

FINAL PROJECT REPORT

Outreach to Families of Children at Risk of Institutional Placement or Currently Residing in Institutions, CI-07-06

PRIMARY GOAL

To ensure that parents and guardians, of children with disabilities who are living in institutions or who are at risk of institutionalization, are fully informed about the community based services and supports that may be available.

PROGRAM PERFORMANCE

Objective 1

Increase the number of families and guardians of institutionalized children who are informed about community services and supports, and choose to move their children into the community.

Accomplishments

Activity A. A Steering Committee of representative stakeholders was established to provide feedback and guidance to the project.

The Steering Committee met on the following dates:

March 31, 2008

April 24, 2008

June 25, 2008

October 3, 2008

Initially the Steering Committee was provided with an orientation to the project. Members of the Steering Committee were asked to share what their organization's role could be in this project and how they might to collaborate with others on these activities. At each meeting, the Steering Committee was provided an overview of the training provided to the Parent Partners and Independent Living (IL) Coordinators. At least one Parent Partner and IL Coordinator participated in each Steering Committee meeting to provide feedback to the Steering Committee about the training and to discuss ideas for future training and other activities. The Steering Committee assisted in the development of workshop documents and the interview format for interviews with families of children who reside in institutions. The Steering Committee discussed outreach and workshop activities planned for staff of institutions and the families of children residing in institutions. The Steering Committee provided guidance about how to proceed with requesting the opportunity to interview families of children in residence from the staff of institutions.

The Steering Committee included the following:

Ed Turner, person with a disability

Joshua Wilson, person with a disability

Department of Education, Susan Cumbia

Department of Health Carrie Eddy

Department of Medical Assistance Services, Karen Lawson and Tammy Whitlock
Department of Mental Health, Mental Retardation and Substance Abuse Services, Dawn Traver
Department of Social Services, Lynette Isbell
Office of Comprehensive Services, Brady Nemeyer
Resources for Independent Living, Deborah Yates
St Mary's Home for Disabled Children, Melanie Perez-Lopez
UCP of Northern VA and DC Area, Betty Thompkins
Virginia Board for People with Disabilities, Katherine Lawson and Linda Redmond
Virginia Health Care Association, Mary Lynne Bailey
Virginia Hospital and Health Care Association, Susan Ward

This activity had a 100% completion rate.

Activity B. Research was conducted to identify institutions where children reside. Steering Committee participants provided information about the institutions that they were aware of that had children in residence. Meetings were held with staff from the Department of Medical Assistance Services (DMAS) and the Department of Mental Health, Mental Retardation and Substance Abuse Services to learn more about the placement of children.

This activity had a 100% completion rate.

Activity C. Five IL Coordinators were trained by the Project Coordinator and DMAS to prepare for conducting outreach to the staff of institutions. The training took place monthly either face to face or by conference call. Using the experience gained from a previous grant project focused on outreach to adults residing in nursing homes, the Project Coordinator provided the IL Coordinators with training about best practices to tailor the outreach for each institution.

The Independent Living Coordinators who conducted the outreach and workshops in the institutions were:

Kimball Gray, Endependence Center of Northern Virginia, Arlington
Samantha Gregg, Endependence Center, Norfolk
Dana Jackson, Blue Ridge Independent Living Center, Roanoke
Andrea King, Valley Associates for Independent Living, Harrisonburg
Deborah Yates, Resources for Independent Living, Richmond

This activity had a 100% completion rate.

Activity D. Outreach was conducted with seven institutions where children reside to inform them of the project and the desire to conduct outreach to families of children in residence. The outreach was tailored based on the interest of the staff at the insitutions. Outreach was conducted with staff of the following insitutions:

Central Virginia Training Center, Lynchburg; Children's Hospital's Transitional Care Unit, Richmond; Holiday House, Portsmouth; Iliff Nursing and Rehabilitation Center, Fairfax; Kluge Children's Rehabilitation Center, Charlottesville; Lake Taylor Transitional Care Hospital, Norfolk; and St Mary's Home for Disabled Children, Norfolk

This activity had a 35% completion rate.

Activity E. Workshops about community services and transitioning were conducted at the following insitutions:

Children’s Hospital’s Transitional Care Unit, Richmond
Holiday House, Norfolk
Kluge Children’s Rehabilitation Center, Charlottesville
Lake Taylor Transitional Care Hospital, Norfolk
St Mary’s Home for Disabled Children, Norfolk

This activity had a 50% completion rate.

