

**VERMONT CHILDREN'S
PERSONAL CARE SERVICES
PROGRAM STATUS REPORT**

June 2005

State of Vermont
Agency of Human Services

Department of Disabilities, Aging and Independent Living
Division of Disability and Aging Services

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INTRODUCTION

Children's Personal Care Services (CPCS) are part of the State of Vermont's requirement to provide services to Medicaid-eligible children under the federally-required Early, Periodic Screening, Diagnosis and Treatment (EPSDT) program. This means that CPCS are an entitlement for those children who qualify.

The goal of CPCS is to provide supplemental assistance with self-care and activities of daily living to Medicaid eligible children with significant disabilities or health conditions at home and in the community. Recipients are provided with one-on-one support from a worker for a specific number of hours.

The Children's Personal Care Services program started in 1995 and was originally administered by the Office of Vermont Health Access (OVHA). In July 2004, CPCS was relocated to the newly-created Department of Disabilities, Aging and Independent Living (DAIL) as part of the Agency of Human Services' reorganization. DAIL makes a logical home for this program because:

- There is a historically strong relationship between DAIL and provider agencies;
- A majority of the recipients have a developmental disability, and many have a physical disability; and,
- A significant number of these children may require adult services from DAIL, thus easing the transition from children services into adult services.

The Division of Disability and Aging Services (DDAS) took over management of Children's Personal Care Services within DAIL. This report is an opportunity to briefly describe the program and what we have learned since July 2004. This report consists of four sections:

- I. *Program Overview*: A synopsis of CPCS and description of provider agencies, personal care workers and family-management of CPCS.
- II. *Profile of Recipients*: A review of basic data on people who receive CPCS.
- III. *Survey Results*: A summary of the Children's Personal Care Survey, including demographic information of children and families served and survey highlights.
- IV. *Looking to the Future*: A description of what works well, where there are challenges, and what is being planned and implemented to improve the program.

Note: CPCS are most commonly provided to children living with parents or foster parents. In an effort to simplify language used in this report, the terms "child" and "family member" have been used interchangeably to describe recipients of CPCS.

I. PROGRAM OVERVIEW

Program Description and Qualification

The Children's Personal Care Services program is a state-plan Medicaid service available to children under the age of 21 who have a significant disability or health condition that substantially impacts care-giving needs (for young children birth through three) and/or the development of self-care skills (older children and young adults). To qualify for CPCS, recipients must be enrolled in Medicaid and need significant assistance with activities of daily living, such as feeding, bathing, dressing, toileting, grooming, positioning, transferring and walking.

The amount of service (number of hours of personal care worker assistance) that a child is allocated is determined through the use of the CPCS Assessment of Need. This assessment measures the amount of additional assistance required by a child to perform activities of daily living. An initial assessment is conducted when first applying to the program and includes a face-to-face interview with the child and child's parents, guardian, and/or other representative. Reviews are then done periodically (at least once a year) to verify continued level of need. An individual cannot receive Personal Care hours if it is determined that the level of care required does not differ significantly from that required of typically developing age peers. The number of hours can be increased or decreased if a new level of need is identified. Allocated hours for Personal Care can be used flexibly in and around the child's home and community.

CPCS Provider Agencies

Intake services for Children's Personal Care Services are provided through a variety of provider agencies; Home Health agencies, including Professional Nurses Services, and developmental and mental health service providers and Children with Special Health Needs/Vermont Department of Health. Many families choose to family-manage their CPCS by hiring their own personal care workers instead of going through a provider agency. Families may have no alternative other than to self-manage if they wish to use CPCS in areas of the state where there are no provider agencies accepting new referrals.

CPCS Provider/Assessing Agencies
(as of 7/1/05)

Addison County Home Health
Bennington Area Home Health
Central Vermont Home Health & Hospice
Children with Special Health Needs
Counseling Service of Addison County
Families First of Southern Vermont
Francis Foundation
Franklin County Home Health
Health Care and Rehabilitation Services of Southeastern VT
Lamoille County Home Health
Lamoille County Mental Health Services, Inc.
Lincoln Street Incorporated
Manchester Health Services
Northeast Kingdom Human Services, Inc.
Northern Counties Home Health (Caledonia Home Health)
Northwestern Counseling & Support Services, Inc.
Orleans-Essex VNA
Professional Nurse's Service
Rutland Area VNA
Rutland Mental Health Services
Sterling Area Services, Inc.
Town of Dorset Nursing Service
United Counseling Services, Inc.
Upper Valley Services, Inc.
Visiting Nurse Home Health
VNA of Chittenden County/Care Connection
Vermont & New Hampshire Alliance Home Health
Washington County Mental Health Services, Inc.

