

Participant Directed Training for Personal Assistance Services (PAS) Management

Preliminary Report on of a Pilot Project Carried out by
the Vermont Center for Independent Living (VCIL) Submitted to
the State of Vermont Department of Aging and Independent Living

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“There is a critical and generally overlooked connection between independent living movement and creation of personal care options .. This needs to be understood to fully grasp what participant directed PAS in particular means and how it should operate.”

Chris Palames, founder of Stavros Independent Living Center,
Western Massachusetts

“Independent living is not a mere collection of services. It is the expression of our will to be independent.”

Judy Heumann, Co-founder Berkley CIL

Acknowledgement

I wish I could start this preface with a roll call of the wonderful individuals who helped us develop and evaluate this pilot program because they were the visionaries behind this report. I hope a later edition of this report will do this. Until then, I will just say that this project owes its success to the diverse and remarkable individuals who agreed to participate. A few staff of VCIL may have created the framework but it was the will, voices, history, experiences and interactions of participating individuals that determined the content and spirit of the project as it evolved.

Over twenty participants helped us design, implement and evaluate program activities. Most were users of Personal Assistance Services (PAS). They shared their stories and experiences and were wonderfully explicit about the disability-related and just human issues this program needed to address. They were frank and generous in their critique of materials and practices and open to collaboration and shared learning. In this pilot project they were as much educators as students and we were fortunate that they chose to be both.

The wisdom and history these individuals brought to this program brings to mind a wonderful story about learning and democracy. The writer and teacher Leonard Fein, son of a Jewish immigrant, tells a powerful story from his father's life. The Rebe (teacher) of his father's childhood school told the class that he had heard there was a far off land called America. He had also heard that in that land there is a city called Philadelphia and that in the city there was a bell. Supposedly on that bell were the words from their holy book saying "Proclaim liberty throughout the land and to all the inhabitants thereof." The Rebe asked any student who made it to American to let him know if that bell existed.

When Leonard's father was old, his community honored him for his strengths as a teacher. At the celebration he rose and told the story of the Rebe and the liberty bell. He went on to say that he had come to America, made his way to Philadelphia and found the liberty bell. He told the crowd who came together to honor him, that on the bell "yes, indeed, there were the words, our words. But the bell was cracked."

He then said, “You honor me tonight as a teacher. I prefer to think of myself as a person who has tried to live his life as a bell-mender.”

This story speaks to me, so deeply, about what education means in a democratic society. Teaching and learning for democracy requires respectful, active and egalitarian discourse. This kind of shared learning and creativity is not always easy to find; but it is what makes a shared freedom possible. The best teachers instinctively know this.

Why do I start this report on a small pilot project with a stranger’s story and his statements about democracy? His story was an immigrant’s story, one many of us can identify with. His journey to America was undertaken amidst hardship and as a search for the opportunity to make his own choices and to find a home, work, education, community, and citizenship. For many individuals with disabilities the immigrant’s journey, a search for the fruits of democracy, is still underway. We have made significant progress in laws and services; yet the road ahead for some (including several of the individuals who gave so richly to this project) is challenging and the destination uncertain. The uncertainty comes not because of any lack of will on their part but because our society has yet to make the American dream fully accessible to those with significant disabilities.

For these reasons and more, VCIL felt that this project needed to be participant-directed and that participants and the project itself would benefit. Despite the challenges this created, it did result in an incredibly rich learning experience for project staff and participants. Based on participant evaluations I would even say that many people who participated would not have chosen to do so if this commitment was not made and adhered to.

Throughout the project, people of diverse backgrounds, ages and disability experiences discussed and explored PAS issues and shared their deeply personal experiences using and managing their (often hard won) PAS services. At the same time, they also raised other concerns. These concerns about health, economics, and opportunity frequently overshadowed PAS training issues in their lives.

Several spoke about their frustration at being unemployed or underemployed for long periods of time; at the lack of accessible and available transportation; at personal care services that fell apart and workers who were under-recognized and under-funded; and at work incentives that still left some individuals behind. Older participants with work histories and family experience with Participant Directed

Attendant Care (PDAC) services spoke of the need for the PDAC program to address the evolving needs of older participants and family PAS providers while also being flexible enough to support job opportunities for younger participants. Several, particularly the younger adults, spoke of being forced to live periods of their lives on the margins of society rather than as full participants in community life.

I was left with the sense of many talented young people having their lives put on hold because of powerful external forces. People spoke appreciatively of the individuals and programs that were helpful but they were frank in sharing the affect of discrimination, inaccessibility and attitudinal barriers to the lives they wanted to live. Too often their voices held another story line about what it was like to be treated as clients, rather than as adults and citizens. As we worked together and I heard their powerful stories I also saw what each of these individuals have to offer their communities, their own great potential for helping mend the broken edge of the liberty bell.

Particular thanks from this author to Nicole Brothers, Sarah LittleFeather, Julie Wright, Hector Racine and Jill Morton for the dedication, integrity and hard work they put into this project. Making the road by walking it may be good participatory action research but it makes for a hard job and frequent uncertainty. Without the creativity, intelligence and sheer stubbornness these individuals put into this project, this project would not have come this far.

Funding for this project came from the Centers for Medicaid and Medicare Services through a contract with the Department of Aging and Independent Living. VCIL gratefully acknowledges the support of both organizations for this training pilot.

Deborah Lisi-Baker
December 28, 2004

History and Purpose of the Project

In December of 2002, the Department of Aging and Disabilities approached VCIL about implementing a pilot project on PAS management for participants in the State's two participant directed attendant care programs.¹ VCIL began to research training interests and needs of individuals participating in these programs.

Working with staff of the Department and an ad-hoc group of personal assistance services (PAS) users and providers, VCIL designed and implemented a survey to better define the interest, focus and viability of a possible training program. The committee monitored the implementation and analysis of findings from the completed survey. Seventy nine percent (79%) rated pay and benefits as critical or very significant (39% or 40% respectively). Seventy nine percent also said that being the employer, as well as directing their PAS care, is important to them; and 91% said they would not like someone else to be the employer. Clearly, users of the participant directed services value the attendant services offered by the state.

Survey results also indicated that the PAS management tasks that respondents described as having the most difficulty with were the "nuts and bolts" tasks such as writing a job description, recruiting attendants, screening applicants, and payroll paperwork.

Respondents reported having the least difficulty with getting to know their attendants, understanding their own care needs and giving direction to an attendant. Respondents credited interpersonal skills (such as planning, good communication, flexibility, and listening skills) and economic need and the use of spouses as PAS workers as the important factors explaining retention of PAS workers for longer than a year.