Activity F. Families of children in residence in institutions who were intested in moving their children to the community were idenitified to the IL Coordinators by the staff at two insitutions. One family heard about the project from another source and subsequently called one of the Independent Living Coordiantors for more information. The IL Coordinators met with these families individually to discuss Money Follows the Person (MFP), Medicaid services and other issues raised by the families related to transition.

This activity had a 100% completion rate.

Activity G. One family was provided with information, referral and guidance to have their child leave an institution during the grant timeline. In addition, two other families began to work with IL Coordaintors to explore community services and to begin the transition process.

This activity had a 50% completion rate.

Performance Measures

CS 03 Programs/policies created/improved formal/informal community supports
Target 1; Actual 1

Grant staff provided training to Community Services Board staff and assisted them with documentation to initiate and plan the MFP process for a child who transitioned.

CS 05 People trained in formal/informal community supports
Target 277; Actual 82

CS 01 Individuals receive formal/informal community supports
Target 2; Actual 1

Demographics

The target population for these activities was children ages birth to 21 with developmental disabilities.

Consumer Participation

The family of the child who transitioned has described a remarkable change in her child's health condition, behaviors and happiness since the child moved home.

Several families of children who are residing in an institution expressed appreciation for being provided with information about Waivers. These families said they did not want their child in an institution but did not know about Waiver slots being available through MFP.

The IL Coordinators had interaction with families of children with disabilities who resided in institutions during interviews with two families, while assisting two families to plan for the transition home of their children and during a workshop at one institution.

Members of the Steering Committee who guided these activities included parents of children with developmental disabilities and people with disabilities.

Barriers

Providing information to the families of children who were institutionalized proved to be a barrier to successfully completing this objective. In order to provide information to families, the project relied on the staff of the institutions telling the families about the workshops. Only one of the ten institutions indicated that families would want the information about community services. Other reasons cited by some of the staff of the institutions were that families are not capable of providing the needed support, that the needed support does not exist in the community or that the family has adjusted to their decision to place their child in an institution and opening the process would be difficult for the family or otherwise not desirable.

Effective Strategies

All of the institutions for which outreach was provided were given information about Money Follows the Person. At one of the institutions, informing staff employed at the institutions about Money Follows the Person helped to garner the interest and confidence that the transition process could work and that the child could live successfully in the community. At another institution, there was a misperception about the availability of Medicaid Home and Community Based Waivers that was addressed which opened an opportunity to conduct a workshop for families of children in residence at that institution. The institutions arranged for the IL Coordinator to provide a workshop for staff and families on a family day previously established for families to visit their children.

Objective 2

Increase the number of families and guardians of children with DD who are at risk of placement learning of community supports.

Accomplishments

Activity A. Workshops about community services for families of children with DD who are at risk of institutional placement and professionals who support these children were conducted by the Parent Partners and the IL Coordinators. Nineteen workshops were held across Virginia with 334 participants.

This activity had a 100% completion rate.

Activity B. The Parent Partners and IL Coordinators received extensive training over an 8 month period to prepare them for conducting grant activities. The Steering Committee guided the training by reviewing documentation and providing feedback about the training process. DMAS conducted six days of training between December 2007 and May 2008 for the Parent Partners and IL Coordinators. The training was held in Richmond with a video conference link to Wytheville Community College for Parent Partners and IL Coordinators in Southwest Virginia. Parent Partners and IL Coordinators received resource documentation about Waivers including copies of the State Regulations for each of the seven Virginia Waivers. In the spring and summer of 2008, conference calls were conducted to focus on each of the Waivers in detail. Workshops materials were developed and updated for the Parent Partners and IL Coordinators to use in conducting their local community workshops.

This activity had a 100% completion rate.

Activity C. The Parent Partners and IL Coordinators promoted their workshops and the availability of information in their local communities. This outreach occurred through the placement of articles about workshops in support group newsletters, at community resource fairs, through the public schools and other locations where families go for services.

This activity had a 100% completion rate.

Activity D. The Parent Partners and IL Coordinators responded to phone calls and emails from families who needed information and referrals to obtain supports to divert institutional placement. These contacts provided information about Medicaid Home and Community Based Waiver services, Medicaid Early and Periodic Screening, Diagnosis and Treatment benefits, the Medicaid Health Insurance Premium Payment, coordination of medical services within schools, sponsored residential placement, provider choice provisions and Medicaid appeal rights. Parent Partners and IL Coordinators reported that 218 people received information and referral from them. The project maintained a toll free number for information and referral about Medicaid Waiver services.