Personal Care Workers

Personal care workers can be agency staff or hired by a family member. Federal and state laws place some prohibition on who is eligible to be a paid caregiver. In Vermont, the following people cannot be a personal care worker for a child:

- Parent (biological or adoptive)
- Step-parent
- Parental domestic partner
- Developmental home provider
- Foster parent
- Anyone serving as the child's primary caregiver
- Anyone younger than 18 years old (though this requirement may be waived on a case-by-case basis for individuals age 16 and 17)

Program Details

Children's Personal Care Services are intended to provide individualized support. The program is designed to be used flexibly, with the option for supports to be provided in a variety of settings, including the community, and to assist with a range of activities. Services include:

- Assistance with bathing, dressing, and grooming.
- Assistance with bladder or bowel requirements.
- Assistance with eating, drinking and diet activities, to include the preparation of meals when necessary.
- Assistance in monitoring vital signs.
- Routine skin care.
- Assistance with positioning, lifting, transferring, ambulation and exercise.
- Teaching new skills to increase or maintain recipient independence and physical and/or cognitive, social and emotional well-being.

The number of hours is assigned based on need, but they can be scheduled as determined necessary by the family. The following are general restrictions to using CPCS:

- Hours allocated are used within a 6-month timeframe. They may be rolled over week-to-week or month-to-month, but must be used within the 6-month timeframe.
- Hours are only billed for one child at a time; 2:1 coverage is not billable.
- Workers are awake and working with the child during billable hours.
- CPCS pays for worker's hours and not for goods or to reimburse expenses.
- Services are intended to supplement, not supplant, parental roles and responsibilities.
- Services cannot be used for school services or job coaching responsibilities.
- The Agency of Human Services sets the hourly rate for CPCS; the hourly wage cannot be supplemented with either private or public funding.
- CPCS cannot be provided during the child's school day or educational program. However, family members who attend college can receive CPCS while there.

Misuse of the CPCS program by a service agency, worker or family member may be considered Medicaid fraud, whether it is intentionally or inadvertently committed. If misuse of Medicaid funds is suspected, the Medicaid Fraud and Residential Abuse Unit of the Office of Attorney General will be notified.

Family-Managed Services

An estimated 80% of families manage their own CPCS instead of using a CPCS provider agency. In the CPCS program, some family members can become paid caregivers.

A fiscal Intermediary Service Organization (ISO) is available to all families who family-manage the CPCS. The ISO works as an agent, processing payroll and taking care of other employer responsibilities such as requesting background checks (required for all personal care workers), withholding employee taxes, reporting taxes, and managing workers' compensation and unemployment insurance. As of June 2004, all families managing CPCS use ARIS Solutions for their ISO services.

There are a number of benefits to families who family-manage CPCS for their child. They include:

- Increased control over hiring, training, directing and firing workers.
- Larger pool of potential workers to choose from when including other family members and people in the community. Personal connections increase options and likeliness of success.
- More flexibility around workers being there during the hours needed instead of predetermined agency shifts.
- Freedom from additional rules governing personal care workers imposed by provider agencies.
- Clearer understanding of the family's and child's needs.
- Fewer outside relationships to manage when hiring workers; do not have to deal with additional agency staff.

There can also be challenges to family-managing CPCS. They include:

- Learning a whole new set of skills to be an employer.
- Increased level of personal responsibility/liability by being the employer.
- Responsibility for finding substitute or new workers when employees cannot work or leave employment.
- Paperwork requirements and other administrative responsibilities.
- Inability to provide benefits to employees (e.g., vacation time, sick days, holiday pay, health insurance). Some provider agencies also do not provide benefits to personal care workers.

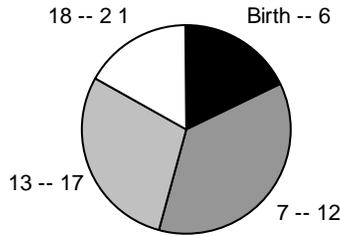
II. PROFILE OF RECIPIENTS

The following is a summary of the data that represents the children who get CPCS. This is a snapshot (as of January 2005) of those who are enrolled in CPCS.

