination of services. The participants'

concerns/comments about their medical home experiences focused on: delay in diagnosis, feeling concerns were dismissed, confusing diagnostic information, little help with care coordination. However, 98% said that they, as parents, want and expect total control and full responsibility over all care decisions

Even though the comments from parents were gathered over time and through different methods and settings, there are clear, common themes. Communication, between medical homes and parents, and between medical homes and specialty care providers—including families "in the loop"—is an essential, but fragile core element of the system of care. Vermont's CSHN program has evolved as an enhancement and assurance of access to coordinated, comprehensive, *specialty* care services which would have been lacking or incomplete without the attention of a team-based, public health effort. CSHN clinical activities and financial supports have also flowed towards these specialty teams and services. As the medical home model has grown and flourished, CSHN has shifted its relationship with PCPs--but around individual children, especially children with "high-tech" needs for whom regular care conferences which include the PCP are essential. The shift in wraparound enhancement, towards primary care and away from specialty services, however, has not become system-wide.

Medical home grant projects, including our own and the Dartmouth Rural Medical Home Improvement Project, have emphasized the value of a written care plan, crafted with families, as a tool for assuring that care is comprehensive, coordinated, and family-centered. For two years, VT has tracked the Medicaid claims for care plans submitted by PCPs for children who have SSI. The rate is low—under 15% (and confounded by the rules around which Medicaid children are eligible for payment for care plans)--and suggests the need for more outreach to PCPs about the benefits of a care plan, strategies for creating a care plan, and expanding the opportunities for reimbursement.

#### Early and continuous screening, evaluation and diagnosis

The assurance that all children are screened continuously for special health needs depends on several interrelated elements: children must have access to the sources of screening; the screening must be performed competently and comprehensively; and the system of care must provide the post-screening next steps. The NS-CSHCN study also found that VT CYSHCN reported more complete screening than regionally or nationally (VT: 74.4%, Region I: 74.2%, US: 63.8%). P2P reported that all parents surveyed (see survey, above) felt that their children

had been screened; 80% said that it was easy or very easy to find appropriate screening or evaluation for their child, and 30% said that the process happened easily when there was a good relationship between the parent and child's PCP.

Screening is an individual process which demands a system-level response. When universal newborn hearing screening was first promoted to hospital nursery decision-makers, the leadership embraced the responsibility—but only if there was assurance of the next steps, the follow-up of positives and tracking through diagnosis. Similarly, as the VDH MCH and AAP leadership promote developmental/behavioral screening in the PCP office, through implementation of the Bright Futures (3<sup>rd</sup> edition, 2007) guidelines and the use of normed screening instruments (AAP Policy Statement: Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental surveillance and Screening, *Pediatrics*, July 2006; 118; 405-420), the system must also assure that there is no gap between screening and follow-up and diagnosis. For developmental screening follow-up in Vermont, there are two, often parallel but complementary, next steps, referral to the state Part C early intervention program (the Family, Infant and Toddler Program--FITP), and the VDH Child Development Clinic, together addressing the functional/intervention (FITP) and neurodevelopmental-medical needs (VDH/CDC) of young children with suspected developmental disorders.

Child Development Clinic's role in response to PCP screening is especially important. We have begun strategic planning to understand the evolution of our VDH/CDC program, the current expectations in relationship to PCPs, families, and community providers, its capacity for its current role, its public health mission and ideal niche in the larger system of care, its need for resources to fill that niche, and strategies to meet its goals. Vermont has identified the system of services for children with developmental disorders, especially autism, as one in urgent need of redesign and support. The Report to the Legislature to Address Services for Individuals with Autism Spectrum Disorders, presented to the VT Legislature on January 18, 2008, recommends PCP screening for autism and other developmental disorders at 18, 24, and 36 months, and recommends funding to increase access to VDH/CDC developmental pediatricians.

#### Adequate public and/or private financing of needed services

The NS-CSHCN survey indicates that a higher percentage of VT families of CSHCN have adequate public or private insurance to pay for the services they need (VT: 69.4%; Region

I: 64.4%; US: 62.0%). 34.1% of VT children live in families with income below 200% of the federal poverty level (Catalyst Center; Boston U). However, a lower percentage of VT families report spending more than \$1000 out of pocket per year than in New England and the US, and a lower percentage who feel that their child's condition causes financial problems for the family.

Even though the VDH/CSHN program has a role as a payer of services for CYSHCN, it is limited in many ways—eligible population, eligible services, eligible providers. CSHN provides financial support for some health services for CYSHCN, but it is a very selective safety net, for a selective group of children, and a selective set of services. Insurance may place limits on frequency or duration which are inadequate for a child's needs, however, with the residual cost shifting to CSHN. Insurance may also restrict access to specific providers. Other services are outside the typical scope of insurance coverage entirely, such as respite care, transportation, lodging, specialized foods, customized DME, over the counter medications, and some therapies such as hippotherapy. Strict definitions of "medical necessity" and "evidence based practices" also serve to limit coverage, particularly in the area of developmental disabilities. CSHN as a payer, even as a gap-filler, is unable completely to fill in the cracks in the health care financing system for CSHCN, neither for the 4500 children enrolled in CSHN programs, nor the 19,937 who are the children who have a SHCN (NS-CSHCN).

## Organization of community services so that families can used them easily (Community Integrated Services, CIS)

The NS-CSHCN for 2005-6 found that a high percentage of families in VT—as did families in the region and nation—reported that services were organized in ways that families can use them easily (VT: 89.3%; Region I: 87.9%; US: 89.1%). Parents surveyed by P2P (see above), however, reported that 55% were dissatisfied or very dissatisfied with how services are organized in VT. 20% said the system was impossible to figure out and hard to navigate. Others pointed out that they did not know about available services and that there was no one designated to help them navigate the system. Many families identify having a partner in care coordination as essential, on an individual level. A care coordination partner for parents can help make even the most fragmented system work for an individual child and family, while not effecting change in the system. In addition, coordination and integration of system components themselves can also make the system itself easier for families to access and use. As a state, Vermont has undertaken—and plans to undertake—major, transformative initiatives in response to the

perception that the system of care and supports for families with the most complex needs is fragmented, "silo"-bound, uncoordinated, and yet duplicative. The Agency of Human Services has responded with multiple care coordination and system integration initiatives, described in the Introduction.

#### Successful transition to all aspects of adult health care, work, and independence

The 2005-6 NS-CSHCN found that a higher percentage of VT families with youth with SHCN reported that their child receive the services necessary to make appropriate transitions to adult health care, work and independence, than regionally and nationally (VT: 52.0%; Region I: 46.1%; US: 41.2%). A larger percentage of the 12-17 year old population is comprised of youth with special health care needs, both in Vermont and in Region I (VT: 19.2%; Region I: 20.0%; US: 16.8%). The birth to 5 year old CYSHCN population (7.6% of all 0-5 year olds in VT) more than doubles in the 6-11 age group (16.6% in VT). At the same time, however, the enrollment in VDH/CSHN *programs* is lowest for the 12-17 age ranges. 29% of VDH/CSHN-*enrolled* children are 0-5 years old; 44% are 6-12 years old, and 16% are 12-17 years old.

In VT as elsewhere, the 18-21 age group experiences multiple cliffs in the support systems they need. Health insurance eligibility declines acutely. Family income ceilings for the Dr. Dynasaur Medicaid program drop from 300% FPL at age 18. The Katie Beckett TEFRA option ends at 18, but some children can continue Medicaid coverage through their individual SSI eligibility Service supports through IEPs end at graduation. VDH/CSHN after-insurance supports end at the 21<sup>st</sup> birthday (if not before, because they have been discharged from a clinic), and are limited in scope. Young adults, for some of whom VDH/CSHN has purchased individual health insurance plans, are ineligible for the state's new Catamount plan for 12 months because of their pre-existing condition.

Transitioning youth to the adult *health care system* has received less attention from AHS. The need is often understated as two-dimensional, the need for continuous health care insurance, and the need to find new care providers in primary care and specialty care. As VT implements the Blueprint for Health, built on the Chronic Care Model for adults, there is an opportunity--and a challenge—to connect transition-age youth with SHCN to the system of care being created around adults with chronic illness. The Blueprint can learn from what is now decades of medical home experience for children and their families, while the children's system can appreciate the Blueprint focus on communication technology, health care algorithms, and promotion of self

management.

## III. METHODOLOGY) Refer to Workplan Table for more details of Goals, Objectives, Activities, Timeframes, Partners, and Evaluation.

The proposed project will achieve its goals through conducting activities in all six elements of the comprehensive community based system of care. As stated in Section I, Vermont will emphasize the elements of medical home, health insurance and financing, and community integrated services. However, the interconnectedness of all the elements is so striking that each objective could find congruence in most of the six elements. The first column of the Workplan table, therefore, is "Crosswalk", showing this interconnectedness.

A Project manager will be hired to orchestrate, facilitate, organize, document the work of the project. P2P will designate a parent co-coordinator to collaborate and motivate in all activities. Considerable effort will be contributed by the MCH director, the CSHN operations director, the CSHN medical director, and the MCH Public Health Specialist. The project will support significant effort by a public health analyst in the Division of Health Surveillance. Together, this group will comprise the project management team.

The Governor's newly created group charged with designing integrated services for children with disabilities is the logical core interagency leadership partner for this project, functioning as a steering committee for the integration of the several integration initiatives just underway. This is the critical moment for getting it right, for pulling the momentum into synergy, and this is the project to do it. The Learning Collaborative process is an ideal methodology to bring clarity, commitment—and achievement—to the task of system change.

We will begin with a period of completing and updating the assessment of strengths and needs for CYSHCN and their families. Essential to the entire project is the enhanced ability (through Health Surveillance/BIN) to collect, analyze, and utilize information from our own (VDH/CSHN; BIN) and other (Medicaid enrollment and claims; MOVE) data to undergird our understanding of population and provider needs, service gaps and duplications, and costs, on which our assessment and innovation must be based.

