

FINAL REPORT
EMPOWERMENT TO PREVENT INSTITUTIONALIZATION
September 30, 2015

Grantee: VACIL

Project Period: 10/1/2013 to 9/30/2015

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a. Project Goal To prevent the institutionalization of people with developmental and other disabilities who experience medical interventions, behavioral stresses or changes in family dynamics that can result in risk of placement in an institutional setting.

The grant proposed conducting an outreach campaign to recruit and train health care and human service professionals in different areas of the state and train them on the resources available to their consumers/clients. The professionals would then share the knowledge gained from the trainings or workshops with their consumers with the end goal of preventing institutionalization of people with developmental and other disabilities.

b. Program Performance

Activity #1a-d Outcomes - Confirming a Steering Committee and establishing a list serve

Accomplishments: This was completed during the first quarter. Eighteen Steering Committee members were identified. Members were trained on the grant during the first quarter and a Steering Committee list serve was established. Steering Committee conference calls soliciting guidance and advice were held the third Wednesday of last month of the quarter.

Demographics: Eighteen Steering Committee members were identified but only seven participated during the course of the grant. These include Mary Mannhardt (consumer), Dana Hicks (DMAS), Teresa Rankin (consumer), Barbara Stewart (Hampton Department of Social Services), Monica Uhl (Partnership for People with Disabilities at VCU), and Marion Vessels (Mid-Atlantic ADA Center).

Consumer Participation: 7 individuals with disabilities were identified to participate as Steering Committee members but only 2 continued to participate during the course of the grant.

Barrier - Continued participation by all Steering Committee members. An understanding of what Steering Committee members could offer and the schedule of meetings prohibited participation by some members.

Effective Strategies - Scheduled regular meetings and conducted a training for all members.

Activity #2 a-c Outcomes - Monthly meetings of work group, training material and community resource document developed

Accomplishments: A work group meeting was held in Richmond in the grant's first quarter to review grant and develop plan. Monthly conference calls were established for the second Wednesday of each month. A training power point, talking points, training guidelines, evaluation forms, impact survey and marketing materials were developed. Consultants developed ten local Resource Directories during the second and third quarters of the grant. During the course of the grant, a Resource Directory was created for the Culpeper area due to a request to present the workshop in Culpeper. As a result, there are 11 local Resource Directories in 11 different communities across Virginia.

The Resource Directories, in brochure/pamphlet form, have received positive comments from across the state due to their size, ease of use, and the amount of information within them. CIL Consultants have noted that in addition to training participants, others including seniors, people with disabilities, caregivers, and family members that have been provided the Directories through other CIL activities are finding the Resource Directories very useful. The Directories were created to educate medical professionals and human service professionals but through the course of the grant, we've found that the Directories are great tools for individuals with disabilities themselves. They can use the resources listed to make informed decisions about their care and they can better educate their own medical providers and caretakers.

Demographics: Consultants from each of 10 different CILS (Access Independence [AI] - Winchester, Blue Ridge Independent Living Center [BRIL] - Roanoke, Clinch Independent Living Services [CILS] - Grundy, disAbility Resource Center [dRC] - Fredericksburg, Endependence Center, Inc. [ECI] - Norfolk, Endependence Center of Northern VA [ECNV] - Arlington, Eastern Shore Center for Independent Living [ESCIL] - Eastern Shore, Junction Center for Independent Living [JCIL] -Wise, Peninsula Center for Independent Living [PCIL]- Hampton, and Resources for Independent Living- Richmond) were identified to work on the grant.

Consumer Participation: Input from CIL consultants (note: CIL staff is comprised of at least 50% of people with disabilities and family members of people with disabilities) and two steering committee members with disabilities reviewed materials.

Barriers: The only concern was what information to include in the Resource Directory and how to include it in one compact publication.

Effective Strategies: What was effective was the format of the publication in the form of a brochure. It was compact, portable, and included information on Medicaid Waivers, housing, transportation, home and vehicle modifications, personal attendant lists, crisis services, state and local resources, assistive technology, aging services, safety, exercise and recreation services, veterans' services and statewide resource directories.

Activity #3 a-b Outcomes - Training Teams Recruited and Trained

Accomplishments: Training teams of four members each were recruited. They were instructed on grant material and delivery of workshop material during one of the three team trainings delivered on July 17, July 23, and July 30, 2014, using the Go-To-Meeting site. Pre and post tests on training material were given to confirm knowledge of material. Teams were then to hold workshops in their localities.

SA01 Performance Measure: People trained in area related to goal/objective: 43

Demographics: Forty team members were recruited with each team consisting of a CIL consultant, person with a disability or a family member, Medicaid Mentor, and medical or human service provider. In addition to identified team members, one Steering Committee member, one CIL director, and one additional CIL member participated in the trainings.