VCIL asked respondents to describe how they get information of importance to them and how they would prefer to participate in trainings to better understand how any training, if developed, should

¹ Vermont uses the term attendant care or participant directed attendant care to describe the services provided to individuals with significant disabilities to assist them with basic tasks such as bathing and bowel care, transferring, dressing, and meal preparation. Nationally, personal care or personal assistance services are more often used. We have used attendant or personal assistant services in this report though the term attendant care is generally used when we are describing participant experiences and Vermont programs.

be provided. Most said they used the television or print materials. A full forty five percent did not have access to a computer. Most said they would prefer one-on-one training tailored to the individual and done in a private setting with the attendant. Most felt it was important to have attendant participation in the trainings.

In addition to completing the Attendant Services Program survey, VCIL staff conducted phone interviews with a network of national experts in PAS programs and self-directed management of PAS services.

While planning this demonstration or pilot project, we noted a few areas of particular concern that we felt called for additional research and assessment.

- Among survey recipients and other users of attendant care we talked with, interest in management training appeared less strong than their concerns about other factors, particularly changes in wages and benefits that would improve work conditions and make it easier to recruit staff. What would this mean when it came time to recruit participants to a training program? Would there be enough interest to engage participants?
- Though the surveys did not indicate a major interest in and need for training on interpersonal skills, VCIL staff and an intern who talked with respondents about the survey found that many were bringing up a range of communication issues affecting their relationship with and supervision of attendants. Did this reflect a critical need that had not been captured in the survey?
- The question of *how* best to engage individuals with disabilities in PAS management trainings seemed like a topic that would benefit from additional research. Although more survey respondents indicated they wanted to learn on their own, or with one-on-one assistance, not all did; and general information about effective learning indicates that independent study can be difficult to maintain and does not work for everyone. We also knew that individual participants have gained (and contributed) a great deal in past group mentoring and learning programs offered by VCIL and Vocational Rehabilitation. Finally, other surveys and focus groups indicated that many individuals with disabilities have a strong interest in getting together for peer support, socialization, and advocacy and shared learning. Despite the fact that organizing accessible peer support and learning programs in a rural state brings with it significant challenges, VCIL felt that these PAS survey

results, by themselves, were not enough to tell us what learning strategies would be selected and would be useful. We felt that a pilot would allow us to explore with actual participants which learning strategies would engage peers and be effective.

- To offer effective learning experiences, it seemed necessary to document and better understand the interplay between needs, preference and results. If individual and group sessions were offered we needed to be able to document and measure the interrelationship, outcomes, and benefits through pre and post assessments and other tools. Similar information was needed on the types of instructional strategies and material formats needed for a responsive program.

Prior to doing the survey, VCIL collected samples of different training materials and interviewed academic researchers, authors of training materials, independent living advocates and PAS project managers throughout the country. Engagement of PAS users in these other programs was inconsistent unless participation in training was a requirement for participation in a funding program. Findings (which were summarized and reported to the state) indicated the need for a more interactive and experiential approach to PAS management training. Several researchers highlighted the lack of outcome-based evaluation.

The strongest recommendation from those interviewed was not to develop another book or set of training programs but to explore ways to operate a more interactive learning program. Individuals with disabilities, researchers, and program managers we talked to raised another concern about traditional training models. Training and support needs change during the life span— as the affects of disability changes, as life circumstances alter, and as PAS programs change or are replaced. Finally, those we interviewed noted something we had already observed in Vermont: There is not a strong consumer interest in training despite the sense researchers and managers have that a well designed training program was needed and would be helpful to participants, attendants and program managers.

VCIL has continued to research and review new training materials and has also received some excellent suggestions from Department of Aging and Independent Living (DAIL) staff as they identified new resources. We found that some of these materials are excellent resources but have not been field-tested.

Using the survey results and the findings from VCIL's interviews and meetings with national experts, VCIL recommended that a pilot for a training program should:

- Appeal to both current and potential self-directed PAS users
- Individualize training to the extent possible— both to promote participant-directed and strengths-based approaches and to effectively respond to individual learning interests, needs, and styles.
- Involve pre and post training assessments with participants
- Build on available materials, particularly those that come with high consumer feedback and include ongoing consumer reviews of individual books, manuals, videos and other tools offered.
- Be viewed as an exploratory process designed to give us more information on individual interests and needs than the survey offered. It should also provide more information and an understanding of effective strategies and viable options for offering independent living oriented PAS training opportunities in a rural state like Vermont.
- Offer opportunities for the participant and attendant to work together to build skills and experience in effective implementation and supervision of PAS services.
- Include optional mentoring, technical assistance and peer support to complement other training approaches and materials.
- Offer individualized links to other PAS related information, peer support and advocacy options and evaluate *how* this access and support influences participant engagement in the program.

Description of Project Activities and Desired Outcomes

The pilot project began in January and went through December 04. The goal was to engage between fifteen and twenty five PAS users in project design and as advisors, testers, peer mentors and evaluators of PAS training activities and materials. The products and materials collected during the earlier research for the project had not been formally field tested, though several of the more popular materials had

been recommended to us by Vermont PAS users, national researchers and managers. We wanted to collect better information on individual training needs of project participants and have these individuals help evaluate the clarity, content and format of activities and materials in terms of their usefulness, interest, and effectiveness in addressing participants interests and needs.

The pilot was designed to test three different options for PAS management training. Participants could chose to use one of these options or a combination, depending on their needs and preferences. The three methods to be tested were shaped by the survey responses. They were:

Individual Use of Tool Kit Materials: The toolkit for the project was a set of written materials and videos for learning PAS management. Individualized use would be initiated by a call from an interested peer and would include both a pre and post assessment of interests and consumer assessment of the affect of the training on the development of helpful skills and ability to manage the specific management tasks. The participant would also agree to evaluate the quality of the training materials.

PAS Training Groups in Rutland and Burlington would integrate skills training, peer support, and evaluation activities into a series of meetings. At least one of the facilitators would be an individual who uses PAS services. Pre and post assessments would be used and all participants would be asked to evaluate the usefulness, accessibility and impact of the sessions.

Individualized Technical Assistance: The budget for the project included funding to hire peer mentors, experienced PAS providers or other consultant services that the participant and trainers identify as useful in improving their management and supervision skills.

As noted above, VCIL's proposal was to identify between 15 and 25 individuals to help us test PAS training materials and methods. We knew that the individual response could be higher but we did not know what level of interest would be generated through project recruitment. Since we were evaluating untested methods we did not want to work with too large a group of individuals. For this reason we were willing to open individual use and assessment of the toolkit to more individuals but felt we needed to limit the numbers of individuals served through the other two options.

Specifically, we were testing the assumptions behind the training program as well as different training strategies:

- If you offered training would respondents come?
- What topic areas, training materials and learning strategies would they select?
- How effective would the materials and strategies be in engaging individuals and helping them learn new skills?
- What elements of the training experience would participants consider most interesting and helpful?