As a result of the reorganization of Vermont's Agency of Human Services in 2005 and of the VDH realignment in 2007, significant planning began to organize and coordinate the state's system of delivery community based care coordination services for families and children. This planning is addressing a major systems change that encompasses a wide variety of statewide systems. Although beginning changes have happened within the services for healthcare and public health coordination, much work has yet to be done. The systems integration grant will be invaluable in organizing the care coordination systems for CYSHCN.

II A. Vision: Families of children with special health care needs partner in decision making at all levels and are satisfied with the services they receive.

GOAL 1: VDH/CSHN is recognized as a model program with respect to integration of family centered care in all its activities.

Parent-professional partnerships must be central to any consideration of systems of care for CYSHCN and their families. Partnerships are not built out of lip service, nor do good intentions suffice. Families are far too invested in the care of their children and there is far too much substantiated literature in support of the family as the axis of the care team for any planning process to give short shrift to family-centeredness. It is an obligation of any CSHN program to start, first, with families when envisioning, designing, and developing systems of care.

We will build upon the findings of previous strengths and needs assessments (such as the Title V 2005 SNA and Section II) and will also bring to this endeavor data from the 2005-2006 NS-CSHN survey. Additional data will be gathered and assessed through surveys of families, advocates, and others activities specific to the work of this grant.

For families truly to partner with the professional on their children's care teams, potential barriers to communication and understanding must be recognized and addressed. While Vermont is a very homogeneous state, cultural distinctions and differences are a reality. We will focus on ensuring that the system of care for CYSHCN in Vermont is culturally sensitive and effective. We will provide appropriate interpretation whenever we are doing the work of this grant. Long term we will ensure that we are in full compliance with the Vermont AHS policy with regard to Limited English Proficiency. Beyond language, though, we recognize that cultural differences may manifest themselves in many ways, some subtle, some not subtle at all. We will take advantage of the opportunities for in-depth family input that this grant offers to build upon our understanding and sensitivity and to inform our partners in care.

With the assistance of Parent to Parent of Vermont, the Vermont Parent Information Center and others who work in support of Vermont's CYSHCN we will not only survey families but will also lend our efforts to the work of advisory councils that focus on the statewide special health needs population to help ensure a strong family presence on each council. We will help to ensure that councils are culturally sensitive and effective. To further strengthen the role of parents in the broad system of care, we will also develop a "report card" system that will enable these councils to "grade" every component of the CYSHCN system of care in Vermont - not only the CSHN program, but primary and specialty care, public and primary healthcare coverage, and even advocacy networks as well.

In a targeted initiative, we will work to ensure that youth with special healthcare needs have a voice as well, either on existing councils or through special Youth Advisory Councils throughout the state. Our needs assessment work early in the grant period will direct our decisions as to whether new councils or efforts to encourage youth involvement on existing councils is indicated. Feedback from youth and families will help us determine the best format for these advisory groups.

Ensuring that parents are true partners in the care of their children with special health care needs is more than gathering information from them. It is also about making useful and understandable information available to them at *times* and in *formats* that meet their needs. The Vermont Department of Health has nearly completed a comprehensive redesign of its website (<a href="http://healthvermont.gov/">http://healthvermont.gov/</a>) and the VDH/CSHN portion has benefited in the process. We will continue to expand and develop our presence on the internet... as evidenced by the addition just this week of resources specific to Autism. That page will be reviewed and supported by our partners at VCHIP, Fletcher Allen Health Care, Vermont's sole tertiary care center, and Autism support groups in Vermont.

II B. Vision: CYSHCN receive coordinated ongoing comprehensive care within a medical home.

MH Goal 1: The Medical Home, with appropriate infrastructure and financial support, is the core support to families with CYSHCN in their role as the ultimate manager of their child's care.

Families have told us emphatically that <u>they</u> are their children's "case managers"—but that they require help and support. We propose to move the medical home to a place of centrality, centered on the family, and help it to support families. We will create a MH workgroup, including PCPs and parents, to guide this planning and implementation process; our original VT MH grant advisory group will be invited to participate. This first year activity will begin with an

analysis of the status and variation in VT MH demographics and services. We will use available datasets, including Medicaid claims data and VDH/CSHN enrollment database to inventory and categorize primary care practices who see CYSHCN, to understand their geographic distribution, caseloads, encounters, range of conditions cared for, billing for care plans, ages served. We will survey primary care practices to obtain a more complete picture of the state of the Medical Home for CYSHCN in VT. Also in the first year, AAP and AAFP will query their membership, and P2P theirs, for examples of effective VT medical homes and the strategies they use. Examples will be showcased in the Grand Rounds and at Academy annual meetings.

We learned from our own and from other states' Medical Home projects that the written care plan is an essential tool. Our project will develop strategies for increasing the use of care plans and tracking MH and family satisfaction with this key partnership tool. To do so will require clarity from Medicaid about the billing requirements and procedures, which are unevenly understood and applied at this time. Medicaid's new Chronic Care initiatives (see Needs Assessment) is also a new and critically important opportunity to expand the use of reimbursed care planning. Our project leadership will work directly with Medicaid policy makers, using the monthly forums we have already established. Use of the care plan will then be promoted through the Academies, and their use tracked through claims data. In addition, the project's Family goals/objectives address the enhancement of the VDH/CSHN website as a core resource for families and Medical Homes.

# MH Goal 2: The MH collaborates and communicates effectively with providers of specialty care, community services and other members of each child's care team to facilitate coordinated delivery of care

Effective collaboration is all about effective communication. Disconnects in communication, between PCPs and specialists, between PCPs and community providers, puts families in the challenging and confusing role of carrying messages, and interpreting meanings and plans. Using a survey we developed for our earlier Medical Home project, we will revise our inquiry of PCPs and specialists, expanding to community providers and parents. We will ask what methods of communication they need and want from each other. Parents will help analyze the information. This activity will begin in year 1. It will be complemented by focus groups for further discussion. The project work team will then develop, pilot, and spread activities for better communication, to support families and Medical Homes as the hubs of coordinated

delivery of care.

## MH Goal 3: Publicly funded case management programs will include family and medical home as central

Although every Medical Home would benefit from an individual staff member as care coordinator, cost estimates of such an expansion even in VT have been overwhelming. At the same time, however, there is an expansion of interest and resources for publicly funded case management. It is imperative that Medical Homes work hand in hand with these programs in the service of CYSHCN. As described in the Needs Assessment, Vermont is embarking on several service integration initiatives impacting CYSHCN and their families. Until now, these interagency efforts have not been consistent in including health needs nor health services in the planning. Our objective is that service planning processes emanating from other sources (e.g., IEP; IFSP; USP; CSP) will increasingly collaborate and establish protocols with the Medical Home and VDH/CSHN. We will review the current protocols and procedures for developing these emerging "integrated" service plans, especially with respect to the role of the Medical Home and family. The project and families will meet with the leadership of these interagency initiatives to discuss the centrality of the Medical Home and its relationship with families of CYSHCN, and to promote Medical Home involvement. Critically important are the two new Medicaid case management initiatives, both designed for adults with chronic conditions but also enrolling children with complex health care needs. Our aim is that the Medicaid Case Management programs will partner with the child's medical home in each and every instance, and with other natural community based partners. Quarterly meetings with the project, Medicaid managed care staff, and parents, will help to refine and assure the partnership of the Medical Home. New protocols for partnership between medical homes and the Medicaid case managers will be developed, implemented and monitored, primarily in years 2 and 3.

## MH Goal 4: VDH/CSHN staff, services and resources are organized to support the family and MH

The resources of this project will enable VDH/CSHN to examine its traditionally specialty-care-based network and establish stronger connections with the Medical Home and family. We will begin with identifying the PCPs serving two groups: VDH/CSHN-enrolled children, and SSI-enrolled children under the age of 16. As above, the VDH/CSHN and the

Medicaid claims databases will be the source of this information. Our objectives are that regional VDH/CSHN staff will create informative, resourceful, supportive affiliations with PCPs for VDH/CSHN-enrolled children; and, SSI-eligible children will be served by Medical Homes, including the use of care plans. VDH/CSHN staff will follow up the data/identification project with outreach visits to PCP practices in the regions, not unlike a "Welcome Wagon" visit. The ideal outcome is that PCPs for VDH/CSHN children will collaborate regularly with the VDH/CSHN contact person for their VDH/CSHN patients. A necessary corollary is that the VDH/CSHN enrollment database requires improvements to perform as a patient information system able to assure efficient and effective communication between VDH/CSHN program, medical homes, and families. With respect to the SSI group, a work group including parents will design methods to engage Medical Homes more fully in their comprehensive care. We will also explore a specific role for the APS case management program with the SSI group. In addition (see BIN under Screening, and in Methodology introduction) the project will support greatly enhanced ability to collect and analyze our data sources in support of needs assessment and patient coordination.

### MH Goal 5: Child Development Clinic will fulfill essential function in support of Medical Home

The Child Development Clinic is an essential partner for the Medical Home. As PCPs increase in the capacity to perform early developmental screening, the VDH/CDC must be ready as the next step, in family-centered evaluation, diagnosis, treatment planning and follow-up. The project will move strategic planning forward into development, piloting, refining, expanding new models that must include components of consultation, evaluation, treatment planning, follow-up, and will be family-centered, collaborative with medical homes and community-based services. The process will require analysis of referral patterns, referral questions, previous, current and future community-based service partners, and an understanding of the rapidly expanding attention to services needed by children with autism spectrum disorders.

# II C. Vision: Families have adequate private and public insurance to pay for the services they need.

Vermont's CSHN program offers limited financial assistance to enrolled families.

For insured children, assistance is limited to after-insurance balances for services authorized by CSHN clinical staff. *After-insurance* translates to balances remaining because of

co-insurance; annual deductibles; non-covered, but medically necessary care; or coverage denied for *other than* a failure to comply with the private payor's administrative rules. For *uninsured* children, assistance applies to any services authorized by CSHN.