Consumer Participation: Each of the 10 teams had a person with a disability identified to be on their team.

Barriers: Trying to schedule four team members at a time when different agencies were able to meet proved to be difficult. As a result, one or two members per team presented at individual, scheduled workshops.

Strategies: Having one or two members, usually the CIL consultant and Medicaid Mentor, train agencies was more effective than having all four team members. It allowed for better scheduling of the trainings. Using personal stories of how resources helped individuals with disabilities brought a personal perspective to the training helping participants to understand how local and state resource can help to support independent living.

Activity #4-a &5-b - Develop and implement an outreach campaign to recruit health care professionals, schedule initial workshops, identify training locations, and conduct three trainings/workshops in each of the CIL localities

Accomplishments: The outreach campaign began August 9, 2014, and included letters to identified organizations, post cards to community medical and human services organizations, press release, Facebook and Twitter posts, community list serve, and flyers distributed at vendor tables, conferences, other trainings and other outreach events. The RIL CIL consultant did a radio interview in Richmond on August 18 and spoke about the grant. Outreach also included one-on-one phone calls. Outreach materials and campaign were reviewed at the three consultant trainings in July, 2014.

Performance Measures:

SA01 Performance Measure - People Trained in area related to goal/objective: 967

SC01 Performance Measure - Training Implemented: 1. Training conducted 74 times

Comments about trainings and Resource Directories included:

1. The presentation was excellent and it helped me learn/understand MFP/EPSDT.
2. Succinct info/valuable information.
3. Great explanation of waivers.
4. Waiver info most effective as it relates to real info to help patients in need.
5. I am new to this line of work so I found the presentation extremely helpful.
6. The Resource Directory was very informative/many of our clients can benefit from the services listed.
7. Information on ADA and Olmstead Act and how they affect the right of people with disabilities.
8. Listing out the resources in VA and explaining what they can do is very useful.
9. Made me aware of resources I didn't know were available./ Wish I had known years ago when my mother-in-law was sent to a nursing home.
10. Going to bring information back to staff meeting.

Demographics: Over the course of the grant, 74 workshops were held across all ten CIL regions training 967 individuals. This is more than double the grant requirement of 405 (9 CILs x 3 trainings each x 15 people per training). The breakdown of trainings across the state are:

	<u>Qtr 4</u> <u>Wrkshps</u> <u>July-Sept</u>	<u>Qtr 5</u> <u>Wrkshps</u> <u>Oct-Dec</u>	<u>Qtr 6</u> <u>Wrkshps</u> <u>Jan-March</u>	<u>Qtr 7</u> <u>Wrkshps</u> <u>April - June</u>	<u>Qtr 8</u> <u>Wrkshps</u>	Totals Workshops	Total People Trained
AI	0	1	0	0	0	1	9
BRIL	0	0	1	2	1	4	52
CIL	0	0	0	12	0	12	33
dRC	0	4	1	4	5	14	166
ECI	0	3	2	4	4	13	394
ESCIL	0	0	1	1	1	3	47
JCIL	0	1	0	6	1	8	62
ECNV	0	1	1	3	0	5	37
PCIL	0	0	2	1	1	4	59
RIL	4	6	0	0	0	10	108
TOTAL	4	16	8	33	13	74	967

Those trained include health departments; social service offices; caregiver agencies; Agencies on Aging; career and technical centers; HIV/AIDS , Lupus, Multiple Sclerosis, and Parkinson's support organizations; TRIAD groups, rehabilitation centers, free medical clinics, behavioral and family services practices; Chesapeake Public Schools, Kids Central Health Advisory organization, veterans'

clinic in Norton, Gloucester Resource Council, Healthy Culpeper community group, Society of Social Workers, VCU Rehab Counselors Class, church nursing program, retirement communities, therapy providers, and VCU Masters of Social Work class. Trainings also occurred at the following medical centers:

1. Russell County Medical Center, Russell Co.
2. Stone Mountain Medical, Hays, VA
3. Spotsylvania Regional Medical Center, Spotsylvania Co.
4. Children's Hospital of Kings Daughters, Norfolk
5. Sentara Leigh Memorial, Norfolk
6. Portsmouth Naval Medical Center, Portsmouth
7. Bon Secours Medical Facility, Suffolk
8. Virginia Medical College - 190 medical students
9. Mt. View Regional Medical Center, Norton

Barriers: Trying to schedule medical personnel was difficult whether it was private practice or in a hospital or rehabilitation setting. This was due to their busy schedules and because they didn't initially understand what the training was about and why it was important for the people they serve. Those that were at the trainings and saw the Resource Directories were very happy to have the information to support their patients/clients and to have it all located in one small, concise document.

