

NEW HAMPSHIRE -- 2001 Community PASS Grant

Identified Problems with the States' Long-Term Care System

- There is insufficient provider capacity in the care available for community care especially through traditional home health providers.
- The New Hampshire Community Based care system has traditionally relied upon professionally managed home care through home health agencies.
- There are significant gaps in the community services that persons with disabilities rely on to remain in the community.
- There is a lack of coordination among the various community organizations supporting different groups of individuals with disabilities throughout the state.
- Consumer-directed personal care options have not been available for large segments of the community including children with special health care needs and many adults of all ages who do not qualify for the independent living center's program.
- The general shortage of direct care workers makes it difficult to provide back-up support in cases where primary caregivers fail to show up.

Perceived Strengths

- Granite State Independent Living (GSIL) is committed to the principle of consumer choice in all aspects of independent living services, including planning and delivery.
- GSIL has 20 years of experience operating the consumer-directed PCA program for wheelchair mobile individuals who can self-direct.
- Most of GSIL's board, management staff, and direct services staff are people with disabilities.

Primary Focus of Grant Activities

- Create comprehensive access to consumer-directed personal care across all disability and age groups by expanding availability of such services to (a) adults with disabilities through HCBC-ECI, including those who need a representative decision maker and (b) children with special health care needs (CWSHCN).
- Increase the availability and retention of personal care workers.
- Identify and address gaps in community services.

Goals, Objectives, and Activities

Overall Goal. To ensure that all individuals with disabilities who want to remain in the community have the option to utilize consumer-directed personal care.

Goal. To develop a model consumer-directed Personal Care Services Program (PCSP) that expands consumer-directed personal care to individuals with disability who have not had access to such services, specifically to (a) adults with disabilities through HCBC-ECI, including those who need a representative decision maker, and (b) children with special health care needs.

Objectives/Activities

- Develop the educational, training, program and system infrastructure to operate and manage the Personal Care Services Program.
- Develop the program and materials so that consumers can access it without the assistance of consumer representatives.
- Develop mechanisms for consumer feedback.
- Provide skills and advocacy training for the eligible consumer or representative.
- Provide skills training to other qualified agencies for creating and maintaining work registries, counseling and support, and monitoring consumer satisfaction.
- Provide assistance for issues related to taxes and withholding, payroll checks, collecting and verifying timesheets, verification of citizenship/legal alien status, and standardized reporting.

Goal. To implement a model consumer-directed PCSP program including outreach and training to populations that have been previously ineligible.

Objectives/Activities

- Provide access to consumer-directed personal care to individuals through the HCBC-ECI waiver and to medically eligible CWSHCN through EPSDT or through a new children's waiver.
- Conduct an outreach and education campaign targeted to those previously ineligible for consumer-directed personal care.
- Expand the general knowledge of and support for consumer-directed approaches to community long-term care.
- Provide education about consumer-directed services to the general public and mail information about the program to newly eligible individuals, inviting them to training seminars.

Goal. Expand the availability of consumer-directed Personal Care Service Programs by providing education, outreach, and technical assistance to a wide array of community entities that support a variety of different constituencies with disabilities throughout the state.

Objectives/Activities

- Prepare and disseminate a manual for the startup and operation of a consumer-directed PCSP by other entities.
- Provide outreach and if desired, training on starting a consumer-directed PCSP program to a wide array of community entities that support a variety of different constituencies with disabilities throughout the state.

- Provide technical assistance to organizations to establish and operate a consumer-directed PCSP for their constituencies.

Goal. Develop and implement back-up personal care coverage models.

Objectives/Activities

- Develop effective mechanisms for providing back-up coverage when a scheduled provider does not arrive by developing one or more of the following, when feasible:
 - C pooled insurance model for backup coverage.
 - C worker cooperatives to supply backup coverage.
 - C pools of college and graduate students in social service fields to serve as backup.
 - C models of back-up coverage through faith-based and other community-based organizations.

Goal. Make available mechanisms to better support the consumer-directed personal care workforce and thereby increase retention of personal care workers

Objectives/Activities

- Assess interest of consumer-directed personal care workers in credit unions, pooled health insurance products, low interest loans, educational incentives for career advancement, and worker owned cooperatives.
- Arrange for access to those benefits that are most important to consumer-directed workers.

Goal. Conduct a Community Services Gap Analysis to identify deficiencies and work to expand the opportunities for individuals to live in the community and to have real choices as to the services they want and need.

Objectives/Activities

Conduct an analysis of New Hampshire’s community programs for individuals with disabilities focusing on how well existing programs provide opportunities to live in the community and real service choices, as well as the adequacy of services, and service gaps.

Key Activities and Products

- Assemble workgroup of GSIL consumers, staff, DHHS personnel, and other key stakeholders to develop policies, procedures, systems, materials, and curriculum to operate PCSP program.
- Arrange for eight outreach/training sessions on PCSP program for potential consumers and case managers.
- Begin offering services to 15 consumers and, by the end of grant, 75 consumers.
- Prepare and disseminate comprehensive start-up and operations manual for other entities that wish to develop their own consumer-directed PCSP program.
- Study the feasibility of various back-up coverage options for PCA and PCSP services and provide a written report. Implement the most promising back-up model(s) as a pilot to 15 consumers, attain feedback to refine model, and then offer the refined model to 75 consumers.

- Prepare written recommendations for review and adoption by workgroup on the development of and interest to consumer-directed personal care workers of specific benefits.
- Prepare written report of consumer-identified gaps in and barriers to the administration, structure, regulation, and operation of the existing system.
- Provide written implementation plan and recommendations to Consumer Advisory Council and policymakers to overcome the gaps and barriers in the system.