Total Enrolled in CPCS – 1,166 children

Child's Age

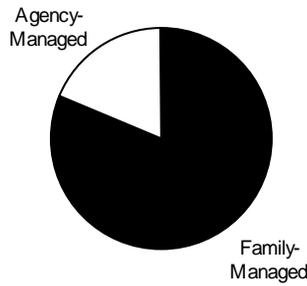
Birth-6	18%
7-12	36%
13-17	29%
18-21	17%
Total	100%



Average age of child enrolled – 12 years old

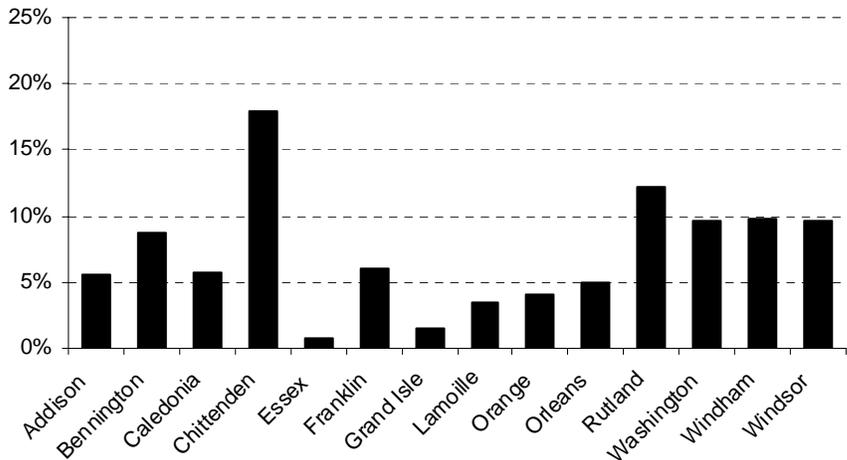
Family-Managed vs. Agency-Managed Services

Family-Managed	81%
Agency-Managed	19%
Total	100%



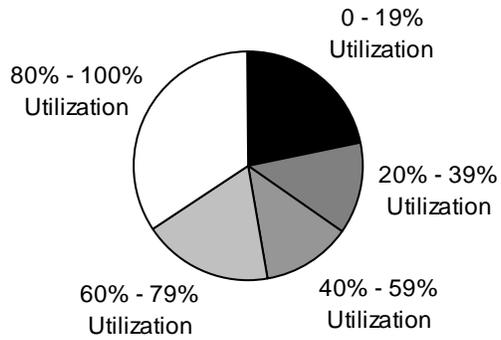
County of Residence

Addison	5%
Bennington	9%
Caledonia	6%
Chittenden	18%
Essex	1%
Franklin	6%
Grand Isle	1%
Lamoille	4%
Orange	4%
Orleans	5%
Rutland	12%
Washington	9%
Windham	10%
Windsor	10%
Total	100%



Utilization of CPCS Hours Authorized

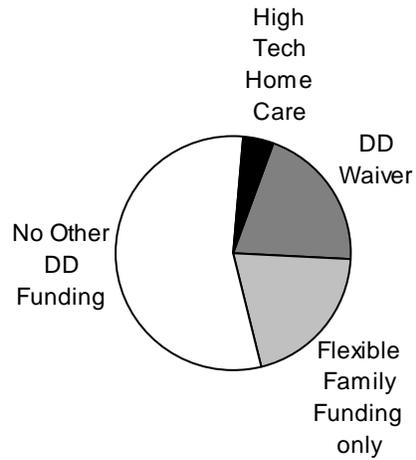
% Used (Range)	% People
0 - 19%	22%
20% - 39%	12%
40% - 59%	13%
60% - 79%	18%
80% - 100%	35%
Total	100%



- Average number of hours authorized per week = 25 hours
- Overall percentage of hours used by all recipients = 64%
- 35% of all recipients use 80% - 100% of their authorized hours
- 22% of all recipients use under 20% of their authorized hours

CPCS Overlap with Developmental Disabilities Funding

High Tech Home Care	4%
DD Waiver	20%
Flexible Family Funding (only)	20%
No other DD funding	56%
Total	100%