Internal Planning: Getting to Sustainability

We also had questions about the kind of program that would be sustainable in Vermont and at VCIL. PAS training managers in other states talked about the programmatic and financial challenges in maintaining viable training services. If the pilot indicated strong demand for a program, we wanted to evaluate whether the desired activities and services could be developed and integrated into our core services without significant restructuring. This was particularly important since funding for future services was uncertain.

Some kind of ongoing service seemed realistic since the core services offered by CILs are peer counseling, skills training, information and advocacy. However, the possibility exists that high demand, specialized or intensive participant needs, or other unanticipated finding from the pilot could indicate particular problems or difficulties to staffing this program by integrating it into other programs and activities at VCIL. VCIL needed to know much more before we moved forward and the best way to learn these things was through direct work with interested peers.

Staffing an interactive and responsive training program raised other likely challenges that included:

- challenges inherent with running the statewide program in a rural state with limited transportation services;
- the diverse interests and needs and disability experiences of current and possible future participants;

- the economic and social barriers to participation experienced by many individuals with disabilities; and
- a fragmented and complex continuum of programs that shape the PAS management skills and experiences of Vermont's attendant service program participants.

VCIL felt that this program, with a small number of interested individuals, would give both VCIL and DAIL an opportunity to evaluate the impact of these issues on program design. It also enabled us to understand the resources, management practices, and skills necessary to staff and manage educational strategies designed to support participant-directed management of PAS.

Now that the pilot has been completed we hope to be able to compare our current capacity with the program recommendations generated by this pilot and determine what VCIL can offer and do well. We want to review our findings with State staff and ASP Eligibility Committee members and with pilot project participants.

The scope of any program in Vermont will be determined, in part, by the financial resources available to support the program. VCIL is committed to ensuring that any program we offer will honor the IL commitment to self-determination and be designed to provide positive outcomes for participants. This pilot gave us a chance to better understand what this approach requires.

Retaining the IL Philosophy as the Driving Force

Principles and standards for independent living centers include participant direction, participation in leadership activities, information to support informed choice, self-determination, and a commitment to participant evaluation. VCIL began using the framework of participatory action to strengthen our use of these principles and standards in program development, advocacy, and peer education activities.

Participatory action comes from a basic premise: that those intended to benefit from any program should be active in the design, implementation and evaluation of the programs and services being created. The United Nations Development Fund noted that participatory action:

1. Helps build the capacity of participants to reflect, analyze, and take action;
2. Contributes to the development of ownership and understanding of what works and what doesn't;
3. Maintains accountability to key constituencies (stakeholders, managers and funding sponsors) by providing experience-based information on the degree to which planned objectives have been met and how well resources have been used; and
4. Gives participants valuable information on effective strategies to improve program management and design. (Source: *Who Are the Questionmakers: A Participatory Evaluation Handbook*, UNDP1977).

Participatory action offers the opportunity to do a “reality check” before full implementation of a program that may not be valued by the intended beneficiaries or relevant to their particular needs, interests and concerns. The interactions, participation and evaluations off all participants are part of determining whether the program model is viable in the proposed setting or environment and adequately accepted by other important stakeholders. These same principles are now guiding leading Japanese and American businesses that are using PAR methods to develop and test product design. A key question for participatory action is will this product or service work in the intended situations and will it benefit the lives of actual participants?

Though this project is primarily a training and evaluation project, the concerns PAS users raised about other issues during the earlier survey phase indicated that attention to other concerns might “add value” to PAS training activities.

We tried to capture participant comments and group dialogue that explore the interrelationship of PAS services with individual interests, and experiences with independent living, education, work incentives and barriers, and civic engagement. Since funding for this project came from a federal work incentive initiative, we were particularly aware of our responsibility to include employment in the range of issues we reviewed with pilot participants. Though this would not concern all participants it is a critical question for participants in social security programs for whom PAS and work incentives are intrinsically linked.

A Brief Summary of Project Activities and Results

The Pilot Project began in January of 2004. VCIL initially convened a cross-program team to assist with project implementation. Nicole Brothers, Advocacy and Education Manager, served as project manager. Staff from VCIL's management, peer advocacy counseling, youth leadership and advocacy programs were given different responsibilities for recruitment, development of materials, review of published materials in the toolkit, and organizing events. Hector Racine, a PAS user and VCIL's Rutland County Peer Advocate Counselor, offered peer-mentor support in the South. VCIL recruited an additional peer mentor to do outreach in the Burlington area and assist with the day-to-day implementation of project activities. The position was filled in January but left and a new person was selected in late March. VCIL was very fortunate that Sarah LittleFeather, one of the project consultants, moved into this role.

Material development and recruitment activities were key activities in the first two quarters of the grant. VCIL staff and project consultants began creating the project forms to document project participation and findings. An intake and interest assessment was created for participants in both individual and group activities. Four toolkits were assembled and materials evaluation forms created for use by participants. A script was also created to help VCIL staff respond to phone calls about the project, walk interested callers through a description of the program, and the resources and opportunities available.

After we received the initial participant interest assessments, staff and consultants began designing the group activities to address the issues identified. Review of the initial interest assessments from participants indicated that employer responsibilities, communication and boundary issues were interests of a majority of pilot participants. Participants were asked to select between the three training models (independent study, peer mentoring and group learning activities). Some chose to participate in more than one approach.

Both staff and peer participants reviewed the toolkit of printed and video materials. The toolkit continues to be added to and revised based on peer evaluations and information requests. For example, a missing piece of the preliminary toolkit was a profile of the Attendant Services Program and how it operates. VCIL interviewed Mike Munieur, Manager of the program, to gather information to create a fact sheet

that was then included in the tool kit. Other materials were collected including an excellent training manual with a corresponding facilitator manual designed by Paraprofessional Institute. This was an invaluable resource during the development of group activities.

Development of the group activities evolved from initial interest assessments and group discussions with individuals from the Rutland and Burlington areas. Both individual interviews and group discussions were held to discuss training options.

Based on the interest and needs assessments Nicole Brothers and Sarah LittleFeather worked with VCIL's Executive Director and project consultants on the development of specialized training modules which included facilitator outlines, resource materials for participants, and evaluation forms. Group sessions were held in November and December and individual use and evaluation of the toolkit was also done extensively. Deborah Lisi-Baker and Sarah LittleFeather took over more of the project responsibilities and additional consultants were hired to help with program development and group facilitation. A peer advocate counselor took on the responsibility of setting up individual use and assessment of the toolkit.

Rutland and Burlington group sessions were scheduled for November and December. Both the Rutland and Burlington groups included time for verbal evaluation of content and activities and participants were also asked to submit a final written evaluation of the experience with the project.

Late in December Sarah LittleFeather facilitated a final focus group evaluation with individual toolkit users and Deborah Lisi-Baker facilitated a similar review with representatives of the Rutland and Burlington groups. Chris Palames and Judy Kimberly of Independent Living Resources also monitored this last session and gave an overview of the shared history of the independent living movement and consumer directed PAS options. This material is being transcribed and put in alternative formats to be added to the toolkit.