This activity had a 100% completion rate.

Performance Measures

CS 03 Programs/policies created/improved formal/informal community supports	
Target 1; Actual 1 Several local departments of social services improved access to Waivers based on the information provided through this project.	
CR 03 Members of the general public estimated to have been reached by council public education, awareness and media initiatives	Target 1,000; Actual 1,200
CS 01 Individuals receive formal/informal community supports	Target 50; Actual 90
CS 05 People trained in formal/informal community supports	Target 75; Actual 416
HE 05 People trained in health care services	Target 198; Actual 416
ED 01 Students have the education and support they need to reach their educational goals through Council efforts	Target 3; Actual 5
ED 02 Infants and young children have the services/supports needed to reach developmental goals through Council efforts	Target 3; Actual 7

QA 10 Number of entities participating in partnerships or coalitions created or sustained as a result of Council efforts Target 32; Actual 34

Demographics

Parents of children with disabilities, providers of Medicaid services, people who determine eligibility for Medicaid Waivers, educators and people with disabilities attended the workshops and received information and referral.

The Independent Living Coordinators and Parent Partners collaborated to achieve this objective.

Parent Partners –

Sandra Coombs, Chesterfield

Patti Cook, Lexington

Joseph Deckard, Weber City

Cynthia Favret, Hampton

Barbara Greenberg, Blacksburg

Sonya K. Johnson, Stephens City

Theresa McMillan, Virginia Beach

Joyce Perkins, Bristol

Sharon Ross, Manassas

Petrina Thomas, Culpeper

Betty Thompkins, Arlington

Didi Zaryczny, Bedford

Independent Living Coordinators -

Access Independence, Winchester, Roseanne Campbell

Appalachian Independence Center, Abingdon, Bill Duncan

Blue Ridge Independent Living Center, Roanoke, Dana Jackson

Clinch Independent Living Services, Grundy, Deborah Rose

disAbility Resource Center, Fredericksburg, Tennie Gratz

Eastern Shore Center for Independent Living, Exmore, Doreen Capers

Endeppence Center, Norfolk, Samantha Gregg

Endeppence Center of Northern Virginia, Arlington, Kimball Gray

Independence Empowerment Center, Manassas, Roberta McEachern

Independence Resource Center, Charlottesville, Brandon Rush

Junction Center for Independent Living, Norton, Sandy Spivey

Lynchburg Area Center for Independent Living, Carmela Greer

Peninsula Center for Independent Living, Hampton, Linda Gurley

Piedmont Independent Living Center, Danville, Jeanette King

Resources for Independent Living, Richmond, Deborah Yates

Valley Associates for Independent Living, Harrisonburg, Andrea King

Consumer Participation

Attendees at the workshops were primarily parents of children with disabilities. Other workshop attendees included people with disabilities, educators, Medicaid service providers and Medicaid Waiver screeners. Evaluation forms were completed by the attendees at the conclusion of the 19

workshops. Of the approximately 340 people who attended the workshops, 117 people completed evaluations.

A sample of responses to the workshop evaluation questions are as follows:

The majority of people rated the workshops as excellent.

In response to the question “What would you suggest be done differently in future workshops?” –

Provide more examples of how services can be used.

More time for questions and answers.

More time for discussion.

The most common response was “nothing”

In response to the question “How will you use the information shared in this workshop?” –

Apply for waiver for my child. Resource tools are great.

To educate people within the school system to get info to other parents.

Using contacts made to get more information.

Now I know where to get started.

Hopefully I will have the “terms” to present to the right persons regarding waivers I need.

In response to the question “What difference do you think this workshop will have for people trying to access Medicaid Waivers?” –

Encourage advocacy; inform us who we can turn to.

Helps with first steps. Very important!

Some will get discouraged. The message to be persistent is important.

It gave me a chance to share my experiences and hear others experiences.

Practical information that will help us to use the services better.

Most beneficial information on the subject that I have found over a ten year period.

Members of the Steering Committee who guided these activities included parents of children with developmental disabilities and people with disabilities. The Parent Partners who conducted these activities were parents of children with disabilities. Several of the IL Coordinators who conducted these activities were people with disabilities.

Barriers

No barriers were encountered with this objective.