For children covered by Vermont Medicaid, assistance is limited to those (few) goods and services deemed by CSHN clinical staff to be medically necessary, but for which Medicaid coverage is denied. CSHN staff have a solid working relationship with decision and policy-makers at Medicaid, so we have had some success in securing coverage through direct negotiation.

CSHN financial assistance is available to all families whose children are enrolled in CSHN regardless of family income or other coverage. Families apply for the coverage.

CSHN applies *cost-sharing* to its financial assistance. Families report family size and income at the time of their initial application and annually on the anniversary of their initial application. CSHN assigns families to a *Cost Share category* on the basis of income and family size, using 225 percent of Federal Poverty as the basis. (Currently, that translates to approximately \$46,500 annually for a family of four.)

- Families who fall below 225% of the FPL and whose children do not have Medicaid are classified "Exempt" meaning that (a) CSHN financial assistance begins with the first dollar of authorized after-insurance cost and (b) the family is asked to apply for Medicaid.
- *Medicaid* means the child has Medicaid coverage and CSHN assistance comes into play only in very limited circumstances.
- Families who are above 225% of the FPL are assigned to one of five *Cost Share* categories, each category having an income-sensitive annual deductible. This deductible is the amount the family must pay before CSHN assistance triggers on.

For FY 2008, the five deductibles range from \$230 to \$600 per benefit year.

#### The setting:

Vermont has a very limited payor community. Essentially, there are three *private* payors in the state: MVP, a New York-based managed care organization; Blue Cross/Blue Shield of Vermont, a non-profit, full-range carrier; and CIGNA, a for-profit full-range carrier. Vermont Medicaid is a major player with its quite generous (SCHIP) coverage available to families up to the 300% FPL level. Approximately 65% of all children enrolled in VDH/CSHN have Medicaid coverage either as sole payor or in combination with private plans. Finally, the state of Vermont has launched a number of innovative coverage plans under the umbrella of Green Mountain Care. Green Mountain Care melds state general fund subsidies, employer-based plans, employer

"contributions," state-federal Global Commitment funds, and policy-holder premiums to extend coverage to Vermonters who might otherwise be un- or under-insured. Children with special health care needs are not the primary target of these plans.

With that as a back-drop, the reality is that CYSHCN and their families continue to face significant unmet coverage needs. Over the years CSHN has provided limited "safety net" coverage as payor of last resort. The ever-rising cost of private coverage has driven employers (still the main source of health care coverage in the state) to seek plans quite different from the standard plans of the recent past. Plans with very high deductibles (sometimes coupled with health savings accounts, but more often not), plans with significant exclusions (physical, occupational, and speech therapies, out-of-network care), and plans with quite low caps on payouts for specific services, most notably prescription medications and the therapies, leave many families to be more under-insured than un-insured. Finally, providers, especially out-of-state providers, are tending away from accepting Vermont Medicaid payment. As a result, the CSHN safety net is being called on more and more by families who, on paper, seem to have coverage, but for whom CSHN's role as second payor is ever-more primary.

It is not for lack of desire to help that we submit this application for the CYSHCN State Implementation Grant. It is our strong desire to help that motivates us, for we know all to well that our safety net is far too small, too tattered, and too limited in its application truly to serve families. It is not a sustainable payment source. It is not realistic to think that funding adequate to the needs of some 5,000 enrolled families for this patient-specific direct service is forthcoming from our traditional funding sources (MCHB Title V and state general funds) nor should it be. As a public health program our resources must be focused lower on the MCH pyramid were we can leverage greater impact and support for more families. We will utilize SIG funds and the three year grant period to work with our partners, most of whom we have already mentioned, to develop insurance coverage that is adequate and accessible to CYSHCN and their families. Carol Hassler, MD, CSHN Medical Director, and Stephen Brooks, CSHN Operations Director, with Brooks as lead, will coordinate the initiative to shift emphasis and reliance away from CSHN's very limited financial assistance capacity and toward other payors far more capable of meeting family need. This effort will be based upon the results of comprehensive needs assessment, building on work done in support of the state's MCHB Title V Block Grant with follow-up assessment tailored specifically to the focus areas of this grant. We will partner with

Parent to Parent of Vermont (P2P), the state's Family Voices entity, and the Vermont Parent Information Center (VPIC), Vermont's designated PIRC agency to complete the needs assessment portion of our work in the first six months of the grant period. We will work with Parent to Parent, VPIC, the Vermont Child Health Improvement Program (VCHIP) and additional partners to assess family need and current public and private coverage, and to develop model coverage plans for presentation to policy makers both within state government and without.

### III D. Vision: Community-based service systems are organized so families can use them easily (CIS Community Integrated Services)

The Medical Home goals and objectives address one very important strategy for making "the system" organized—a source of care coordination. The family and Medical Home, in partnership with a care coordinator from within or without, can approximate a smooth-functioning "virtual" system of care for an individual child, no matter how complex or fragmented the components. Our Community Integrated Services goals and objectives, however, address the obverse of that coin, the organization of the system itself. The more coordinated, rational, readable, communicative the system itself, the more directly accessible to families the services will be—and the less burdensome on the layer of care coordinators.

## CIS Goal 1: All AHS integrated children's services initiatives are effectively linked, and where feasible, merged, to achieve greatest benefit for families and CYSHCN

The multiple initiatives emerging from VT/AHS for integrating children's services are described in the needs assessment. The Governor has just designated a 5-member group to design integrated services for children with disabilities. We intend for this newest group to serve as a steering committee, with project resources and leadership, to integrate the "integrating initiatives." The project will facilitate this group representing leadership of each initiative, to review the missions and process of each initiative and to strategize methods to assure coordination of effort, collaboration, efficiency, and innovation. We have the commitment (see letters of support) from members of the Governor's group, which also includes the MCH Director, key member of this project, to pull all the initiatives together into a meaningful whole. Parents will be key participants in the group. Project staff will track this integration through an annual report—a map of the goals and relationships—will inform the initiatives and assure the greatest benefit for CYSHCN and families.

## CIS Goal 2: In every region, Medical Homes and families participate in community-based initiatives such as Building Bright Futures (BBF)

Originally focused on early child care services, BBF has expanded to encompass integrating many services in support of young children and young families. However, health care has been a relative latecomer to the community process. We will work with the AAP to define strategies that will increase medical homes' abilities to participate in the BBF regional councils and to infuse health and public health approaches into the global planning effort. Similarly parents participate in some BBF regional councils. P2P will be supported in recruiting and mentoring parent participants in BBF.

## CIS Goal 3: VDH/CSHN staff are fully integrated into local coordination systems as the local CYSCHN health resource experts; see also MH Goal 4

A 1987-1990 SPRANS grant enabled VDH/CSHN to expand from a Burlington-based program to one with a regional presence—in some regions. Those regions enjoy a "walk-in" information capacity, ease of team care conferencing, home visits—and the regions without find informal teaming and collaboration less frequent. VDH/CSHN/CDC strategic planning will address, design, and implement increased and equitable regional presence and resources. A VDH/Office of Local Health/CSHN workgroup will be established to build a consistent CSHN presence in each region, working with State Personnel where needed to blend/reallocate positions so that no new positions are needed. The CSHN regional staff will solidify connections with Medical Homes (see MH Goal 4), and will represent the system of care for CYSHCN in the community. We will also explore the resources which would be needed to increase the formal connection of regional VDH/CSHN/CDC staff with regional P2P/VPIC representatives, through our collaboration with P2P/VPIC. In addition, the project's Family goals/objectives address the enhancement of the VDH/CSHN website as a core resource for families and Medical Homes.

III E. Vision: All children and youth will be screened early and continuously for special health care needs.

## Screen Goal 1: The Medical Home will be the core ongoing resource for health and developmental screening

The assurance that all children are screened continuously for special health needs depends on several interrelated elements: children must have access to the sources of screening; the

and records from VDH/CSHN programs. Under this project, BIN will maintain its identification and outreach efforts. In addition, the BIN public health analyst will expand his support to VDH/CSHN for essential, enhanced surveillance and data analysis, both for needs assessment and patient care, and will participate in all information system activities of the project (see Methodology introduction).

## Screen Goal 3: Community based sources of screening will collaborate and coordinate with Medical Home to assure comprehensive screening

Children also receive screening from sources other than medical homes; coordination with the medical home is essential so that the family can be sure the medical home has the most comprehensive view of their child's health concerns. Key screening collaborators will be identified, such as WIC, Part C, Headstart, and schools. The project will inventory the prevalence, practices, relationship to the Medical Home and status of childhood screening resources and their follow-up next steps. Strategies for improving the connection of these screening resources to the Medical Home will be designed, piloted, implemented and monitored.

The project will collaborate with P2P to increase self-advocacy of families for early and continuous screening, through promoting <u>Bright Futures</u> guidelines and expectations to families

The new Medicaid APS program includes a component whereby a health status assessment is performed with enrolled patients, including children. This health status assessment, designed for adults as a health self-management tool, is a new source of health screening for the children who are targeted by APS outreach. Through the existing VDH/MCH/AAP/AAFP working group and its regular meetings with Medicaid, the project will forge agreements with Medicaid to assure that all APS Health Assessments of children are expanded to coordinate with the Medical Home.

## III F. Vision: YSHCN receive services necessary to make transitions to all aspects of adult life.

Goal: Provide a smooth transition from adolescence to adulthood and independent living

That the transition from the children's system of healthcare to the adult system is difficult is substantiated in our strength and needs assessment, the stories of families enrolled in VDH/CSHN, and our own observations.

screening must be performed competently and comprehensively; the system of care must provide the post-screening next steps; and the multiple sources of screening must be coordinated for best effectiveness. This goal addresses the quality of the practice of screening. Our aim is that Medical Homes will screen children using best practice guidelines. The new edition of <u>Bright Futures</u> has just been published. The project will promote its use, through continuing education presentations of <u>Bright Futures</u> around the state, focusing on expanded developmental screening guidelines created by VCHIP and the VT AAP and added to the comprehensive <u>Providers' Toolkit</u>. The presentations will also include guidelines for next-steps to assure timely and appropriate follow-up for positive screens.