Consultants

VCIL is very appreciative of the quality of support provided to the project through the consulting services of Paula Cope and Associates, Julie Wright, Jill Morton, and Chris Palames and Judy Kimberly of Independent Living Resources. Because so many of the issues identified in the interest assessments and follow up interviews by staff centered on communication, conflict resolution, role clarification and

power dynamics in relationships, VCIL felt it was important to work with consultants who had background in these issues and in group process. VCIL's access consultants Rene Wells and James Ross provided additional support on the logistics and related accessibility preparations for the final focus group session. Sarah also networked with a few national resources, including contacting the authors of the Paraprofessional Training Manual.

Paula Cope provided technical support to staff as did Jill Morton and Julie Wright. The experience these individuals have with group dynamics and conflict resolution was invaluable to us during the design of group activities and in clarifying the role of group facilitators.

We were fortunate in the attendants who helped staff our group activities. Armistead provided much of the PAS support. Laura Hill, a personal assistant who works with Sarah LittleFeather, also provided extraordinary assistance. Individual attendants were respectful of the participant directed nature of the project. When asked, they also shared their perspectives on the activities and issues addressed in this program. VCIL very much appreciates the contributions these dedicated individuals made to this program.

Sarah LittleFeather was hired as a peer mentor consultant in April and took over day-to-day management responsibilities when Nicole Brothers left VCIL for other work in August. Her passion for participant-directed programs and for quality PAS services had a huge affect on the integrity of the program. Several participants noted how important it was that the program included a user of PAS services as a co-facilitator. This is particularly true in Burlington where VCIL's PAC for the area is not a PAS user. (Hector Racine, VCIL's Rutland area PAC, is a PAS user and participated in the project both in testing materials and in helping to organize the Rutland group).

We expected requests for other individualized mentoring and consultation services and anticipated using some of the funds to hire skilled peer mentors and trusted PAS providers to help individuals learn how to train staff in specific PAS activities; such a proper transfers, bowel and bladder care. Interest in these options was identified and should be built into any future activities; but participants identified communication issues and employer responsibilities as more immediate needs. Most of the funds for consultants were therefore allocated to these issues and were used to develop and facilitate group activities and plan some individualized follow-up with participants who requested this service.

Results, Challenge, and Lessons Learned

The project was not without its problems and delays. (This is an understatement.) These became part of the learning process. As one participant said at the end, “life happens.” Dealing with it taught us some useful lessons for the future. Here are some highlights of “lessons learned” from this project.

Administration and Staffing

A peer mentor hired early in the project did not work out and a key staff member dealt with a life threatening illness. Both of these experiences had a significant affect on project staffing and implementation. Some of the peers hired to coordinate services for the Rutland and Burlington group did not carryout all the tasks they had agreed to do. The project manager had to take on many of these activities. Though this approach involved peers and can create participant leadership, it probably makes more sense to manage administrative tasks internally.

The formal skills and techniques for managing group process, training and evaluation need to be taught to other VCIL staff and potential peer leaders through formal training and mentoring. Training on group process skills and overview of training methodologies needs to happen early and technical assistance should be available as needed throughout this kind of project.

Early delays in project implementation made the last four months of the project particularly challenging. The time needed to build trust and help participants in both individual and group activities gain experience in using some of the skills presented was curtailed. The commitment and teamwork of the two facilitators, Nicole Brothers and Sarah LittleFeather, helped move the project from what some participants saw as “just another study” to a participatory process that was trusted by most participants. More time would have resulted in a more in-depth evaluation of both materials and process.

The project confirmed that it was absolutely essential that at least one of the lead staff and co-facilitators of any group work needs to be a person with a significant disability who use PAS services. This was absolutely pivotal to the trust, teambuilding, and leadership

development activities the project used and was critical to VCIL staff having any credibility with participants.

Recruitment

Participants were recruited in three ways. VCIL sent PSA and ads to eight community papers in the Burlington and Rutland regions. We worked with the state's Attendant Services Program on a mailing to ASP participants in June and VCIL later sent out a mailing to potential Burlington area PAS users identified in our data base. All these outreach efforts generated very small returns. By far the greatest response came from staff outreach to individuals who use personal care services. Phone networking, outreach at the annual RDAC picnic, community meetings within Rutland and Burlington and a workshop held at the Youth Leadership Forum in August generated the greatest response. The time taken for less successful recruitment efforts delayed start of the training and evaluation activities but also demonstrated the challenges involved in project outreach and recruitment activities.

As we noted earlier, we were somewhat concerned that it might prove difficult to recruit participants for PAS training. We were right. We started with traditional outreach strategies in part to make sure that all ASP participants had an equal opportunity to select participation if they were interested. Both advertising and a mailing to ASP participants took some time to implement and did not attract people to participate.

The two most viable strategies for recruiting participants were through networking and building on natural support groups of peers in Rutland and Burlington.

Existing group dynamics had advantages and disadvantages for the project: the group buy-in in each region helped move the project forward. At the same time, some members of each group, particularly in Burlington, were more invested in the pilot project than others. A few vocal members had other advocacy issues they were more interested in and a need to control meeting agendas. For the most part the group sessions were successful in spite of this, but the program would have been more focused had we narrowed membership to those individuals who expressed a high degree of interest in and commitment to a training process. (We believe that enough trust had been developed between facilitators and participants that it could have

been done, but the project timeline meant that this was not possible. Facilitating this change would have required additional sessions.)

Problems with recruitment are not unique to this project. For example, different organizations in several states using standard recruitment methodologies to recruit participants for the respected Living Well with a Disability Program had very similar experiences. Vermont's experience marketing the Medicaid for the Working Disabled Program also indicates a strong predilection by individuals with disabilities to depend on word of mouth and informal networking over other strategies.

This experience highlights the need for further analysis of and experimentation with other information dissemination and recruitment strategies. Participants in the final focus group suggested that information about the project and some of the training tools be sent to all applicants and new enrollees. It also seems important to continue to explore, develop and then market the program by the particular offerings, characteristics and qualities that make people more likely to participate. Key values to pilot participants included the support for individual concerns, respect for different learning styles, the help available from other participants, the creative learning generated by the group process itself, the opportunity to socialize as well as learn, and the pleasant location and good food. People also felt the more stories and examples from real PAS users, the better.

Eligibility: Defining Participant Directed

Initially the state asked VCIL to narrow eligibility to participants in the State's participant directed attendant care programs. Understandably, DAIL staff wanted to make sure that any products developed would be relevant for this group. They were also concerned that recruiting from other PAS programs might have an unintended consequence of creating false expectations that (for example) ASP funds would be available to them or that they would be found eligible for the program after they completed the pilot project.