III. SURVEY RESULTS

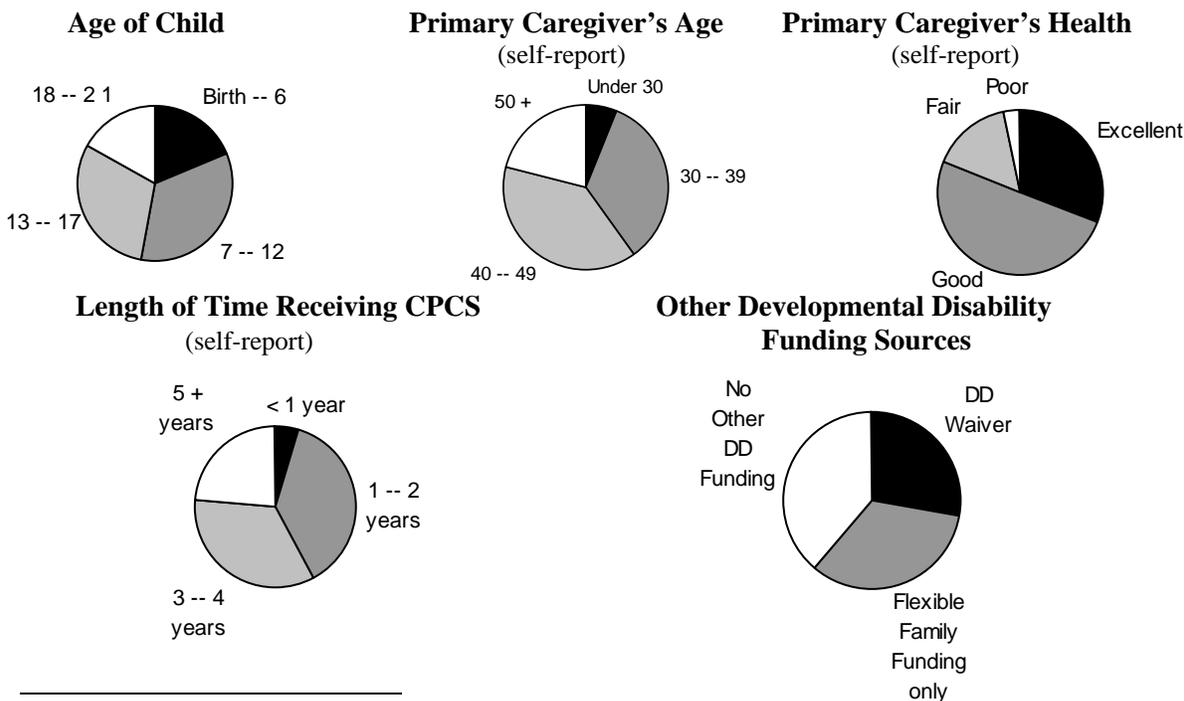
When the CPCS program transferred to the Department of Disabilities, Aging and Independent Living, the Division of Disability and Aging Services (DDAS) conducted a baseline satisfaction survey of families participating in the program. The intent of the survey was to get initial feedback about the program to which future changes can be compared and to provide some insight into the issues facing the program and guide improvements.

A mailing list with the names of children who were reported as getting CPCS as of June 2004 was provided to DDAS by the Office of Vermont Health Access. A total of 1,237 surveys were mailed out to families of those children in the fall of 2004. The number of completed surveys returned was 379, giving a response rate of 33%¹.

The survey results provide a general picture of who is receiving CPCS and information on the families' perspective of those services, including the application and set-up process, personal care workers, what is working well and where improvements are needed. The survey also included a number of open-ended questions at the end of the survey. The following is a summary of the survey results. A list of survey questions and results is provided in the Appendix.

Demographics of Survey Respondents – 379 Children

The Children's Personal Care Survey results give a general picture of the children and families who get CPCS.



¹ This percentage does not include 82 surveys that were undeliverable (e.g., incorrect address, no longer getting CPCS).

Children getting CPCS

- Services are fairly evenly spread across children of all age groups.
- Almost 90% of families identify their child as having a developmental disability.
- Over 60% identify their child as having more than one general disability (developmental, emotional/behavioral, and/or medical).

Caregivers of Children getting CPCS

- Over 20% of the caregivers are age 50 and over.
- Over 80% of the caregivers report having good to excellent health.
- Almost 30% of the time the caregiver is the only adult in the home who provides care to the family member.
- 24% of the caregivers report getting CPCS for 5 or more years.

Personal Care Services

- 28% of the children receive DD home and community-based waiver funding, and 33% receive Flexible Family Funding, in addition to CPCS.