## Screen Goal 2: Families and MH will have timely access to follow-up for positive screens, especially for children with suspected developmental concerns

With the emphasis on improved Medical Home developmental screening, the project will focus on assuring that there is a system of developmental follow-up to respond to concerns raised by screening. The VDH/CSHN Child Development Clinic is a statewide program of interdisciplinary (developmental pediatrician, medical social worker, nurse practitioner, neuropsychologist) teams providing diagnostic evaluations, treatment planning and follow-up for young children with developmental concerns. As developmental screening improves in comprehensiveness and timeliness, the system must be ready to respond. The VDH/CDC strategic planning and implementation process will assure that there is an ideal fit between medical home and family needs as identified by screening. The strategic planning process has been initiated from within, and also includes a pilot family advisory committee in one region (see needs assessment), and through the project will expand to include input from PCPs and community partners. Service data will be used monitor timeframes and trends in referral concerns and outcomes. New models of service, such as quick focused consults, will be piloted, and appropriate staffing levels will support implementation.

The project will continue the early identification and referral work of the Birth Information Network, which was created by a Centers for Disease Control grant with the goal of reducing morbidity and mortality due to birth defects. BIN has worked to create a system to identify infants (up to one year) with specified birth defects that may respond to early intervention and treatment by the health care system, refer families to appropriate services. BIN uses data sources such as vital records, Medicaid claims, reports from hospitals and physicians

In Vermont, the Agency of Human Services (AHS) has taken as a priority the readiness of the state's youth to transition into the adult world...work, education, independent living, age-appropriate health care. We will address the goal of smooth transition from adolescence to adulthood and independent living for Vermont's CYSHCN by means of a number of collaborative initiatives, including readiness to work, but focusing *primarily* on the healthcare system in our state.

We will work with the AHS JOBS program to help inform CYSHCN and their families as well as their care teams, of transitional resources that are available to them.

Our primary focus, though, will be on the transition from the pediatric medical home to the adult or family practice setting. We will work to help CYSHCN and their families make informed decisions when choosing pediatric care and pediatric medical home and will work with the family and the medical home to ensure that there a planned and considered transition to adult care, and that the transition be smooth and supportive.

Finally, we will work with our colleagues in Children's Mental health to ensure that services, including transitional services, for youth with mental health needs are available, accessible, and evidence-based. We will work with Vermont's Department of Mental Health as they plan for and implement their own State Implementation Grant to strengthen services to youth and their families. Our goal, and that of the mental health programs, will be to ensure that our work is complementary and not redundant.

We are particularly excited by the opportunity we have to begin, along with the Vermont Blueprint for Health, to develop a community-based model for the management of chronic disease in children ready to *plug into* the Blueprint model that now focuses on adults with or at risk of chronic disease.

As we have stated throughout, we will base our work on transition in the pediatric medical home. We believe strongly that child health is centered at the medical home. Because VDH/CSHN has very strong ties with the Vermont Chapter of the Academy of Pediatrics and the Academy of Family Practice, we are well positioned to work with both groups not only to develop transition plans, but to put those plans into practice for the benefit of Vermont CYSHCN. In our work plan as well as our planning table, we will go into more detail, including our plans to assess readiness among pediatric and adult/family primary care to provide meaningful and timely transition guidance and services to CYSHCN in Vermont.

#### IV. WORKPLAN

Please refer to table, following

The work plan has been designed to fully utilize the skills and expertise of VDH leadership and our state and local partners and is intended to take full advantage of the opportunities presented by the serendipitous organizational initiatives that have burgeoned over that last few years. Finally, Vermont is fortunate to have many committed parents and advocates who are willing to commit to this grant's goal of creating a comprehensive, community based, and responsive system of care for CYSHCN.

Three VDH leaders will be primarily involved in grant oversight and implementation. All three VDH leaders will coordinate closely in orchestrating the complex systems changes objectives. Carol Hassler, MD, the Medical Director of Vermont's Children with Special Health Needs Programs and Steve Brooks, the Operations Director of CSHN, will provide project oversight. Steve Brooks will direct the hiring of the Project Coordinator, oversee the actual creation and management of appropriate contracts, and manage the project's budget. Dr. Hassler and Dr. Wendy Davis, Director of the Division of Maternal and Child Health, will coordinate on establishing partnership with PCP's and other professionals central for implementing grant activities.

The Project Coordinator will be responsible for management of the implementation plans for each objective, support advisory groups relation to grant activities, establish relationships with community groups and professional organizations, communicate with state staff on policies and procedures. In addition, the Title V Planning Specialist, Sally Kerschner, will assist with the completion of the Strengths and Needs Assessment. The key personnel will coordinate on insuring the completion of evaluation activates and incorporating the evaluation information into grant activities for systems improvements.

CROSSWALK	GOAL	OBJECTIVE	ACTIVITY	Timeline	VDH/Partners	Evaluation
		Vision: Families partner in decision making at all		eceive.		
MH CIS	Family Goal 1: VDH/CSHN is recognized as a model	1.1. Families are central to a culturally sensitive information exchange among professionals with regard to treatment and care plans.	1.1.1. Evaluate state's CSHN program's communication with families for clarity, completeness and cultural appropriateness	Year 1 8/08	P2P/VPIC (VFN after 7/1/08)	Measure family satisfaction with
Transition	program with respect to integration of family centered care in all its activities	regard to treatment and care plans.	completeness and cultural appropriateness		FITP	regard to effectiveness of communication
	Caso in an is assistant				FAHC-CSC	with state's CSHN program.
			·		CHaD	.Measure family satisfaction with
					Condition-	regard to
					specific networks	effectiveness of communicating
					VCHIP	among professionals and
			1.105		VDH Health	families;
MH CIS		·	1.1.2 Evaluate information exchange among all partiesincluding state's CSHN program, primary care, specialty care,	Year 1 9/08	Surveillance	Measure primary care satisfaction
Transition			referral sources, and families.			with regard to effectiveness of communication
						with state's CSHN program
MH			1.1.3. Establish criteria to evaluate quality of	Year 1 12/09-	┪ .	see above,
CIS Transition			communications among all parties to the care of CYSHCN	1/09		utilizing VCHIP &
			(timeliness, usefulness, accessibility, clarity)			Surveillance capacity
MH CIS			1.1.4 Revise existing communication tools and processes and/or create new tools for	Year 2 july- sept		
Transition			families using information from Year 1 assessment.	Sopt		·
MH				Year 2 june -	1	
CIS			1.1.5 Revise CSHN referral and intake	aug		
Transition			system for effectiveness in communicating between professionals and families			
MH			1.1.6 Using assessment from Y1, create	Year 2 june-	1.	
CIS Transition			family mentor system using Community Parents as mentors	may		
MH			1.1.7. Maintain systems (as developed in Y1)	Year 2 June-	•	
CIS			for families to be involved in all aspects of	May		
Transition		N	grant implementation. Insure that families			
			are seated on Advisory Committee and that their feedback is included in all grant			
			activities			
MH			1.1.8 Newly developed communication tools	Year 3 June -	7	. Annual spot
CIS			and systems in full use in year 3.	May		surveys of families
Transition	1		Assessment of effectiveness underway.			and other

				 stakeholders
MH CIS Transition		1.1.9 Referral and intake system fully implemented. Assessment of effectiveness underway.	Year 3 June - may	. Annual spot surveys of families and other stakeholders
MH CIS Transition	1.2. CSHN program demonstrates strong working relationship with parent support networks, statewide	1.2.1 Inventory existing groups whose missions relate to CYSHCN and identify areas of the state where groups do not exist or whose activities have diminished.	Year 1 1/09- 2/09	Survey affiliated/partnered groups and participating families for evidence of CSHN program's commitment to family input and
MH CIS Transition		1.2.2 Partner with existing councils and advisory groups in each of the 12 AHS regions, statewide, whose missions include CYSHCN and systems of care to assess level of family representation and participation.	Year I 04/09- 05/09	participation. begin meeting w/groups w/designated VDH/CSHN staff representation in each
MH CIS Transition		1.2.3. Establish regular meetings of CSHN and VFN management teams to review data (including stories and qualitative data from families) for PDSA improvement actions.	Year 1 12/08	establish recurring meetings.
MH CIS Transition		1.2.4 CSHN supports data validity and compatibility initiatives at P2P/VPIC (VFN).	Year I	
MH CIS Transition	1.3. CSHN program partners with parent advisory groups to institutions serving children (FAHC/DHMC)	1.3.1 Liaison to children's specialty care at FAHC and DHMC.	Year 1 11/08- 1/09	See above.
MH CIS Transition		1.3.2 Collaborate with existing family advisory councils at FAHC & DHMC.	Year I 11/08- 1/09	See above
MH CIS Transition	1.4. CSHN program identifies and partners with condition-specific parent/advocacy groups to seek their input on the system of care for CYSHCN	1.4.1 Assess and develop relationships with other parent support groups, such as those that are created around a specific disease or issue.	Year 1 3/09- 4/09	See above
MH CIS Transition	1.5. CSHN program and its partner organizations promote concept of Parents as Mentors within the several advisory group	1.5.1 Assess existing need for family mentor system using Community Parents as mentors	Year 1 5/09 – Year 2 6/09	Survey families affiliated with al partner agencies
MH CIS Transition	1.6. In all its actions, CSHN program demonstrates and models cultural sensitivity and competence as evidenced in parent ed publications and incorporated into provider ed activities.	1.6.1 Establish "report Card" system as means for councils to grade the system of care for CYSHCN	Year 1 11/08- 05/09	evaluate first round of report cardsvalidate in council meetings
MH CIS Transition	1.7. Integrate data collected by P2P/VPIC (VFN) and CSHN to develop combined view of the CYSHCN population statewide.	1.7.1 Continue to support data validity and compatibility efforts at P2P/VPIC (VFN)	year 2 June- may	
MH CIS		1.7.2Continue regular meetings of CSHN and VFN management teams to review data	year 2 June- may	