Given the small response from Participant Directed Attendant Services Program participants, VCIL decided to recruit additional participants from the Group Directed Attendant Care (GDAC) program and from other users of personal assistance services. VCIL felt strongly that the GDAC model was created as a participant directed option. When the GDAC program at Anderson Parkway was started, individuals were not allowed to participate in the program if they were considered unable to

manage their own PAS services. We also accepted some individuals who use agency directed services but expressed interest in the program. Several individuals had experience with more than one program model. In addition, VCIL felt that individuals often move between programs and individualized PAS training would enhance the likelihood of success with any program. The comments, concerns and recommendation of pilot participants later affirmed this approach.

The state had also been concerned about inviting PDAC applicants who had not yet been found eligible to participate. The fear that pilot participation might be incorrectly understood as step toward enrollment, thereby raising false hopes or expectations, is a legitimate concern. At the same time project participants' own experiences indicated the likelihood that many individuals would benefit from a training program though they are not yet on a PDAC. Both young adults and more recently disabled older individuals who participated in the project clearly described their frustration at being left to figure out basic management task on their own. Similarly, two long- term users of PDAC services said that the project would have been helpful to them soon after they became disabled. This indicates that a program should be made available to a broader potential group of participants– though every effort should be made to separate participation in a voluntary training program from the State's eligibility determination process.

Accommodations and PAS Planning for the Group Sessions

Great care was made to ask about, plan for and accommodate PAS, transportation, and meal issues. Participants were asked to be very specific about their accommodation needs. The two hotels used for the group sessions (the Grand Hotel in Killington and the Clarion in South Burlington) were chosen because of their work on accessibility and their willingness to provide needed accommodations. They both provided excellent service. Although VCIL does not expect that most future meetings will be overnight sessions, we wanted to make sure that participant evaluators were housed in a similar manner to other consultants working on an evaluation project. Because the group activities were carried out in a relative short span of time, bringing people together in a hotel environment had some logistical advantages as well. Even with careful planning, some accommodations were not identified ahead of time. One participant was sensitive to sounds and another to the hotel lights in ways we had not anticipated. Accommodation needs can affect individual as well as group trainings and need to be addressed in any future work.

Two focus groups were held at VCIL and at the library in Middlebury. These are the kinds of locations we are more likely to use for trainings. The activities needed to prepare for this program exemplify what will be needed for future group events. VCIL's access consultants Rene Wells and James Ross offered to handle food and logistics for the last session. They were careful to plan everything: from the availability of the right kinds of drinking containers and anticipating the need to make temporary raisers to increase the height of some of the table to making sure that the meal was presented in the most accessible manner. As Middlebury residents, they were able to connect us with many local resources and they chose to donate most of their time. VCIL will update our materials on planning for accessible meetings to include some of the best practices from this project, including some additional questions on accommodations needed for participants. As Rene Wells puts it, "To plan inclusive meetings you need to anticipate the interests of three groups: persons with disabilities and others participating in the program, participating support workers and presenters, and staff of the facility itself." This is the approach that both Sarah LittleFeather and Rene took in their coordination of hotel and community events.

The degree of individualized accessibility planning can take a great deal of time. Time needs to be built in for organizing these accommodations and for the actual provision of PAS services during the program. In one case an experienced PAS user significantly underestimated her own PAS needs. This caused difficulties during the program but also resulted in greater awareness on the part of the participant for a more honest assessment and planning of PAS needs. One participant required Braille materials and several appreciated having both print materials and verbal presentations on the topic areas.

Time Restrictions

Staff changes and recruitment problems meant that we had fewer months to field test training materials and activities. The program would have benefited from additional months for material development and testing. With more time, individual mentoring and group activities could have been scheduled. Staff and consultants would have preferred to have more time to refine activities and test individual sessions. Evaluations indicated that participants would also have liked and benefited from additional sessions to work on different skills, but felt the topics and format made sense and addressed prioritized issues. VCIL plans to continue follow up work with individual participants who

have requested this and to hold follow up meetings with both the Rutland and Burlington groups. We are also doing a more formal analysis of evaluation ratings now that all the evaluations have been received.

A participatory action project needs the time for staff preparation, development and training of peer leaders, responsive development of training materials and activities, and careful evaluation. Given that “life happens” and time needs to be allowed for unanticipated delays or problems, this project should have had a two year time line. Since the grant period was only one year it created some arbitrary timelines that affected how the project was implemented. This is actually an argument in support of building project activities into ongoing funding even if start up funds are needed from other sources to prepare staff, identify and train peer leaders, and build training materials and methods.

Other

Both facilitators and participants noted that training needs were not always clear to people before the project started. Nicole Brothers noted,

I recall receiving pre-assessments from participants and agreeing with the other facilitators that the participants seemed not to know yet what they could benefit from being training on. Thus, the first two days of the workshop were born. Perhaps this was erroneous on our part, but I am more inclined to think there is a better way to approach this knowing what we know now. Perhaps there is some way to show potential participants what it would look like to have expertise in a particular skill area as a frame of reference before they fill out an assessment.

If somebody fills out the assessment indicating that they have no trouble with most skill areas, they are not a good candidate for the training project (that is something we missed with one participant in Burlington). I'm not certain where to go with this issue, but I still believe it is critical, even though I'm not certain how to improve the process in this regard.

I think there are two key lessons here: one is that we need to allow time for interactive exploration and learning among participants so they have a context in which to assess their training needs. The second is that individuals who identify themselves as not having

problems with management and communication tasks may or may not have them, but if they do not see themselves as needing training, it will be difficult to engage them in a participatory learning process. Their self-assessment should be accepted and they should not be selected for participation. Balancing these two issues will sometimes be challenging, as it was in this project. One or two participants who were not engaged were distracting to others. At the same time, one participant who was very experienced with PAS management felt that he still gained a great deal from participation; but he had made a decision, up-front, to engage fully in the process and this made it work for him.

Peer Evaluation Methods and Results

Intensive testing of the toolkit, of group strategies and of individual one-on-one services occurred during the final quarter of the project (October-December) though some group planning sessions occurred in the summer and early fall. The following section summarizes these activities and findings from each. It is not possible to put all of the evaluation feedback in this report but we will continue to explore this rich source of program information and act on additional information as project review continues.

Three methods were used to capture peer evaluation information. Participants evaluated the toolkit materials, individual activities and group sessions. Careful notes were taken on participant use and response to each activity and ending discussion; and final focus groups were held with a representative group of both individual toolkit users and participants in the group sessions. Both the facilitators and Ms. Lisi-Baker also observed and noted different nonverbal information regarding group dynamics, participant engagement, interactions between participants, attendants and staff to gain additional information on how the program was being received and used by participants. VCIL plans to do additional evaluations with participants in a few months to see if their evaluations of the value of the project change over time. We believe this will provide additional information on the impact and usefulness of pilot activities for individuals who manage their PAS services.

Copies of evaluation tools are included in the appendices of this report. What follows is a brief summary of the evaluation methods used for each of the project activities and our preliminary findings.