Effective Strategies: Realizing that people with disabilities would benefit if more medical and human service personnel than had been trained had the information in the Resource Directories, the Consultants began a "Blitz" to distribute the Resource Directories to a greater population of those in the medical and human service professions. See Activity #6-a-b.

Activity #6-a-b, Successful Methods and Strategies for Outreach, At Risk People Served, Project Barriers:

Accomplishments: Each CIL consultant visited numerous medical practices and agencies within their locality to discuss and distribute their local directories. The Blitz resulted in 5,413 Resource Directories distributed to 291 medical, human service, and community organizations across the state.

Performance Measures: SC03 Organizations engaged in system change efforts: 291

Demographics: Resource Directories were distributed to medical offices, human service and community organizations throughout the state to include included community Service Boards, Rehabilitation Centers, Department of Social Services, a pharmacy, medical clinics, doctor and therapy practices, veterans' clinics, health departments, nursing homes, school parent resource centers, and libraries, Area Agencies on Aging, and a Department of Rehab Services office. See attached list.

Consumer Participation:

Barriers: Despite the use of developed outreach materials, consultants noted that community connections and personal networking worked best when doing outreach. This likely is because CIL members are very connected to the communities in which they work. Use of a community-wide list serve were helpful for RIL and dRC and information on its website also helped the dRC with outreach. ECI had success with a mass mailing. CIL consultants also noted volunteering to be a presenter for targeted groups, agencies, and organizations that already had set meeting times was helpful.

Difficulty connecting with individual medical practices and hospital discharge and social workers was a constant throughout the grant. As noted above, scheduling time with medical professionals and their office managers was difficult due to the nature of their office schedule and work. To combat this issue, CIL consultants implemented the "Blitz" strategy. The Blitz was an all out effort by the CILs to get the Resource Directories in the hands of more medical professionals and human service agencies and their consumers.

Another barrier was the return of impact surveys. The surveys were originally sent via email for training participants to complete and return but that yielded only 11 replies. The survey was then converted from hard copy to Survey Monkey but only 19 responses were received using this method.

Effective Strategies: In order to distribute the Resource Directories to a greater population of the grant's targeted audience, CIL consultants utilized the Blitz. The Blitz consisted of visiting numerous medical practices and agencies over the last quarter of the grant to discuss and distribute the Resource Directories. The Blitz resulted in 5,413 Resource Directories distributed to 291 medical, human service, and community organizations across the state .

In order to get more impact studies returned, a CIL member dedicated several days to contacting of all the training participants via email and/or phone in an effort to get survey results. The responses we did receive yielded excellent results and are listed below. RIL and CILS also contributed "success stories" they identified as a result of information received through their trainings/workshops.

C. Stories about People with Disabilities

1. Information provided at the local HIV/AIDs agency helped case managers identify different transportation options for a consumer with a disability so he could more readily access his community.
2. 55-year-old woman received information on environmental modifications and was able to get a ramp for her home. She now has the freedom to navigate her community, visit friends and family, and exit her home in case of an emergency.
3. Parent of 15-year-old diagnosed with autism was provided information from the training regarding EDCD waiver and EPSDT. The child was referred to VCU Child Development Center for an assessment for services.

4. Because of an EPI training, a man, approximately 55-years-old, post-stroke, found resources to assist him with housing and resources to manage his finances. The man feels that a family member is taking advantage of him and is trying to be proactive to take care of himself.
5. A 66-year-old woman with Parkinson's disease and other medical concerns lived in a nursing home and her husband wanted to bring her home but thought it would be impossible due to her level of care. After learning about Money Follows the Person through EPI, his wife moved back home. The house had been modified using MFP funds and the woman was able to access personal care services through a waiver.
6. A Pastor who attended an EPI training shared the information with his parishioners. Using EPI resources, he received help securing a wheelchair ramp for the church to assist the church's aging congregation. He keeps EPI Resource Directories available at his church for anyone that may need them.
7. A 63-year-old man learned about and now accesses an Adult Day Program.
8. A family used EPI Information to contact the disAbility Law Center about "alternatives to guardianship." The family had received so much misinformation and was now able to make an informed decision that benefited both their child and themselves.
9. A nurse whose brother is in a nursing home and is not eligible for MFP is working towards the goal of transitioning her brother out of a nursing home. She is using resources listed in the EPI Resource Directory to locate personal care attendants and other supports located in the directory.
10. At an EPI training at VCU, a significant architectural barrier was identified and brought to the attention of the VCU ADA Compliance Officer. The Compliance officer noted that VCU would make it a top priority to correct the issue and has since notified CIL staff that the accessibility issue was corrected. Individuals with mobility concerns would not have been able to access the facility if the EPI training team had not been there.
11. A Social Work student who works at a doctor's office disclosed at an IEP training that her office was not architecturally accessible. When the issue was brought to the attention of one of the doctors, he said they would carry anyone up the steps if needed rather than put in a ramp. Using EPI information the student took resources back to her employers to make them aware

of their legal obligation to remove barriers as well as the tax credits that are available for making the change.