Transition			(including stories and qualitative data from families) for PDSA improvement actions.			
			1.7.3 Maintain systems (from Y2) and	77 27		
MH				Year 3 June -		Annual reports to
CIS			continue to insure that families are involved	may		CSHN
Transition			in all aspects of grant implementation.	7,		management
MH	·		1.7.4. Family involvement is sustained in	Year 3 June –		Annual reports to
CIS		•	future CSHN program planning initiatives to	May		CSHN
Transition			ensure that families are seated on Advisory			management
			Committee.			
MH		·	1.7.5. Continue regular meetings of CSHN	Year 3 June		Annual reports to
CIS			and VFN management teams to review data	May		CSHN
Transition	•		(including stories and qualitative data from	[ .		management
			families) for PDSA improvement actions.			
			These meetings are now sustainable and			
		•	continue as a permanently operationalized	[		
			communication after grant funding ends.			
MH		1.8. Receive regular feedback from advisory groups	1.8.1 Insure that families are seated on	year 2 June-		
CIS		that represent and support CYSHCN and their	Advisory Committee	may		
Transition		families as to the F-C and C-C of services they				
		receive (beyond CSHN program services and	·			
	•	including				
MH			1.8.2 In collaboration with other	year 2 June-		
CIS			organizations establish or reinvigorate	may		
Transition		·	CYSHCN-oriented advisory groups in un- or			
Transition	İ		under-served areas. Insure that families are			
			seated on Advisory Committee.	1		
MH			1.8.3. develop "report card" system for local	year 2 june-	·	
CIS		· ·	advisories to "grade" the state's delivery of	august		
Transition			family-centered and culturally-competent			
Transmon			services (beyond the traditional CSHN			
	·		services)			
MH			1.8.4. Based upon "Report Cards" from	Year 3 June -		CSHN Annual
CIS			vested advisory groups, statewide, CSHN	May		Report available
Transition			issues annual report to stakeholders	iviay		for review.
Transmon			measuring progress in key areas of family-			Tor review.
			centeredness, cultural competency, and			
	İ		transparency.			
NII		1.9 Establish in-service training for CSHN and	1.9.1 Training and refresher in F-C, C-C	Year 3 June –		Review of
MH		contract staff in best practice of family-centered and	integral to new hire orientation, staff annual	May		personnel files,
CIS			performance reviews, and contract renewals.	iviay		
Transition		culturally competent services.				contract/grant
			Fully sustainable.	+ ** * * * * * * * * * * * * * * * * *		files.
MH		1.10 Family mentoring will be enhanced and	1.10.1 Family mentor system using	Year 3 June –		. required report
CIS		supported statewide.	Community Parents as mentors is statewide.	May		from P2P/VPIC
Transition				<u> </u>		>VFN
		Medical HomeVision: CYSHCN receive coordinat		cal Home		
Family	MH Goal 1: The MH, with	1.1A MH work group, including parents, will be	1.1.1 establish workgroup, involving	Year 1 &	Parents, AAP,	Group established,
CIS	appropriate infrastructure and	established to guide and design MH activities	members of the original VT MH grant	Ongoing, begin	AAFP	meetings
	financial support, is the core		advisory group	9/08		documented
	support to families with		, , , ,	1		
	CYSHCN in their role as the					
	C 13HCM III their fole as the			_L	1	1

-	ultimate manager of their child's care.					
CIS \$		1.2 The status and variation in Medical Home demographics and services will be assessed and analyzed regionally	1.2.1 Using available datasets, Medical Homes (including group, solo, hospitalowned) will be inventoried statewide, for caseload, range of conditions, use of careplans, age range.	Year 1:12/08- 6/09	Health Surveillance; Medicaid	Report generated PH Grand Rounds
Family CIS			1.2.2 Assess status/ability of FQHC/Rural Health Clinics in providing primary care service for CYSHCN by survey	Year 1: 12/08- 3/09	ORH	Report generated
Family CIS		1.3Examples of effective VT MH and their strategies will be showcased	1.3.1 AAP and AAFP will query primary care membership; P2P will query parents through newsletter, results compiled, presented at annual meetings	Year 1: 9/08- 3/09	P2P, AAP, AAFP	Report generated; presentations made
Family CIS \$ Transition		1.4 The comprehensive care plan as a strategic tool for partnering with families and for communication and collaboration with other providers will increase in use, Medicaid reimbursement, and family satisfaction	1.4.1 Clarify with Medicaid the billing and payment procedures; promote through academies and activities developed to increase use of plans; monitor through claims data	Year 1: 9/08 clarify; 11/08- 6/09; promote; 6/09 to end, monitor	AAP, AAFPMedicaid,	Promotion meetings and activities; monitor claim rates
CIS family	MH Goal 2: The MH collaborates and communicates effectively with providers of specialty care, community services and other members of each child's care team to facilitate coordinated delivery of care	2.1 The methods of communication and collaboration which medical homes, and specialists and community providers, want and need from each other will be documented, studied, and will inform next activities. Parents will observe and participate in analysis	2.1.1 Update VT medical home 2003 primary/specialty survey.	Year 2: 6/09 – 12/09	VCHIP; AAP; P2P	Survey completed.
CIS family			2.1.2 Focus groups of medical home, specialty, and community providers will be asked to address communication needs	Year 2: 6/09- 12/09	VCHIP; AAP; P2P	Focus groups completed
CIS Family			2.1.3 strategies for better tools for communication defined and spread	Year 2: 12/09 to end	VCHIP; AAP	Use monitored
CIS family	MH Goal 3: Publicly funded case management programs will include family and medical home as central	3.1 Service planning processes emanating from other sources (e.g., IEP; IFSP; USP; CSP) will increasingly collaborate with the Medical Home	3.1.1 Current protocols for developing these service plans will be reviewed with respect to MH and family role	Year 1: 9/08- 12/08	VCHIP; AAP	Report completed
CIS family			3.1.2 Project will meet with leadership of these interagency initiatives to promote medical home and family involvement; design method to monitor	Year 1: Begin meeting by 3/08; design method by 9/09; document change, to end	AHS; VCHIP; P2P	Document improved MH and family involvement
CIS Family \$		3.2 Medicaid Case Management programs will partner with child's Medical Home in all cases	3.2.1 Establish quarterly meetings with Medicaid case management initiative leadership, AAP/AAFP; parents	Year 1: 7/08, ongoing	Medicaid, APS, AAP, AAFP, P2P	Meetings documented
CIS Family \$			3.2.2 Project and AAP will work with APS and Medicaid to establish protocols for case management including family and medical Homes roles; monitor improvements	Year 1: New protocols, by 3/09	Medicaid, APS, AAP, AAFP; P2P	Protocols completed. Family and PCP surveys of satisfaction

CIS \$ Family	MH Goal 4: Title V VDH/CSHN staff, services and resources are organized to support the family and MH	4.1 Medical homes serving VDH/CSHN enrolled children and SSI-eligible children will be identified	4.1.1 Medicaid claims data will be reviewed for SSI objective; VDH/CSHN database, for VDH/CSHN children	Year 1: By 12/08; ongoing quarterly queries	Medicaid; epi?	Reports generated
CIS		4.2 VDH/CSHN regional staff will create affiliations with medical homes in their regions	4.2.1 Initial outreach visits to regional practices; PCP feedback form	Year 1: By 03/09		Visits documented; feedback form to PCPs
CIS Family		4.3 PCPs for VDH/CSHN children collaborate regularly with the VDH/CSHN contact person for their VDH/CSHN patients.	4.3.1 Maintain database of VDH/CSHN primary contact person; develop other strategies	Year 1: By 03/09		Database maintained; survey of PCPs for feedback
CIS Family \$		4.4 Improve VDH/CSHN patient information system to assure efficient and effective communication between VDH/CSHN program, medical homes, and families	As above	Year 1 & ongoing		
CIS Family \$		4.5 SSI workgroup, including parents, will create method to engage medical homes in care planning for children with SSI coverage;	4.5 Create workgroup; promote medical home and care plan	Year 2 and 3	SSA, disablitly determination unit, Medicaid, APS	Title V State Performance Measure
CIS Family \$ Screen	MH Goal 5: Child Development Clinic will fulfill essential function in support of Medical Home	5.1. Create a strategic plan for VDH/CSHN/CDC services to insure VDH/CDC fulfills essential functions in support of Medical Home developmental screening and response.	5.1.1 Continue with Child Development Clinic (VDH/CDC) strategic planning process (beginning Nov 2007) with VDH/CDC professional advisory committee	Year 1: 7/08 &ongoing	P2P; AAP;	
CIS Family Screen		5.2 The VDH/CDC system of services will include components of consultation, evaluation, treatment planning, follow-up, and will be family-centered, collaborative with medical homes and community-based services	5.2.1 develop, pilot, improve, expand new model	Year 2 & 3		
		Vision: Families have adequate private/pub	lic insurance to pay for the services they need			
CIS Trans Family	Financing Goal 1: Improve the financing and reimbursement of services and benefits needed by CYSHCN and public/private insurance plans adequately address the medical and related needs of CYSHCN and their families	1.1. CYSHCN have access to insurance	1.1.1. Assess ideal components of insurance coverage for CYSHCN for presentation to policy makers and insurers. Include recommendations for insurance needs for YSHCN who are over age 21.	Year 1 sept- march	Medicaid Catamount Health Private payors BISHCA VDH Health Surveillance Division P2P/VPIC > VFN Consultant to review coverage offered by private plans in other states.	Survey of families NS-CSHCN data
CIS Trans Family			1.1.2 Continue to develop outline of ideal /essential components of insurance coverage for CYSHCN for use in presenting to policy makers and insurers.	year 2 June- may		Survey of families & NS-CSHCN data