I. Individual Toolkit Use

Two sets of individuals reviewed the toolkit materials. In all, eleven individuals agreed to use toolkit materials and evaluate them for their content, clarity, and usefulness. A simple evaluation form was provided and VCIL also offered to help individuals fill out the survey if they needed assistance. Two individuals who used sections of the toolkit also chose to participate in group training activities and some of the toolkit materials were used in group and individual mentoring sessions.

Six individuals from the Burlington area agreed to review the toolkit materials and a peer mentor from that community facilitated an evaluation meeting to highlight strengths, concerns and recommended changes or additions to the toolkit.

Five additional reviewers were selected from peers in VCIL's database whose records indicated involvement in waiver and attendant care services. VCIL decided to focus the recruitment on peers in Washington, Orange, Windsor and Caledonia counties. Peer Advocate Helen Johnke contacted peers to let them know that the toolkit was available. Most were not interested or appropriate for the program because they were not using PAS services or were not self managing their services. Only seven were interested in participating in the pilot and only five chose to do so. After the reviews were completed, a final focus group was held to bring these people together to share their experiences with the toolkit and their recommendations for the future.

Evaluation Results from Individual Toolkit Users

Excellent recommendations came from individual and group discussions. They included:

- creating an updated and readable table of contents
- a glossary of key terms used in toolkit materials
- dating the materials
- and eliminating the written materials that used technical language and was not written in a way to be accessible to individuals with limited reading skills.

The group also felt that each item needs its own descriptive summary covering common elements (i.e. intended audience, primary contents, format(s), and space for reader comments) and individualized peer assessment sheets designed for each toolkit item rather than a generic sheet used for all reviews. Participants felt that the newer video set

had some good information but the audience for the videos was unclear. Much of the information was presented from a provider perspective but users still felt it contained some useful information.

Participants highlighted the value of materials based on personal experience. Three of the manuals seem to be rated best by most participants though the title of one of these (“Dealing with Attendants from Hell”) was disliked by some participants and their attendants. The Burlington group suggested that more information should be included on dealing with an abusive attendant. All of these suggestions are excellent and most will be added to the toolkit format in January of 05. It may take us more time to develop an individualized assessment tools for each item.

It is important to note that people had very different responses to some of the more sensitive issues in personal care management. A member of the final focus group on the project was very interested in more information on personal assistance. Both groups raised this issue as a gap in most PAS training materials. However, an individual toolkit reviewer noted (about one book that is very explicit about using an attendant to help with sexual activities), “Are you kidding!? No one in their right mind working as a PCA would come into my bedroom and ‘rearrange’ me so I could have a sex life. The client has to figure out how to have a sex life of their own.” This reviewer also felt that questioning job candidates or current attendants about their personal interests was inappropriate and intrusive while others found this a useful way to find a compatible worker.

The importance given to questions about how to handle issues like sexuality and personal interests came up in all three learning modes (toolkit use, group sessions and one-on-one mentoring). Many participants felt that the toolkit materials often tried to simplify issues by presenting prescriptive rules for decisions about boundaries between PAS users and providers that, in reality, people will have to work out individually. They felt this is particularly true for individuals who manage their own PAS services and may have other relationships with the individuals who provide their attendant care. The diverse experiences, lifestyles and beliefs individual attendants and users of attendant care have about these deeply personal issues means that essential topics like sexuality, abuse, and intimacy must be fully addressed in the toolkit. These issues are significant and sensitive enough that they probably also need to be addressed in the introduction to the toolkit and any related training activities.

II. Individual Mentoring

Less individual mentoring was done than had been anticipated. Three people requested individual mentoring. This was primarily due to start up delays, not lack of interest, since group participants noted the value of continued work and individualized follow up on their areas of interest. Issues that people who participated in individual mentoring requested included boundaries, recruiting, and dealing with conflict. We are still collecting evaluations for these sessions. Several participants were interested in continuing to develop a peer network to provide peer support and training.

III. Group Sessions

Six individuals participated in the Rutland group and nine joined the Burlington project. The group activities were designed to span four days and about 28 hours of active learning. This does not include the pre and post planning and evaluation activities with participants. The focus of the exercises had been determined from the individual assessments done with participants and follow up meetings with each group. Some individuals also requested additional one-to-one mentoring on some of the training topics.

The agenda for each day is given in the appendices of this report. Participant evaluations gave positive reviews to these activities. The first two day training session opened with ice-warmers and team building exercises. A few participants recommended fewer breaks and more work and the Rutland group in particular felt the second two day session was more focused (as often happens with a new group process).

The group sessions were developed by based on individual assessments and the follow up focus groups and planning sessions with Rutland and Burlington participants. Modules were created and presented that addressed six topics: conflict resolution, setting appropriate boundaries, talking about sensitive issues, advertising, writing job descriptions, and writing a work plan and schedule for PAS services. In these sessions, participants were presented with tools and techniques for clarifying employer/employee roles and shown examples of effective (and ineffective) communication to help participants better understand, recognize and build effective and respectful relationships with PAS workers. On the last day each group had a short presentation and question and answer period on

employers legal responsibilities. They also reviewed participant-tested strategies for recruiting staff Members wrote job descriptions and a recruitment ad and shared them with the group.

Participants found the sessions on personal planning (i.e. Your Ideal Day, Your Ideal Attendant) to be both fun and enlightening. (PAS workers found it helpful as well: Staff of the Armistead (an organization that manages PAS services) took some of these exercises back to their employer to discuss at a staff meeting.)

Exercises selected addressed often overlooked but essential steps in participant direction of services. Exercise on life planning, for example, made it easier for participants to see and understand the importance of self-awareness. It is difficult to hire and supervise PAS workers, and to get the PAS services you need, if you haven't taken the time to think through how you spend your time, how your disability and lifestyle affects your PAS needs, and what you want to do with your time.

Sarah LittleFeather noted in her project review that, "One size fits all training methods are not appropriate for this group of individuals on the topics [peer assessments addressed]. There are too many factors that require individualization. However, a group training could and should be developed further around general employer/employee relationships and how attendant care can impact on one's life."

Participant Evaluation of Group Activities

Three methods were used to capture peer evaluation information. Participants were asked to submit evaluations of materials and presentation strategies used, and of their evaluations of each group sessions. Careful notes were taken of the Rutland and Burlington evaluation discussions and final focus groups were held with a representative group of toolkit users and participants in the group sessions. VCIL plans to do an additional evaluation with participants in a few months in order to see if their evaluations of the value of the project change over time.