Effective Strategies

The Parent Partners and the IL Coordinators were already active advocates in their communities. This experience and the relationships they had with other organizations in their communities helped to ensure that they were able to promote their workshops widely in their communities.

ASSESSMENT OF SYSTEMIC IMPACT

Through the practical experience of assisting a family with transition, information was shared with DMAS that should help improve the transition process in the future.

The Project Coordinator and one of the IL Coordinators serve on the DMAS MFP Workgroup and were able to share the knowledge they gained through this project with the Workgroup. For instance, the time it takes for a child to obtain a psychological evaluation for the determination of whether the child will receive the IFDDS Waiver or the MR/ID Waiver based on a diagnosis can significantly slow down the transition process. Knowing this, people involved in future transitions can begin to obtain the needed psychological evaluation in the earliest stages of transition planning to avoid unnecessary delays.

Relationships forged with the staff at institutions should help to encourage them to reach out to Independent Living Coordinators for information in the future.

The workshops conducted for families of children with disabilities who are at risk of institutionalization included information about the IFDDS Waiver and MR/ID Waiver waiting lists and advocacy strategies to address these waiting lists. These informed families are now better prepared to work collaboratively, as well as individually, to educate legislators and others about the need to fund waiting lists.

It can be very difficult for families to find accurate information about Medicaid Waiver services. Expanding the number of people who can provide information and training about these services (Parent Partners and IL Coordinators) has helped to ensure that more advocates are available in communities throughout Virginia to provide accurate and easy to understand information about Waivers to families and professionals who work with children with disabilities.

SUSTAINABILITY PLAN

The Endependence Center will continue to fund and staff a toll free number for calls about Medicaid Waiver services.

The IL Coordinators that conducted outreach activities at the institutions will continue to maintain contact with these institutions on a regular basis to strengthen collaborative relationships and to provide updated information.

The Project Coordinator will provide feedback to the Money Follows the Person workgroup based on information learned through these ongoing activities.

The Endependence Center is in the process of entering into an agreement with DMAS to obtain additional data that could be useful in targeting outreach activities to facilities with children in residence.

An annual update on Medicaid Waiver services will be provided by the Endependence Center to the IL Coordinators and Parent Partners. It is critical that the IL Coordinators and Parent Partners be encouraged to continue their own education about Medicaid Waiver services and remain committed to expanding the number of people they reach through providing information and workshops. The majority of IL Coordinators and Parent Partners have stated they will sustain and expand their activities to help families access needed services.

FUTURE ACTIONS

Due to the significant changes that are likely to occur within Medicaid in the coming year due to budget challenges, the workshop material should be thoroughly updated.

Many families are accustomed to obtaining resource information through the Internet. In order to reach a larger audience electronic methods of training and resource sharing such as Internet-based training should be pursued. And other families prefer traditional paper formatted resources. To meet the needs of these families, the (green) Medicaid Waiver Guide should be updated and a brief brochure about Waivers should be developed. Virginia Easy Access should be encouraged to expand the information available about home and community based services for children with developmental disabilities.

At the beginning of the project there was the expectation that up to 90 interviews would be conducted with families of children residing in institutions. The purpose of these interviews was to learn about the circumstances that led families to making a decision to have their child live in an institution. We were only able to conduct two interviews. After discussions with the staff of the institutions, we learned that the staff did not see any benefit in conducting the interviews or know any parents that would want to participate with the interviews. At the end of the project, one institution offered to provide copies of the interview questions to the families of children residing in this institution and allow the parents to decide for themselves whether or not to respond to the items in the interview format. This opportunity is being pursued by the IL Coordinator in the region in which this institution is located. Information that is gained from these subsequent efforts will be shared with VBPD.

Providing information about community services to families of children who reside in institutions needs to be done on a periodic basis so that families have the information readily available. This could be accomplished during the annual resident reviews.

Foster family, adoptions and other options should be explored for children who reside in institutions who no longer have their birth parents involved in their lives.

The process for placement in an institution should be reviewed by DMAS to ensure that families are provided information about community services and intensive support coordination/case management prior to making a decision about the manner of long-term care services the child will receive.

Training for hospital discharge planners, local Departments of Social Services and Departments of Health, medical professionals and others responsible for planning services for children who are in hospital settings or who are otherwise at risk of institutionalization should be provided on an ongoing basis. The training is needed so that these professionals can provide families with accurate information and support in order to prevent the institutional placement of children with disabilities.