Trans Family	only where need is clear and documented (medical necessity, no other payor, no other recourse)	of last resort policies and practices, particularly assurance that all other potential payors have been exhausted.	dec	practice review.
CIS Trans Family		1.3.2 Reconfigure financial supports to families – financing for direct services vs. care coordination	year 2 June- may	Policy and practice review.
CIS Trans Family	1.4. Eligible CSHN families fully participate in Medicaid insurance program.	1.4.1. Utilize Medicaid application as application for CSHN financial assistance in year one.	Year I july	Assess compliance.
CIS Trans Family		1.4.2 Investigate potential strategies for incentives for families to apply to Medicaid.	Year 1 june- dec	Evaluate benefits to family of Medicaid coverage.
CIS Trans Family		1.4.3. Assess data system requirements to enable real time review of CYSHCN Medicaid eligibility status by state's CSHN program.	Year 1 june- dec	Review progress of work group.
CIS Trans Family		1.4.4 Continue Y1 activities of adopting Medicaid common application as standard application for CSHN financial assistance, including amending any relevant administrative rules.	Year 2 june- august	Assess compliance and reception on policy by families and OVHA eligibility determination unit
CIS Trans Family		1.4.5 Develop accessible and intuitive system to determine Medicaid status of CYSHCN enrolled in state's CSHN program.	Year 2 august- jan	test data extracted against chart and manual client status review.
CIS Trans Family		1.4.6 Develop plan with partners to address gaps and inconsistencies found in Katie Beckett eligibility determinations across the state	year 2 jan-mar	Eligibility outcomes review
CIS Trans Family		1.4.7 Use system created in Y1 to identify Medicaid eligible families and assist with enrollment.	year 2 June- may	Pilot in-person and/or phone- based TA to families applying for Medicaid
CIS Trans Family		1.4.8 Implement Katie Beckett strategies as determined in Y2.	Year 3 July	family survey; assessment by OVHA eligibility determination staff
CIS Trans Family	State's CSHN program resources are directed toward needs clearly identified through current and thorough needs assessment	1.5.1Study opportunities to participate in CCP/CCMP – ID specific subgroup of CSHN for pilot	year 1 sept-dec	Evaluate existing CSHN resources in proposed pilot area(s)
CIS		1.5.2 Identify or create screening tools to use	year 2 july-sept	Test protocols and

Trans Family			in CC/CCMP program interventions ?ID specific subgroup of CSHN for pilot cshn/cc/ccmp collaboration			outcomes with CCMP/CC field staff (or managers)
CIS Trans Family			1.5.3 . CSHN services and resources realigned as result of progress toward greater participation of public and private third party payors and relegation of CSHN POLR funds as last recourse.	Year 3 December - May		Assessment of utilization of CSHN POLR funds; VDH/AHS fiscal reports showing allocation of CSHN resources to core functions.
CIS Trans Family	·	1.6. YSHCN are adequately insured after reaching the age of 21 years	1.6.1 Develop system to identify youth nearing age 21 and create informational materials and internal protocols to address applicable insurance systems.	Year 1 oct		Compare queries against chart review.
CIS Trans Family			1.6.2 Implement system of identifying youth and offering counseling as to insurance options.	Year 2 June- august		Compare queries against chart review. & Pilot initial contacts with YSHCN and their families based upon database
						queries of medical status, payor information, care plan status.
CIS Trans Family			1.6.3 Make operational the system of identifying youth who will be nearingage limit of 21 years and offer counseling to family as to options.	Year 3 january		
CIS Trans Family		1.7. All parties involved in issues of adequate insurance for CYSHCN are well informed as to needs and options.	1.7.1 Collaborative work group convenedto ensure broadest grasp of issues, option, and resourcesearly	year 2 nov-jan		Review notes and progress report(s) of work group
CIS Trans Family		·	1.7.2 With partners, CSHN provides (or ensures provision of) TA to provider community, families, and others working with CYSHCN and their families.	Year 3 January - may		Survey of partners.
			and continuously for special health care needs			
MH CIS	SCRN Goal 1: MH will be the core ongoing resource for health and developmental screening	1.1 Medical Homes will screen children using best practice guidelines	1.1.1 Support regional roll-out and promotion of Bright Futures guidelines by AAP VT through continuing education meetings around the state	Year 1	AAP, AAFP	
MH Family CIS	SCRN Goal 2: Families and MH will have timely access to follow-up for positive screens, especially for children with	2.1 maintain current high rates of newborn screening, timely diagnosis, and low lost-to-follow-up rate	2.1.1 Maintain necessary newborn screening staffing levels	Year 1 & ongoing		NPM

OIC			1.1.3 Develop system of TA for families to	Year 3 june –		Family survey;
CIS Trans		•	access alternative financing systems in	sept		SLAITS data;
		·	response to assessments of Y1 and Y2.			1b. Reports of
Family			response to assessments of 11 and 12	,		interaction with
						policy makers,
						payor
						administrators,
						regulators.
- CTO			1.1.4 Report re: essential components of	Year 3 June		105010101
CIS	·		insurance coverage for CYSHCN is	january		
Trans	·		distributed to appropriate policy makers and			
Family			insurers.			
				i i	•	
CIS			1.1.5. Coordinate with OVHA/CCP/CCMP	year 3 june -		
Trans	1		to implement tools developed in Y2. ??ID	sept		
Family			specific subgroup of CSHN for pilot	•		·
rainity						
CIS			1.1.6 System to readily identify a CYSHCN	Year 3 january		
Trans			program client's Medicaid status is fully			
Family			operational			
railiny			•			
CIS		1.2. CYSHCN medical needs are paid for by	1.2.1. Assess coverage (and services	year 1 july-sept		Chart review and
Trans		public/private insurances except in extraordinary	covered) for children who access CSHN			survey of families
Family		situations.	Financial Assistance			
1 anning						
CIS			1.2.2. Assess applications and outcomes for	year 1 nov-jan		Eligibility
Trans			Katie Beckett (DCHC) for consistency are			outcomes review
Family			over age 21.	1		
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CIS			1.2.3. Assess extent of (and gaps in)	year 1 sept-		Survey of families
Trans			coverage to CYHSCN by private payor	march		and providers
Family	*		plans.			
CIS			1.2.4 Use assessment information to develop	year 2 June-		Chart and ledger
Trans			strategies for alternative payment options for	may		review and survey
Family			families who access CSHN Financial	1		of families
_			Assistance			& Survey of
			·			families and
		·				providers
CIS			1.2.5 Institute Medicaid common application	year 3 july		Family survey
Trans			as standard application for CSHN financial			
Family			assistance			
CIS			1.2.6 the strategies developed in Y2. are	1		
Trans			finalize as permanent program operations	year 3 january		
Family		+				
CIS		1.3. Title V Payor of Last Resort (POLR) funds used	1.3.1. Evaluate state's CSHN program payor	Year 1 june-		Policy and

	suspected developmental					
	concerns					
MH Family CIS			2.1.2 Complete and implement EHDI/NBS database, establishing access for Medical Homes	Year 1: Finish by 3/09	·	
MH Family CIS		2.2 VDH/CDC responds promptly to positive developmental screen referrals by medical home	2.2.1 design improvements through planning group (see MH 4.1.1)	Year 1	AAP, families	
MH Family CIS			2.2.2 Expand models of service to include quick focused consult, with appropriate staffing levels	Year 2 and 3	AAP, families	
MH Family CIS		2.3 Birth Information Network will identify newborns (up to 1 year) with targeted conditions and provide to all families information about public health VDH/CSHN resources	2.3.1 support data collection and outreach effort; monitor connections made; expand to Medical Home outreach	Year 1: Ongoing; expansion year 2		
MH Family CIS		2.4 BIN will provide greatly expanded health surveillance and data analysis support to VDH/CSHN for needs assessment and patient care	2.4.1 expand data collection and outreach effort; monitor connections made	Year 1: Ongoing; expansion year 2		
MH Family CIS	SCRN Goal 3: Community based sources of screening will collaborate and coordinate with Medical Home to assure comprehensive screening	3.1 The prevalence, practices, interrelationships and status of childhood screening resources and their follow-up next steps will be inventoried and reviewed for opportunities for collaboration with Medical Home	3.1.1 research existing screening resources and methods	Year 2 and 3	VCHIP	
MH Family CIS			3.1.2 Identify key collaborators: WIC, Part C (FITP), Headstart, education	Year 2 and 3		
MH Family		3.2 Increase self-advocacy of families for early and continuous screening	3.2.1 Promote Bright Futures guidelines/expectations to families	Year 1 and 2	P2P	
MH Family Easy to Use		3.3 Forge agreements with Medicaid to assure that all APS Health Assessments of children are coordinated with the Medical Home	3.3.1 AAP/AAFP/Medicaid care coordination leadership	Year 1	AAP, Medicaid, APS	Document agreement
	Vision:	Community-based service systems are organized so fa	milies can use them easily (CIS Community I	ntegrated Services	)	
MH Family Transition	CIS Goal 1: All AHS integrated children's services initiatives are effectively linked, and where feasible, merged, to achieve greatest benefit for families and CYSHCN	1.1 Steering committee of integration initiatives will assure coordination, collaboration, efficiency, innovation	1.1.1 Establish steering committee; annual report	Year 1 & ongoing: Begin 9/08	AHS leadership; P2P	
Family MH	CIS Goal 2: In every region, Medical Homes and families participate in community- based initiatives such as Building Bright Futures	2.1 Strategies to increase MH and family participation will be designed and implemented, and monitored	2.1.1 MH/P2P workgroup to design what it takes; recruit representatives.	Year 1: 6/08- 6/09	P2P, AAP/FP	Increased participation documented
MH Transition	CIS Goal 3: VDH/CSHN staff are fully integrated into local coordination systems as the	3.1 VDH/CSHN/CDC strategic planning will address, design, and implement increased and equitable regional presence and resources	3.1.1 VDH/OLH /CSHN workgroup to design; work with State Personnel where needed to blend/reallocate positions	Year 2 and 3		New org chart;