Note: It was found that survey respondents were significantly more likely to get waiver funding or Flexible Family Funding than non-respondents.

Personal Care Workers

- 75% of the families hired their own workers and family-manage their child's services.
- 35% of children received services from paid workers who were members of their family. The majority of paid workers were people previously unknown to the family.

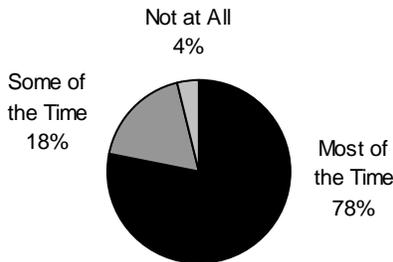
Survey Highlights

- In addition to providing assistance with activities of daily living (personal care), families reporting additional benefits to the services. Of these families:
 - 89% say services give them and their family member a break.
 - 77% say services provide social/community activities for their family member.
 - 72% say services provide supervision for their family member.
 - 57% say services provide skill training for their family member.
 - 20% give other reasons (e.g., allows them to work, provides exercise, safety, companionship, gives family member a life).
- Families do not use some or all of their personal care hours. Of these families:
 - 28% say they cannot find workers.
 - 11% say they cannot keep workers (too much turn over).
 - 9% say their agencies cannot find workers.
 - 23% give other reasons (e.g., scheduling issues, quality/reliability of workers, pay is too low, no time to find workers, workers want full time work).

- It is difficult to find or retain workers. Of these families:
 - 35% say it's because of the hours of the day or the days of the week when the help is needed.
 - 34% said it's due to low wages.
 - 27% said it's due to lack of benefits.
 - 24% said it's due to type and difficulty of the work.

Application Process

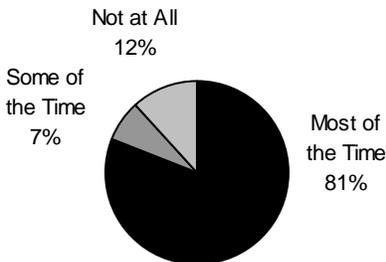
Did the Personal Care application happen in a timely way?



- 71% said the CPCS assessment process was easy to take part in.
- 67% said their family's needs did not change at all to make the 6-month assessment necessary.
- 88% said the assessment/plan development process was respectful.
- 76% said they receive information that describes the CPCS program and its rules.
- 75% of the families who hired their own workers said the people at the Intermediary Service Organization were respectful and courteous.

Setting up Children's Personal Care Services

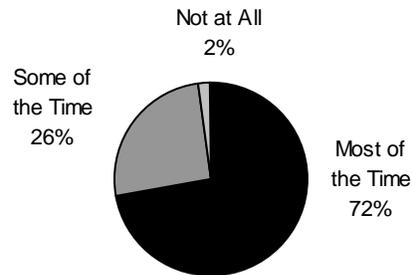
If you hire your own workers, did you have a choice in managing your own services?



- 83% said the Notice of Decision was provided in a timely way.
- 17% said they were not notified of the appeals process for CPCS.
- 66% said they had a good experience with the agency who hires their workers.
- 53% said they had a good experience with recruiting workers.

Personal Care Workers

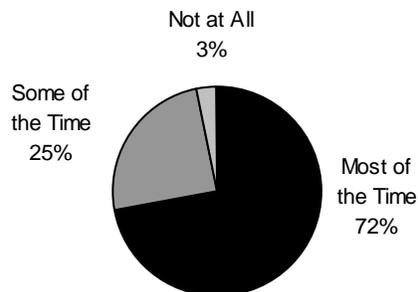
Did your Personal Care worker(s) provide services to your satisfaction?



- 74% said Personal Care workers were respectful of their family and their family life.
- 55% said they did not have problems with their Personal Care worker not showing up or canceling at the last minute.
- 45% said frequent change in Personal Care workers was not a problem.
- 21% said they were not able to find Personal Care workers for all the times needed during the day and week.

Personal Care Services

Did Personal Care services meet your family's needs?



- 62% said they used all the Personal Care hours that were allotted to their family member.
- 85% said Personal Care services made a positive difference in their family member's life.
- 37% said they would use case management/service coordination services if it became a part of the CPCS services
- 88% said Personal Care services were helpful overall to their family's well being.

Comments

The following is a brief summary of the responses to the open-ended questions at the end of the survey. The comments chosen are those that were mentioned by twenty (20) or more people who completed the survey.