Deborah Lisi-Baker attended the first day and the last session of both the Rutland and Burlington groups to thank participants and ask for their comments on the overall project and the group experience. Both the facilitators and Ms. Lisi-Baker also observed and noted different nonverbal information regarding group dynamics, participant

engagement, interactions between participants, attendants and staff to gain additional information on how the program was being received and used by participants. Deborah also held a separate meeting with the workshop facilitators to collect their feedback. One of the facilitators was not able to attend this session but submitted written feedback. In addition, the project manager and consultants kept extensive information about how the project was unfolding throughout each of the groups and shared this information with Deborah Lisi-Baker who was supervising the implementation. It will take us some time to fully analyze all this information; but this analysis will provide more complete information on the impact and usefulness of pilot activities for individuals who manage their PAS services.

Summary of Final Evaluation Meeting Middlebury VT. December 18th 2004.

Three project participants from Rutland and two from Burlington met in Middlebury to for the final evaluation session. They were brought together because they represented a range of ages, PAS management experience and disabilities. They were all participants who remained very engaged in the PAS training process. Three others (two from Central Vermont and one from Burlington) had been invited to participate but at the last minute were not able to join the group.

Chris Palames and Judy Kimberly from Independent Living Resources, Inc. came to this closing session to give an overview of the history and relationship of participant directed attendant care services to the independent living movement principles and practices. VCIL also asked them to summarize the key recommendations from the group and to highlight any underlying issues that need continued review and integration into program development. Their participation has been extremely beneficial to the project.

Here are some of the observations and recommendations participants gave when we asked them to share their initial expectations of the project, strengths and weaknesses they saw, particularly important issues to address in this type of training, and other issues relating to attendant care they felt needed to be addressed.

The PDAC program pays a spouse and family member but does not offer respite and back up support by other PAS providers. This can put a large strain on the family and negatively affect the relationship. PDAC has helped many people with significant disabilities to have the

support they need to maintain their independence and work but at what cost? The program needs to offer the salaries and benefits that will attract and maintain effective backup and respite workers. The program needs to recognize that family members can't keep providing all the care (as participants and their family grow older) and needs offer respite options and other resources.

** * * **

If immediate families are providing PAS support, it is all the more important that individuals and their PAS workers are supported in talking through difficult issues, finding ways to manage and separate PAS issues so they do not interfere with or take over intimate relationships.

** * * **

I went to a college and that is when I first started dealing with managing my own PAS issues. Before then my family did most of my PAS. It took ADA complaint to get the college to provide the needed accessibility and accommodations. Then I moved into my own apartment and had to deal with finding the PAS I needed. It was a hard thing to take on.

** * * **

It was helpful learning the specifics of being an employer since I became one without any preparation: It would be helpful to practice these more. The communication exercises were very helpful and dealing with conflict. I know this [pilot] was just a start but I learn by role playing and experiential learning and think the training should offer a lot of direct practice.

** * * **

I have been managing my own attendants for 25 years. At first I thought this project was just like others: promising a lot but not really leading to anything (other than) a report somewhere. But there is something about this project that has felt very different. I am pretty optimistic about it actually. I hope I am right to be...we will see. Going through the personal planning, looking at employer responsibilities made me step back and think about managing PAS from a fresh perspective. It is easy to get in a rut but this project made me think about the best practices and helped clarify how important they are for both the employer and the attendant. I have tried to encourage some

of the other “older” and experienced PAS users to get involved. I think they have a lot to offer younger folks, but it is hard to convince them that getting out to these kinds of sessions is worth it. Well, I felt the same way at first, so I can understand that...but I hope we can convince them.

* * * *

We got a lot from each other and the group process. I learned a lot from listening to others experiences and because of the trust that we had, we were comfortable with each other.

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I think the real problem is that people don't understand—our society doesn't understand— and value the work. That's why we have trouble recruiting and that is why people doing it are so poorly paid and don't get benefits. We have to change this to solve a lot of the other problems we are talking about.

* * * *

This is not a criticism of the session but I had not had training in recruiting workers before and even though I used all the suggestions from the training I still have not gotten any responses. I did everything and I am still not reaching the right people. We need to work on this.

* * * *

Sometimes the issues of PAS can get in the way of a personal relationship. They take over and the relationship gets lost. Working on how not to have that happen...that is important for this program since we hire our spouse or family member.

The issue of friendship and personal relationships between PAS users and providers is always presented as a rigid “no” and even the tapes presented these as ground rules. I thought it was really important and found it very helpful that Nicole and Sarah played the tapes and went over the boundaries issues as guidelines, not as rigid rules. They were very good at explaining that the guidelines were just that, guidelines to help set up and maintain clear boundaries but that it was up to you

and the folks you worked with to work out what makes sense in each situation. If we really mean that services are participant- directed, we need to be able to deal with the reality of personal friendships and even romance. This needs to be developed and addressed more in the training.

** * * **

I think it would be good to have both PAS users and attendants doing these sessions together. Both parties need to know how to clarify responsibilities and expectations, talk openly about conflict or concerns. Many of the attendants have not had any training in this either.

** * * **

We needed to work on communication, roles first; but it would be great to be able to make our own training tapes for other new PAS workers. This was something we weren't ready to do with this pilot but would be great to create. Then we could show new attendants and other individuals with disabilities "how" to do things like transfers for and with specific people.

** * * **

You always have to train the person who works with you, even if others have trained them. It's the people who may or may not have skills but are willing to learn or are willing to let go of some of what they have learned to understand your needs that are best at this work. Some people refuse to listen. I would rather have someone who can come with a blank slate, a willingness to learn from me what works for me.

** * * **

Home health sucks. Well they don't always suck but you have to get them to listen. It isn't the direct care worker that needs to be trained as much as the person above them, the supervisors.

It is as important to be able to supervise, direct the home care workers from an agency as it is to direct the ones you recruit yourself. They both work for you– or should. It can be hard to do when people aren't used to taking direction or have been told that they don't work for you but for the agency.

* * * *

Often, the best PAS workers are from nursing homes. They've had to do the concrete tasks of PAS over and over again and know a lot of the work cold; but they also want to spend more time and appreciate having the time to do it well and to have a personal connection.

* * * *

Most of my PAS workers start out as friends and become PAS workers. Sometimes the roles get confused later. I found it hard to deal with problems. As a person with a disability, it is hard to be direct with friends about my needs and how I want things done. Maybe because it is hard, I tend to get mad and just yell at them rather than working these things out. The communication skills from this pilot have given me examples of how to be direct without being angry. This is real helpful.

* * * *

I am living in Rutland and working part time. I have a master's degree but have not been able to get a job that uses my training and abilities. A key issue for me is the issue of having family members doing my care. There are some real problems with having family members (other than spouses) being paid to do personal care. Maybe it shouldn't happen...They want to do what they want when it works for them. And they see it (the funding) as money for them but not as money for my services that I have a right to control. They want to provide services when they want to and it is difficult to get them to accept that I have a right to direct how my care is provided. I think it is a problem to have parents or other family members providing the care. I think the training on boundaries, conflict resolution, taking control and responsibility is really important and hard to do without this kind of program [the training pilot].