	local go-to health resource experts; see MH Goal 4					
MH Family		3.2 Explore increased formal connection of regional VDH/CSHN/CDC staff with regional P2P/VPIC	3.2.1 meet with P2P/VPIC	Year 2	· P2P	
<u>-</u>		representatives	·			
		Vision: CYSHCN receive services necessar	y to make transitions to all aspects of adult life			
MH	Transition Goal 1: Provide a	1.1. CSHN programs are well coordinated with	1.1.1. Meet with JOBS/AHS Transitional	Year 1 may -	AHS/JOBS	TV PM: %
\$\$ CIS	smooth transition from adolescence to adulthood/independent living.	AHS/JOBS initiatives.	Services to understand their program offerings, assess areas of collaboration, and define our role in supporting YSHCN and their families.	year 2 july	Mental Health Voc Rehab DOE DOL Act 264 administrators VPIC/P2P (VFN) VCHIP AAP	Children with chronic emotional, developmental, or behavioral problems who received mental health care in the past year
					AAFP	Survey of youth and young adults and their families as to their awareness of transition and tools that would be helpful.
						Survey PCP's as to extent of transition guidance they provide and tools that would be helpful to them.
						Survey family practice and adult practitioners as to most essential transitional guidance from their viewpoint
MH \$\$ CIS			1.1.2 Collaboration with JOBS/AHS Transitional Services is operational. Year 1 communication is resulting in effective collaboration on youth transitional programs.	'Year 2 june - May		. Quarterly reports of collaborative group to CSHN management.
MH \$\$ CIS			1.1.3 Collaboration with JOBS/AHS Transitional Services is operational, Ongoing effective collaboration on youth transitional programs is normative and sustainable.	Year 3 january		Family survey. Status reports of AHS/JOBS administrators.
MH		1.2. Families and Youth/Adults with SHCN are	1.2.1. Work with medical home to coordinate	Year 1 june-		

\$\$ CIS	supported and informed when establishing relationship with medical home.	early transition initiatives.	may		
MH \$\$ CIS		1.2.2 Identify adult practitioners who are willing to see adults with SHCN (both private and FQHC/.RHC) and develop actions to assist them to become familiar with transition tools (CME credits?)	year 1 Jan-may		
		1.2.3 Identify patients of the CSHN program, including the CDC, for whom transition supports are especially appropriate.	Year 1 - Oct		
		1.2.4 Vermont-specific developmental checklist to aid families is drafted and tested with parent representatives in year 2.	Year 2 June - may	1	responses of parents in test group.
		1.2.5. Other specific tools to assist with transition are in development.	Year 2 June - may		
		1.2.6Coordination with CCP/CCMP (OVHA) to assess the policies/content of these programs' services with respect to YSHCN and transition plans is underway.	Year 2 June - may		Reports of discussion provided to CSHN management
		1.2.7 Vermont-specific developmental checklist to aid families and other specific tools to assist with transition are distributed to PCP's with TA as to use in clinical practice with youth and families.	Year 3 February		
		1.2.8 Coordination underway with CCP/CCMP (OVHA) to assess the policies/content of these programs' services with respect to older YSHCN and transition plans.	Year 3 September		

	1.3. Youth and adults with SHCN have access to PCP's who are trained in their special wellness and specific medical needs.	1.3.1 Assessment activities to create/adapt Vermont-specific developmental checklist to aid families. Create/adapt other specific tools to assist with transition	year 1 may – year 2 august		·
·		to assist with transition			
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		1.3.2 Begin coordination with CCP/CCMP (OVHA) to assess the policies/content of	Year 1 dec-feb		
		these programs' services with respect to older YSHCN and transition plans.			
		1.3.3 Identification of and assistance to adult practitioners who are willing to see adults	Year 2 oct- january		. Register of
		with SHCN (both private and FQHC/.RHC)	January		contacts, responses, and results of survey
		underway.			of identified practices.
			77. 0.7		
		1.3.4 System of incentives and information around transition tools in development	Year 2 June - may		. Based on survey of practices.
		(perhaps including CME credits).	· .		
		1.3.5 Information exchange among Medical	Year 3 january		Survey PCP,
		home and adult/family practices to facilitate transition of YSHCN.			Medical Home; Reports of
	1.4 Coming Comments with months health and James	1.4.1 Coordinate with Dept Mental Health to	Voca 1 iula		working groups.
	1.4. Services for youth with mental health needs are	1.4.1 Coordinate with Dept Mental Health to	Year 1 july-	1	Table showing

	accessible and evidence-based	identify areas where CSHN SIG and their SIG may provide opportunities for collaboration (and to minimize redundancies).	sept	Objectives, Goals, and actions for the two grants with commonalities designated.
		1.4.2 Meet with state-level administrators of Act 264 to understand that law and identify opportunities for collaboration with CSHN programs.	Year 1 August	Progress reports to CSHN management
		1.4.3. MOA describing collaboration under development	year 2 august- sept	
		1.4.4 Areas of collaboration with regard to Act 264 are clarified and working agreements are at least in draft form	year 2 dec- march	
		1.4.5 Coordinate with Dept Mental Health (esp on activities that may result from SIG grant application)	year 3 – June - May	Title V Performance Measure: % Children with chronic emotional, developmental, or behavioral problems who received mental health care in the past year.

#### V. RESOLUTION OF CHALLENGES

- 1. Organizations and initiatives with which VDH/CSHN programs must collaborate are undergoing major changes in funding, mission, and organizational structure; their leadership expresses the intent of collaboration with VDH/CSHN on the goals of this grant, while concerned about the necessity of finding stability within their own changing systems before taking on a "special" subpopulation such as CYSHCN. We respond to these concerns with the following: 1) The activities of this project will assist in program planning and development through research based components for CYSHN population which will add substance to the final product and 2) The components as developed for CSHN will also complement and support the development of the program activities for other subpopulations, such as all children and youth or all adults with chronic conditions. 2. Due to capacity limitations, CYSHCN are not being actively considered as immediate priorities by VDH leadership for the Blueprint for Health, an adult chronic disease focused initiative, although there is a specific goal of care coordination for CYSHCN in the long range BP strategic plan. Children who have special health care needs will eventually "age-out" of the pediatric health care systems and become adults with chronic illness an opportunity to include this population in the Blueprint programs.
- 3. CIS: Efforts to create a coordinated system of care coordination for families have been developing for several years through planning between the Vermont Department of Health and the Department for Children and Families. More recently, the AHS Secretary has charged a planning group with designing a plan to integrate services for children and families throughout AHS which will involve planning that will overlap with the goals of the Integrated Systems grant. This CIS initiative (see Introduction) will involve complex change and significant shifts in traditional paradigms by many programs. The MCH Division Director is to play a major role in this planning and welcomes the opportunity to insure that the needs of CYSHCN are included in the planning that lies ahead.
- 4. Sustainability: VDH Leadership is committed to the mission of the CYSHCN Integrated Systems Grant and will support efforts by the Division of Maternal and Child Health and the VDH/CSHN Programs to institutionalize the grant goals. Financial stability is of major concern. The grant is designed to have specific effects on the financial systems to create financial stability by the end of the grant period through expansion of insurance coverage and reduction in VDH/CSHN role as payer of last resort. Some VDH/CSHN statewide clinical services will transition from the

delivery of specific clinical services to the role of enabling services. VDH/CSHN staff will become more linked with the burgeoning care coordination programs (such as those by Medicaid and Blueprint) and with medical homes, and can act as care coordination specialists providing technical assistance to other care coordination personnel statewide, enabling more efficient delivery of clinical services in the communities where CYSHCN live and want to receive their care.

#### VI. EVALUATION AND TECHNICAL SUPPORT CAPACITY

The Vermont Child Health Improvement Program: It is anticipated that a contract will be arranged with the Vermont Child Health Improvement Program (VCHIP,) a research and quality improvement program based in the Department of Pediatrics in the University of Vermont's College of Medicine. VCHIP's mission is to optimize the health of Vermont children by initiating and supporting measurement-based efforts to enhance public and private child health practice. Since its inception in 1999, VCHIP has focused on improving the health of Vermont's children and families by conducting research and evaluation studies and quality improvement projects on a variety of topics (e.g. preventive services, prenatal care, asthma, attention deficit hyperactivity disorder, immunizations, adolescent substance abuse, teen safe driving).

As the Executive Director of VCHIP, Dr. Shaw leads 25 faculty and staff in her program and is responsible for VCHIP projects and work that involves over 30 UVM faculty in the Departments of Pediatrics, Family Medicine, Psychiatry, and Obstetrics & Gynecology. Dr. Shaw is principal investigator for several federally funded projects designed to improve delivery of health care to children, and holds the position of Research Associate Professor of Pediatrics at the University Of Vermont College Of Medicine. Nationally, Dr. Shaw is the co-chair of the American Academy of Pediatrics Bright Futures Steering Committee and Education Center Project Advisory Committee and co-editor of *Bright Futures Guidelines for Health Supervision of Infants, Children, and Adolescents, 3rd Edition* (Oct 2007 publication). Patricia Berry, MPH, joined the faculty at UVM/VCHIP a year ago. She has over 30 years experience in public health, the majority of which was spent at the Vermont Department of Health as a senior administrator and at times, the acting state Title V Director.

Dr. Krulewitz is an experienced practice-based research analyst and has extensive experience in analysis and presentation of data to primary care practices, stakeholders, and community groups in a manner that is actionable for improving the system of care.

VCHIP is providing technical support to three clinical divisions within the Children's

Specialty Center at Fletcher Allen Health Care (FAHC - Vermont's only tertiary hospital, located in Burlington) to examine current systems of care, identify best practices and relevant national guidelines, collect data on the health needs, examine trends in health outcomes, and develop actionable changes to result in improved processes and outcomes of care, to assist these clinical divisions with implementing patient registries and examining opportunities to improve patient education materials by making information accessible via the World Wide Web. Evaluation of this and other pilot projects will guide the direction of these programs. VCHIP will continue to engage pediatric sub-specialists to inform systems changes and improved coordination of care for CYSHCN. VCHIP has been doing this work in collaboration with VDH/CSHN program and with this MCHB/ICS grant, is fully committed to integrating these projects into the plan to improve Vermont's system of care for CYSHCN.