What things do you value or feel are most beneficial about the Personal Care program?

Benefits for the Family

- Gives family a break.
- Allows flexibility – program, hours, hiring.
- Allows parents to work/go to college.
- Keeps child at home/helps family survive.
- Provides time for family/other children.
- Provides time for self.
- Reduces stress.
- Provides time to take care of household responsibilities.
- Improves quality of life for family/have a normal lifestyle.

Benefits for the Child

- Provides social skills training/development.
- Opportunity to integrate and be safe in the community.
- Opportunity to work toward independence/independence from parents.
- Opportunity to be with someone other than parents.
- Opportunity to get out and do activities outside of home.

What would you change to make the Personal Care program better?

- Better pay to workers/opportunity for raises.
- Maintain worker pool, network or database of workers and substitutes.
- Better training for workers/help with training.
- Benefits for workers – insurance, sick pay, vacations.
- Eliminate re-assessment/change from 6 month to yearly assessment.
- Flexible wages/hours/payments.
- Assistance with paperwork, application, forms, background checks.

IV. LOOKING TO THE FUTURE

The Division of Disability and Aging Services instituted a number of changes to CPCS since assuming responsibility for the program in July 2004. Some of the modifications are based on changes that occurred due to the transfer of the program from OVHA to DAIL. Other revisions are intended to streamline the administration and functioning of the program and/or provide families with more flexibility and control over services. There are still many more improvements needed to the program, but this first year has been a good start.

Program Successes

Local Partnerships

Prior to July 2004, Maximus provided the customer service role for CPCS. As of July 2004, the Maximus contract was cancelled and they no longer perform reassessments and serve as a “case manager” for family’s receiving CPCS. The Division of Disability and Aging Services has coordinated with local partners and reassessments are now being done by developmental and mental health agencies, Home Health Agencies, including Professional Nurse’s Services, and Children with Special Health Needs. This change not only saved almost half a million dollars annually, it also keeps children and families connected with community resources and helps develop contacts locally.

Future: Develop more assessor agencies and increase the number and distribution of provider agencies, thus providing families an increase in choice as to whether or not to family-manage services.

Assessment Period

DDAS has extended the assessment renewal period from six months to one year.

Future: Upgrade technology to allow allocation of services for the full year.

Redesign Program

A workgroup has been formed to consider the redesign of the program. The group consists of a broad representation of stakeholders, including parents, providers and advocates. Currently the group is designing a new assessment tool and care plan and creating guidelines for CPCS. A user’s guide and employer handbook will also be developed.

Future: Explore how best to use an ongoing advisory group.

Transition to Adult Services

There are a limited number of service options for adults with physical and developmental disabilities. Quarterly meetings between representative from CPCS and other adult service programs have begun in order to facilitate better transitions for young adults leaving CPCS. Ground work is being laid to help everyone understand the purpose, process and eligibility criteria of the various programs to expedite referrals to services.

Future: Continue collaborative meetings to work toward, and refine, a smoother transition for young adults leaving CPCS. The group is working to untangle many of the different eligibility criteria, access points, and application processes into adult services.

Consolidation of ISOs

The Agency of Human Services ended a contract with one of the two Intermediary Service Organizations (ISO) that were providing payroll services to families who were family-managing, making it necessary for many of these families to be transferred to a different ISO.

Future: Continue to explore alternative ISO options.

Data System

For the first time in the program's history, data are readily available that show who is enrolled in CPCS and the amount of allocations and utilization of hours.

Future: Continue efforts to collect better and more meaningful information about CPCS.

Integration of Children's Services

Initial efforts have been made to integrate children's services within DDAS through the developmental disabilities waiver, Flexible Family Funding and the High Technology Home Care program. An introduction of unified service plans has allowed DDAS to be more flexible, creative and economical in the provision of CPCS.

Future: Continue collaboration with OVHA in working toward effective and integrated services.

Program Challenges

Since CPCS is one of the few programs that provides 1:1 staff support for children with disabilities, there is a growing demand to access these services. The increase in applications into the program has brought a number of challenges.

Growth

When CPCS began in 1995, it was projected that the program would grow to serve no more than three hundred (300) children. In January 2005, 1,166 children were actively enrolled in the program. It was estimated that by the end of FY '05, the program would have increased by an estimated 27% during the fiscal year. This kind of growth places huge administrative pressure on the program, resulting in an increase in the time it takes to process applications and a reduction in access to staff.