* * * *

I went away to college and deliberately chose not to select a college based on their disability services. The college I went to organized some PAS services but it fell apart when the provider could not meet my needs. They told me it was not possible to use students as PAS workers, saying they would not be reliable. I decided that I was just

going to reach out and ask students to help and see what happened. Everyone told me that it wouldn't work; that you couldn't rely on students. Actually they were great. I was lucky that I didn't have any bad experiences, or abuse. . .It was the first time I had to have men do my personal care. I had to have them help with very intimate things like menstruation. People got to know me while wiping my butt and became friends later. Reaching out to strangers and the response I got changed my whole relationship and expectation of PAS. I called them my people. They were there for me.

* * * *

A participant directed approach to PAS management is what we want, whether it is in a PDAC program or managing the day to day services offered through a home health agency.

* * * *

Can this project become part of VCIL's peer counseling program or related to it in some way so some of us can be paid to continue this work?

Other Issues Raised

A key issue raised by participants throughout the project was the need to continue to revisit and address the issue of relationships between PAS users and the PAS provider both in participant directed and in agency directed programs. As one of the consultants said, *I don't care what you put in writing and in rulebooks. When individuals are working together on something as intimate as personal care there is always the chance that romance will happen. That is a basic reality. It isn't going to go away. We have to be ready to deal with it. Training needs to help both parties deal with this in a way that is healthy, respectful, and gives people the tools to deal with the issues and keep the relationship and boundary issues mutual and clear.*" Friendship and romance were the subjects of lengthy discussions in both groups, emerged in the toolkit review and at the final evaluation session. Participants felt strongly that this needed more content and time in a PAS training program for participant directed services and in meetings with PAS providers.

One of the facilitators echoed something several participants brought up,

It was interesting to see that while attendant care management issues are seen as important in the lives of those who use this service, it seems that poorly directed care at least gets the survival needs met. The main issues for those who can see themselves working then become employment and transportation. Even poor attendant care gets them up and ready for their day. The younger adults were more concerned about work and transportation. Retirement age participants seemed more focused on quality care and training issues. Not that it was unimportant to the younger group but that the younger group was more easily pulled off training issue focus by wanting to discuss transportation or employment problems.

Though PAS management was the focus of this program, participants raised other issues. We kept "parking lot" notes on topics that came up that we could not address in these trainings. They include: consumer responsive agency run services; equal salaries and benefits for participant directed attendant care; improved group directed care options and related housing needs and resource issues; education and dialogue on disability and sexuality, employment barriers; and the expansion of the peer mentoring and leadership opportunities available for individuals with disabilities in Vermont. We have agreed to hold a follow-up summit with interested participants later this winter to address some of these interests.

Participants also wanted to see this peer-training and leadership model continue, to see it further developed, and to actively involve more individuals. The question of how this should be done and how skilled mentoring services will be maintained needs to be worked on with interested participants, VCIL staff, and others.

Conclusion

Our goal with a pilot project was to develop a PAS training model for users of participant directed attendant care that retained the political premise of disability rights, what consultant and activist Chris Palames calls a citizenship approach to the disability experience. We did not feel that a CIL should offer a prepackaged training program or manual. Instead we wanted explore ways to build a training approach that reflects and builds on the interests, concerns, and engagement of

participants. To do this we had to be willing to “make the road as we went along.” Fortunately, despite some trepidation, the state endorsed this strategy.

To make this program true to these roots required us to honor participatory action in the creation and testing of materials. It was essential that the interactions, life stories, interests and experiences of the participants shape program development and evaluation. The initial interest and needs assessments with individuals and the early discussion groups with Burlington and Rutland participants were all intended to elicit this kind of information and peer direction.

As the project unfolded, we found that this approach was part of what drew people to and engaged them in the project. Final evaluation sessions and project evaluations confirmed that many of the peers who chose to participate did so because of their interest in helping to design and evaluate a peer training program as much (or even more) than for the training for themselves.

Project activities and findings were far richer and more useful because of the participation of the individuals who shared both their questions and their hard earned solutions to living with a disability. Most participants demonstrated a remarkable willingness to share their lives and experiences and to learn from one another and the project. This added greatly to the project.

Both adult education and participatory action principles remind us that some of the most important educational experiences do not happen in traditional classrooms. Education that is open to the experience and wisdom of ordinary individuals builds new roads to knowledge and understanding. This is the kind of education that people can take with them into their lives. We wanted to honor this approach in our pilot of a PAS management education project. This open and interactive process made possible a “reality-based” assessment of what is needed in an educational program intended to help people manage PAS services amidst the human concerns and everyday realities of living with a disability.

We were testing a way to support a more respectful and interactive learning model for self-directed PAS services. Dialogue, individualization, and mutual respect are things most individuals want from a learning program and this approach is particularly important in programs for individuals who manage their own services, or would like to. The skills honed in participatory education are the same as those

needed for the effective management and maintenance of effective PAS services. All too often these are skills people are somehow expected to find on their own.

Two underlying concerns emerged during this project. One was to understand *how* basic human interactions and behaviors define much of what is good and bad about personal assistance relationships and management. Participants talked about power and how it is experienced: between persons with disabilities and family members that assist them; between individuals who use PAS services and the individuals who enter their lives as PAS workers; and between clients of agencies, the direct service workforce and those that manage PAS programs. Several participants said that providers sometimes say their program is participant directed without really understanding what real participant direction requires. People talked frankly about their own communication shortcomings and about the need for PAS users, direct service providers, state agencies and local provider organizations to build a real understanding of what participant direction means.

Participants in the group sessions also shared their desire to do more than participate in learning sessions or toolkit review. They were interested in being part of social action to make other improvements in PAS services: to increase their availability, to expand their value for both the workforce and for program participants; to explore their implications for independent living and work opportunities in the decades ahead. Participants talked about the need for good benefits and work conditions and livable wages for PAS workers. They talked about the need for programs to continually reform themselves to address the changing needs and interests of current and future participants.

Almost all project participants spoke about need for easier access to reliable PAS and respite services, and the need for PAS programs and other disability services and educational programs to build real opportunities for personal and economic success for both attendants and for individuals with disabilities. Participants also spoke together and to VCIL about what self directed PAS services requires of individuals and organizations and expressed great interest in helping Vermont build programs, policies and services that promote dignity, self-determination, and mutual respect in disability related programs and services.

This project is a small beginning. One of the things we hope will come out of it is a useful way to teach and learn PAS management skills.

Another is a network of active citizen advocates and peer mentors working with us on attendant care issues and related disability issues.

The participants in this pilot project spoke more than once about the pivotal place participant-directed attendant care has had in their lives and in their own participation in work and independent living. They wanted to the peer-training program to continue to develop and to serve as a catalyst or forum for building better PAS/attendant care services for the future. We are committed to honoring both these requests.

Deborah Lisi-Baker
Vermont Center for Independent Living
December 27, 2004