Relevant Experience: VCHIP uses research methodology that combines program evaluation theory, techniques of quality improvement, clinical epidemiology, adult learning theory, and information technology to design projects and interventions to engage health care professionals, state agencies, and community partners in implementing changes to improve health outcomes. VCHIP faculty and staff have extensive experience in designing, implementing, and evaluating multi-site, multi-year research and quality improvement projects. VCHIP has considerable resources relating to the collection, analysis and reporting of quantitative and qualitative data, including four fulltime equivalent PhD and masters level data analysts, an experienced data support staff and the support of research and clinical faculty from a broad array of disciplines at the University of Vermont. VCHIP has conducted evaluations of statewide initiatives that targeted specific patient populations as well as evaluating projects that involve multiple agencies and partners working together to meet the needs of a specific group (e.g., Youth Health Improvement Initiative). VCHIP's ongoing evaluation of the Vermont Blueprint for Health provides an illustration of successfully building a large-scale evaluation system and communicating evaluation findings. VCHIP is conducting both the formative and summative evaluations of this initiative to inform program planning and implementation, identify gaps and barriers to implementing the system of care, and support plans for sustainability. VCHIP is using a mixed methods approach with foci on the collection of quantitative measures (e.g. surveys, questionnaires, medical record review) and the application of qualitative assessment through interviews and focus groups. VCHIP collects and analyzes data and develops evaluation summaries that are used by the Vermont

Blueprint for Health to understand the efficacy of their chronic illness care initiative and plan for future implementation.

Evaluation Plan: VCHIP will evaluate the impact of program activities to improve access to quality, comprehensive, coordinated community-based systems of services for CYSHCN and their families. Evaluation activities will focus on the six MCHB core outcomes identified in the grant guidance and will describe the relevance to the use of evidenced based practice within the medical home. VCHIP will coordinate its evaluation activities closely with the Title V program, family and youth representatives, and relevant community agencies and ensure data collected will guide and inform continuous quality improvement activities. VCHIP will obtain University of Vermont Institutional Review Board approval for evaluation activities as needed. VCHIP will coordinate with Title V and other relevant community agencies to report on the eight MCHB discretionary grant performance measures identified in the program guidance. The evaluation is intended to assess the impact of changes in systems of care on key process and outcome measures for children and youth with special health care needs and their families and to inform plans for sustainability beyond the period funded by the HRSA grant. In essence, it will track progress toward, and guide planning for, the vision of an improved, comprehensive and all-inclusive system of care for CYSHCN in Vermont that is in the forefront of the national Title V community.

Monitoring and reporting process measures: VCHIP will monitor and report on key process measures that reflect the degree of success of interventions to integrate community systems for CYSHCN. This formative evaluation is focused on ensuring that the goals and objectives outlined in the work plan are achieved and to build upon successful strategies for system integration as well as identify and ameliorate problematic aspects of the intervention should they arise during development. Measures will be collected from observations, planning and implementation documents, attendance/participation of key stakeholders, interviews with partners (e.g., Title V, families/youth with special health care needs, community agencies, payers), and ongoing assessment of available databases such as the Birth Information Network.

These measures will enable the VCHIP evaluation team to answer the following assessment questions regarding the effectiveness of the ongoing system integration activities:

• How closely did the implementation match the plan? What types of deviation from the plan occurred? What led to the deviations? What effect did the deviations have on the planned intervention and performance assessment? Who provided (program staff) what services (modality, type, intensity, duration), to whom (individual characteristics), in what context

(system, community), and at what cost (facilities, personnel, dollars)? How well and at what pace are the incremental steps advancing to the vision and goals?

Monitoring and reporting outcomes measures: The key outcome measures that VCHIP will use as indicators of whether the state implementation team is achieving its goals, objectives, and outcomes will be collected through a mixed methods approach that combines quantitative and qualitative data to inform the evaluation. Outcomes that will be assessed include the six MCHB core outcomes, in each case, as percent of CYSHCN.

And the Catalyst Center National Chartbook Indicators:

Percent of children and youth with special health care needs whose families pay \$1,000 or
more out of pocket in medical expenses per year for the child; Percent of CYSHCN with any
unmet need for specific health care services; Percent of CYSHCN without a usual source of
care when sick (or who rely on the emergency room)

In addition, VCHIP, in collaboration with Title V, community partners, and youth/families will address the following questions:

• What program/contextual factors were associated with youth/family and system level outcomes? What individual factors were associated with outcomes? How sustainable were the effects, both for youth/family and system level change?

Using evaluation data for Quality Improvement (QI): Under this grant, an evaluation team will be formed as a subset of the overall grant advisory committee. In order to promote continuous quality improvement during the project, VCHIP will conduct regular reviews of progress towards grant goals using all available data, develop recommendations for improving implementation of project activities and provide these data and recommendations to Title V and key partners on a monthly basis at evaluation meetings. In addition, VCHIP will present measurement and evaluation components of the integration activities at the national Learning Collaborative hosted by NICHQ. Networking and sharing improvement strategies, lessons learned, and challenges will provide a unique opportunity to learn from other states and share Vermont's innovations and solutions.

**Evaluation Activities:** Evaluation activities will be guided by grant guidelines as well as questions that arise during early phases of planning and intervention. Evaluation will center on the following series of activities and will likely evolve as new strengths and areas for growth emerge.

VCHIP will evaluate the involvement of CYSHCN and their families by tracking their representation on, attendance at, and influence of key committees. VCHIP will examine meeting minutes and conduct interviews with youth/families to determine whether the youth/family's ideas and concerns were voiced, acknowledged, and acted upon during the planning, implementation, and

evaluation components of the grant activities. During year one, VCHIP will identify recent family satisfaction data sets to serve as baseline measures and to inform project planning. VCHIP will then gather family satisfaction measures collected by partner organizations, clean and analyze the data as needed and prepare reports of results over time (i.e. run charts). VCHIP's expertise will ensure appropriate methodologies, interpretation and application of the data collected and/or accessed are utilized.

VCHIP will coordinate evaluation activities through Title V and community partners such as the Vermont Chapters of the American Academy of Pediatrics and American Academy of Family Physicians to build upon the accomplishments of the medical home grant. Specifically, VCHIP will track progress to engage federally qualified health centers (FQHC) and rural health centers (RHC) in becoming medical homes for the children, youth and families they serve, particularly for CYSHCN. VCHIP will monitor the development of the CYSHCN Strengths and Needs Assessment to be completed in the first six months of year one and assess the implementation of changes and systems improvements identified in this needs assessment in the subsequent years of the grant. VCHIP will coordinate activities with Title V personnel to track and report state and national measures such as the percent of CYSHCN who receive coordinated, ongoing, comprehensive care within a medical home. Data from a variety of current datasets (e.g., the Vermont Birth Information Network, a database of Vermont-resident children diagnosed with structural and chromosomal birth defects) will be used to inform systems planning.

VCHIP will develop statewide process and outcomes measures to evaluate policy and systems changes to maximize 3<sup>rd</sup> party reimbursement and ensure a better distribution of Title V funding for children and youth with special health care needs (i.e. moving from a disease specific focus to serving all children with special health care needs). VCHIP will work with Title V to assess insurance coverage and services reimbursed for children who access financial assistance from the CSHN clinic. In years 2-3, VCHIP will assess the effectiveness of the systems developed to identify transitioning YSHCN and provide counseling on insurance options and to provide technical assistance to families accessing alternative financing systems.

VCHIP's evaluation of early and continuous screening will focus on the statewide implementation of the AAP Bright Futures Guidelines released in October 2007. Process measures will be developed to assess access to the new guidelines by pediatric health care practitioners, knowledge of developmental screening guidelines, and attendance at regional meetings to train

health care practitioners on the developmental screening guidelines. VCHIP will analyze survey data collected by partner organizations to assess the use of best practice guidelines and families awareness of the screening process and access to follow-up assessments and referrals.

The evaluation of the proposed program's influence on youth transitioning successfully from adolescence to adulthood and independent living will focus on the facilitating factors and barriers to young adults with special health care needs identifying and developing relationships with appropriate adult practitioners. VCHIP will also examine developing supporting systems to ensure they are providing smooth transitions between pediatric and adult health care practitioners.

#### VII. ORGANIZATIONAL INFORMATION

The Agency of Human Services (AHS) is the largest of the agencies of state government, and is headed by the Secretary of Human Services, who reports to the governor. The Vermont Department of Health (VDH) resides within AHS. As a result of a 2006 realignment within VDH, there is now a Division of Maternal and Child Health which contains the offices of the Children with Special Health Care Needs. The Division of MCH also administers the Title V MCH Block Grant. VDH/CSHN is overseen by a Director of Operations and a Medical Director. The three main MCH and CSHN leadership positions (MCH Division Director, Operations Director and Medical Director) will be involved in the oversight of the Integrated Services grant. VDH/CSHN also contains the programs of Newborn Metabolic Screening and Newborn Hearing Screening. The MCH Director has responsibility for the implementation of the entire Title V grant. Other programs under the responsibility of the Division of MCH include Early Periodic Screening, Diagnosis, and Treatment (EPSDT,) School Health, and Women Infants and Children (WIC.)

The Division of MCH works closely with the Office of Local Health, which is responsible for the oversight of the VDH's twelve local health district offices. The Division of MCH and the OLH work together in a spirit of close collaboration on MCH public health issues and the "front-line" administration of VDH programs and services. In addition, the MCH Division collaborates closely with other key programs and departments around MCH public health issues, including Emergency Medical Service, HIV/AIDS, Injury Prevention, Public Health Nutrition, and the data management and analysis services.

See Introduction and Needs Assessment for discussion of AHS reorganization.