Future: There will be a need for increase in program staff in order to maintain timely processing of applications and access to staff. Budgetary pressures surrounding the Vermont Medicaid program will clearly impact financial resources available to CPCS in the future.

Scope of Program

While other children's services across the state scale back (e.g., developmental disabilities waiver, children's mental health), more families turn to CPCS to create an intensive program of supports which is often beyond the intended scope of the program. Additionally, the CPCS program doesn't have a mechanism to quantify complex family circumstances. The program is designed to consider only the child's needs and abilities and is not intended to mitigate effects of sociological and economic problems.

Future: Find ways to integrate funding sources so families can get a variety of needs met while maintaining the highest possible level of control of their lives.

Service Provision

A major issue troubling CPCS is historically low utilization. Currently, utilization rate is only around 65%; meaning one-third of all hours allocated go unused. Families often are not able to use all the hours that have been assigned for a variety of reasons, the most common being difficulty finding and retaining workers.

Future: Make changes that will keep growth of program in check, resulting in having the proper number of hours allocated and a better percentage of the allocated hours used.

Administrative Challenges

The shift of oversight of CPCS from OVHA to DAIL brought a number of administrative challenges. Progress is being made to address these issues but more needs to be done.

Future: Reorganization of DDAS and an ongoing dedication to the evolution of CPCS will help:

- **Create a meaningful quality assurance system,**
- **Devise multiple strategies for preventing Medicaid fraud,**
- **Continue to improve transition of children into adult services,**
- **Address fluctuating Medicaid eligibility for specific individuals, and**
- **Contend with budgetary constraints in an entitlement program.**

APPENDIX

SURVEY RESULTS – MULTIPLE CHOICE QUESTIONS

Application Process

1. Did the Personal Care application process happen in a timely way?

(N=357)

Most of the Time	78%
Some of the Time	18%
Not at All	4%
Total	100%

2. Was the initial Personal Care assessment process for Personal Care services easy to take part in?

(N= 363)

Most of the Time	71%
Some of the Time	25%
Not at All	4%
Total	100%

3. Did the questions on the Personal Care assessment do a good job identifying your family member's needs?

(N= 366)

Most of the Time	68%
Some of the Time	26%
Not at All	6%
Total	100%

4. Did your family's needs change enough to make a 6-month assessment necessary?

(N= 338)

Most of the Time	16%
Some of the Time	17%
Not at All	67%
Total	100%

5. Was the Personal Care assessment/Care Plan development process a respectful one?

(N= 366)

Most of the Time	88%
Some of the Time	10%
Not at All	2%
Total	100%

6. Were people at the Office of Vermont Health Access respectful and courteous?

(N= 299)

Most of the Time	86%
Some of the Time	10%
Not at All	4%
Total	100%

7. Were people at the Office of Vermont Health Access knowledgeable and effective?

(N= 297)

Most of the Time	75%
Some of the Time	20%
Not at All	5%
Total	100%

8. Were people at Maximus respectful and courteous?

(N= 226)

Most of the Time	86%
Some of the Time	12%
Not at All	2%
Total	100%

9. Were people at Maximus knowledgeable and effective?

(N= 224)

Most of the Time	86%
Some of the Time	12%
Not at All	2%
Total	100%

10. If you hired your own workers, were people at the Intermediary Service Organization (ISO's Acumen or ARIS) respectful and courteous?

(N= 281)

Most of the Time	75%
Some of the Time	21%
Not at All	4%
Total	100%

11. If you hired your own workers, were people at the Intermediary Service Organization (ISO's Acumen or ARIS) knowledgeable and effective?

(N= 283)

Most of the Time	68%
Some of the Time	26%
Not at All	6%
Total	100%

12. If an agency hired your Personal Care workers, were people at the agency respectful and courteous?
(N= 118)

Most of the Time	88%
Some of the Time	10%
Not at All	2%
Total	100%

13. If an agency hired your Personal Care workers, were people at the agency knowledgeable and effective?
(N= 117)

Most of the Time	68%
Some of the Time	29%
Not at All	3%
Total	100%

14. Did you receive information that describes the Personal Care program and its rules?
(N= 334)

Most of the Time	76%
Some of the Time	14%
Not at All	10%
Total	100%

Setting up Personal Care Services

15. Was the Notice of Decision provided in a timely way?
(N= 363)

Most of the Time	83%
Some of the Time	14%
Not at All	3%
Total	100%

16. Was the information on the Notice of Decision clear and easy to understand?
(N= 360)

Most of the Time	79%
Some of the Time	16%
Not at All	5%
Total	100%

17. Were you ever informed of the appeal process for your Personal Care services by the Office of Vermont Health Access (OVHA)?
(N= 263)