12. A hospital case manager used EPI information to assist a patient in need of durable medical equipment needed to make a successful transition home. The equipment arrived in a timely manner allowing the patient to return home rather than go to a long-term care facility. the case manager continues to share EPI information with other hospital staff and has asked for a training for his staff.
13. A program coordinator of an adult day center, after participating in an EPI training, sought to use resources she learned about to secure home modifications for two consumers. Coordinator collaborated with CIL staff to secure estimates and discuss modification considerations. EPI information was shared with the families of these individuals for future use.
14. A participant at an EPI training shared information with a family member who was living at home and was at risk of moving to a nursing home. The family member was assisted in applying for Medicaid but she also needed home modifications. Information on contractors was shared with the individual and she has sought estimates from contractors. She will also follow up with CIL staff on other resources needed to maintain her independence.
15. A social worker who is also a certified housing counselor and an EPI training team member helped an individual to secure a grant through the VDHDA to convert her existing bath tub in her "accessible" apartment to a roll-in shower.
16. An adult protective services worker helped one of her consumers to secure durable medical equipment. The consumer had a wheelchair and a walker but was having trouble getting from a sitting to a standing position. The APS worker felt the individual would end up in a nursing home if she didn't receive a lift chair. Working with a social worker who was an EPI training team member, the individual was able to secure funding to buy a lift chair.
17. An adult with disabilities in Roanoke was able to access Money Follows the Person after receiving information from EPI training team.
18. A person received waiver information from an EPI training and secured waiver services.
19. Individual received information on Medicaid Waivers and has been screened for Long Term Care.

20. A person who worked as hospital housekeeping staff stated that she also worked as a CNA because she felt "called" to do so. She had worked for an agency but was dismissed because they could not give her enough hours to work. She noted that it was hard to find work "because so many people were being placed in nursing homes these days." She wanted to find full-time work as an personal attendant so she could help people stay in their own homes and have a rewarding job at the same time. CIL staff shared EPI information with her so that she could pursue the type of employment she loves.

d. Assessment of Systemic Impact of Grant

"Somewhere, something incredible is waiting to be known." This quote by Carl Sagan epitomizes the Empowerment to Prevent Institutionalization grant. For many people with disabilities who want and should be living at home in their community among friends and family, things like accessible housing, transportation, attendant care and other independent living support services seem nonexistent or unreachable. In addition, family members and many providers also believe these things are unattainable or never knew they existed. But somewhere these incredible services were waiting to be known and the EPI grant helped to make that happen.

Through the EPI grant, something as simple as the gathering of local and state resources into a compact, manageable, one page form and providing it to people with disabilities, their family members, caregivers, providers, and even the general public, has and will continue to benefit the lives of Virginians with disabilities. As shown through the personal stories listed above, knowledge of resources can go a long way towards changing lives. And as knowledge of resources continues to grow, so, it is hoped, will advocacy efforts to ensure the availability and funding of those resources not only by people with disabilities, but also by family members, caretakers, and providers alike.

e. Sustainability of Plan

CILs will continue to publish and distribute their Resource Directories. One CIL that did not participate in the grant has already inquired about creating and distributing Resource Directories in its locality and all CILs will be encouraged to create their own Resource Directories. CILs do not cover all parts of the state but do cover the majority of it. Community members not located in a part of the state covered by a CIL are encouraged to contact CIL grant coordinator for information on how to reproduce the Resource Directory in their locality. CILs will also continue, at least once per year in the coming three years, to provide an EPI training in their regions. CILs will also continue to update their Resource Directories, at least annually, to ensure accuracy of information.

f. Future Actions

In order to have the greatest impact, it is necessary for people with disabilities and their family members to have basic resource information in their hands as soon as possible after diagnosis so they can make informed decisions with regards to services available to support independent living. Providing access to all the Resource Directories in some format and/or providing CIL contact information (note: a core requirement for all CILs is to provide information and referral) to physicians, therapists, and social workers across the state would have a great impact. State governing boards or professional organizations could provide this information on their websites for all providers to access and use/distribute as needed to their patients.