Consumer Partners and Consumer Involvement in Planning Activities

In addition to Granite State Independent Living, a consumer-run and controlled entity, a separate consumer advisory committee was established to assist in the planning and implementation of the grant.

Consumer Partners and Consumer Involvement in Implementation Activities

- A consumer-controlled workgroup consisting of a majority of consumers who use or will use consumer-directed personal care will be formed and meet regularly to guide the development and operation of the new model program. This workgroup will design all aspects of the program, from outreach and training materials to performance standards. In addition, the workgroup will periodically review the feedback from consumers of the new program and use the feedback to refine the program.
- Eight consumers who use the new program will be added to the workgroup and will assist in evaluating accomplishments and goals.
- A Real Choice Consumer Advisory Council (CAC) will comprise 100 percent consumers. Members of the CAC will serve on the project's workgroup that is charged with (1) guiding the community service gap analysis and (2) reviewing the activities of all systems change grants.
- Groups that work with families include the Children's Alliance, Parent to Parent, the DD Council, the Traumatic Brain Injury Association, Children, and Adolescents with Chronic Health Conditions, and NHAMI.

Public Partners

- State Committee on Aging.
- Division of Developmental Services.
- Medicaid agency.
- Commissioner of DHSS.
- NH DEAS.
- Governor's Office.

Private Partners and Subcontractors

- University of New Hampshire and other local colleges.
- Project Dollars and Sense.
- NH Community Loan Fund.

- Quality Care Partners.
- CSNI/AA.
- Franklin Pierce Law Center Institute for Health, Law & Ethics.
- Susan Flanagan (EP&P Consulting, Inc.).

Public and Private Partnership Development/Involvement in the Planning Phase

Public Partners

The following public partners were involved in planning the grant through a series of ongoing meetings to conceptualize and refine the grant application:

- New Hampshire Department of Health and Human Services.
- Director of the Office of Medicaid.
- Division of Elderly and Adult Services.
- Division of Developmental Services.
- University of New Hampshire, Institute on Disabilities.

Private Partners

The following private partners were involved in planning the grant through a series of ongoing meetings to conceptualize and refine the grant application:

- Franklin Pierce Law Center, Institute for Health Law and Ethics.
- Susan Flanagan (EP&P Consulting, Inc.).

Public and Private Partnership Development/Involvement in Implementation

Public Partners

- The State Committee on Aging will assist in conducting outreach.
- The Division of Developmental Services, the Medicaid agency, and the Commissioner of DHSS will assist in outreach to individuals newly eligible for the PCSP program, assist in the community service gap analysis, and implement recommended changes.
- The NH Division of Elderly and Adult Services (DEAS) will assist in outreach to individuals newly eligible for the PCSP program; assist in the community service gap analysis; and provide technical assistance.
- The Governor's Office will assist in implementing the recommended changes identified in the community service gap analysis.
- The University of New Hampshire will assist in the development and implementation of back-up models utilizing students.
- Franklin Pierce Law Center Institute for Health, Law & Ethics will assist in conducting the community services gap analysis, advocate for implementing the recommended reforms, and assist in developing back-up coverage and worker retention benefit programs.

Private Partners

- Project Dollars and Sense, the NH Community Loan Fund, and Quality Care Partners will assist in the development and implementation of back-up models, in accessing expanded benefits to retain quality care givers, and in retaining benefits.
- CSNI/AA will assist in conducting outreach.
- The DD Council will assist in conducting outreach.
- Susan Flanagan (EP&P Consulting, Inc.) will develop the model program materials, training manuals, operating manuals and outreach materials, conduct training, and provide technical assistance.

Existing Partnerships That Will Be Utilized to Leverage or Support Project Activities

The Granite Supports Project, a public private partnership between Granite State Independent Living and the State of New Hampshire, funded by the Medicaid infrastructure grant for Ticket to Work will be awarding funds to other qualified agencies for start-up of consumer-directed personal care service programs.

Oversight/Advisory Committee

A Consumer Advisory Council will oversee all aspects of the grant, including the model program, the back-up coverage and retention project, and the community service gap analysis; and will ensure that the project undergoes continuous quality improvement

Formative Learning and Evaluation Activities

- Conduct quarterly reviews of case files and records to determine if deadlines and milestones are being met.
- GSIL project staff will complete a Progress Evaluation Chart on a quarterly basis.
- Consumer-controlled working group will meet quarterly to discuss project outcomes and effectiveness and prepare written recommendations.
- After reaching milestones, project staff will survey or interview PAS/PCSP consumers and other stakeholders to assess their satisfaction with the program and to solicit suggestions for change. Survey and interview results will be shared at least quarterly with project staff and the consumer-controlled working group.

Evidence of Enduring Change/Sustainability

- The program will ultimately cover its own operating costs through Medicaid reimbursement.
- By partnering with a number of entities that are designing and developing employment benefits for the traditional direct care workforce in the state, it is more likely that consumer-directed caregivers will have long-term access to benefits.

- The models for back-up emergency coverage will be self-sustaining (e.g., student cooperatives that rely on a mix of academic credit and work-study will likely to continue once established).
- The community service system gap analysis will result in systemic changes, including funding by traditional funders.

Geographic Focus

The grant is statewide in scope of the intended impact. However, aspects of the grant, such as piloting of the new PCPS program or specific back-up models may be limited to a specific geographic area in the initial pilot phases (to be determined).