Most of the Time	75%
Some of the Time	8%
Not at All	17%
Total	100%

18. Was the appeal process clear?

(N= 214)

Most of the Time	77%
Some of the Time	13%
Not at All	10%
Total	100%

19. Were you satisfied with the way appeals were handled (e.g. timely, fair, respectful) by the Office of Vermont Health Access?

(N= 67)

Most of the Time	79%
Some of the Time	11%
Not at All	10%
Total	100%

20. If an agency hired your Personal Care workers, did you have a good experience with them?

(N= 126)

Most of the Time	66%
Some of the Time	27%
Not at All	7%
Total	100%

21. If you hired your Personal Care workers, did you feel you had a choice as to whether to manage your own services or not?

(N= 298)

Most of the Time	81%
Some of the Time	7%
Not at All	12%
Total	100%

22. Was your experience with recruiting Personal Care workers a good experience?

(N= 316)

Most of the Time	53%
Some of the Time	32%
Not at All	15%
Total	100%

Personal Care Workers

23. Did your Personal Care worker(s) provide services to your satisfaction?

(N= 372)

Most of the Time	72%
Some of the Time	26%
Not at All	2%
Total	100%

24. Did you have problems with your Personal Care worker(s) not showing up or canceling at the last minute?
(N= 363)

Most of the Time	11%
Some of the Time	34%
Not at All	55%
Total	100%

25. Were frequent changes in your Personal Care worker(s) a problem for you?
(N= 310)

Most of the Time	18%
Some of the Time	37%
Not at All	45%
Total	100%

26. Were you able to find Personal Care workers for all the times during the day and week when you needed them?
(N= 365)

Most of the Time	41%
Some of the Time	38%
Not at All	21%
Total	100%

27. Was the Care Plan useful to you and your family member?
(N= 342)

Most of the Time	66%
Some of the Time	27%
Not at All	7%
Total	100%

28. Did your Personal Care workers do things that were identified in the Care Plan?
(N= 345)

Most of the Time	75%
Some of the Time	23%
Not at All	2%
Total	100%

29. In general, were your Personal Care workers respectful of you and your family life?
(N= 366)

Most of the Time	74%
Some of the Time	24%
Not at All	2%
Total	100%

30. Was it required or necessary that you be at home when the Personal Care worker was with your family member?

(N= 355)

Most of the Time	74%
Some of the Time	24%
Not at All	2%
Total	100%

31. If so, why was this?

(N= 74)

Most frequent responses:

- Some things need 2 people / need a back up / so I can be reached at all times
- Specific/complex needs – medical, lifting/transfers, medications, behavior, seizures, safety
- Training, supervision, quality assurance
- Just at the beginning (new workers) / during transitions
- Peace of mind / reassurance
- Don't trust workers

Personal Care Services

32. Did you use all the Personal Care hours that were allotted to your family member?

(N= 366)

Most of the Time	62%
Some of the Time	23%
Not at All	15%
Total	100%

33. Did your family member make progress toward the goals in the Care Plan?

(N= 348)

Most of the Time	53%
Some of the Time	42%
Not at All	5%
Total	100%

34. Did your Personal Care services make a positive difference in your family member's life?

(N= 366)

Most of the Time	85%
Some of the Time	14%
Not at All	1%
Total	100%

35. Were Personal Care services available when your family needed them?

(N= 368)

Most of the Time	62%
Some of the Time	33%
Not at All	5%
Total	100%

36. If case management/service coordination became a part of the Personal Care program, do you feel you would need that service?

(N= 266)

Most of the Time	37%
Some of the Time	22%
Not at All	41%
Total	100%

Note: The 5-point scale shows N/A = 26 and D/K = 73.

37. Did Personal Care services meet your family's needs?

(N= 371)

Most of the Time	72%
Some of the Time	25%
Not at All	3%
Total	100%

38. Were Personal Care services helpful overall to your family's well being?

(N= 371)

Most of the Time	88%
Some of the Time	11%
Not at All	1%
Total	100%