

STATEWIDE REPORT

Consumer-Directed Services in Virginia

LISTENING POSTS

Partnership for People with Disabilities
Virginia Commonwealth University

BACKGROUND

In 2002, the Partnership for People with Disabilities at Virginia Commonwealth University (VCU) entered into a contract with the Virginia Department of Medical Assistance Services (DMAS) to provide training and technical assistance on consumer-directed (CD) services provided under Virginia's Medicaid Waivers. Currently, CD services are available to individuals with disabilities and their families in three of Virginia's Medicaid Waivers: the Consumer-Directed Personal Attendant Services (CD PAS), the Developmental Disabilities (DD), and the Mental Retardation (MR) Waivers. The contract to the Partnership is funded through a three-year federal Real Choice Systems Change grant, entitled *Consumer Choices for Independence*, from the Centers for Medicare and Medicaid Services (CMS) to DMAS. The Partnership's role on this grant is to "collaborate with other state agencies and consumer based organizations to ensure that individuals and families can realize full and meaningful participation in communities, while exercising choice and control of needed supports through the implementation of CD services as included in Virginia's Waivers."

An initial step in the process of developing training and technical assistance was to form a Training Advisory Team, consisting of representation of individuals receiving CD services in Virginia's Waivers, state agencies, and providers. To orient the team to a common understanding of CD services, the Partnership used the *Consumer Direction Tool*, developed by the National Association of State Units of Aging and the Home and Community-Based Resources Network (funded by CMS). The *Consumer Direction Tool* uses the goals of the Americans with Disabilities Act (ADA) to assess the level of choice and control in a state's CD services. ADA's goals include opportunity, participation, independence, and financial security. The Real Choice Training Advisory Team members gave their assessment of CD services provided under Virginia's Medicaid Waivers in terms of the goals of the ADA. They also encouraged the Partnership to listen to individuals across the state who are receiving and providing support through CD services to get their view of appropriate next steps.

PROCESS

This report represents a summary of the comments obtained through Listening Posts held in eight locations in the Commonwealth and from write-in comments from individuals statewide who were unable to attend a Listening Post. Staff from the Partnership, with the assistance of local advocates, went to the localities to hear from individuals with disabilities, families, providers, and others about their experiences with Virginia's CD services. The Partnership facilitated 12 meetings in December 2002, and in January, February, and March 2003, and gathered input from 89 individuals who work with recipients of CD services or who depend on CD services. Two meetings were scheduled in most locations to accommodate as many individuals with disabilities, family members, and providers as possible.

Each Listening Post meeting used a simple but comprehensive process to gather participants' thoughts and ideas on how CD services are working in the CD PAS, DD, and MR Waivers. Participants

actively engaged in a process of listing what should be continued, what should be started, and what should be stopped with regards to CD services. A group discussion was then facilitated which enabled participants to share their list of comments and develop a group summary at each meeting. Site summaries were developed from the group summaries. This statewide report, a compilation of the site summaries, has been organized according to common themes as they relate to the goals of the ADA. The Partnership staff will use this information to make decisions on content and process in the provision of training and technical assistance. The comments that go beyond the scope of training and technical assistance will be shared through this report with state agencies and consumer based organizations to promote full and meaningful participation of individuals and families in their communities.

The Listening Post process did not focus on the lack of funds or the waiting lists, although these issues cannot be ignored and were raised at all the sites. The participants at the Listening Posts requested that the issue of funding for those individuals, not as fortunate as themselves in having Waiver services, not be forgotten. Additionally, the information gathered at the Listening Posts should not be considered "research." The comments presented in this report represent the views of participants in the Listening Posts and should not be viewed as representative of all individuals receiving CD services through Virginia's Medicaid Waivers.

PARTICIPANTS' COMMENTS AND SUGGESTIONS

"Level the playing field. Make CD services in the three Waivers consistent."

Quote from group summary from Wytheville

The most frequently voiced suggestion from participants of the Listening Posts was that the three Waivers that include CD services be revised to have the same regulations and process. It was suggested that one set of CD services regulations be created, taking the most flexible and supportive regulations from each of the existing Waivers. Participants noted that as Virginia has had more experience in CD services, the process has improved and more choice and control has been given to individuals with disabilities and their families. In Virginia, according to participants, the CD PAS Waiver was used to model CD services in the DD Waiver, which was used to model CD services in the MR Waiver. Participants stated that as the Waivers were developed and enhanced, the older Waivers were not updated to include the most innovative and useful components of the newer Waivers. Many participants at the Listening Posts agreed it is time to create one set of regulations for CD services that take components of existing Waivers, and new components (suggestions from participants) that promote the principles of consumer direction. They believe an inclusive set of regulations would create conformity in eligibility, types of CD services, definitions, provider qualifications, hours, co-pays, funding and payments (salaries), manuals, paperwork, and the process to follow. The participants strongly agreed that by creating a set of the most flexible and responsive regulations for CD services across the Waivers, Virginia would move closer to the intent of consumer direction, offering more choice and control.

Providers attending the Listening Posts stated that the lack of conformity in CD services across the three Waivers is also confusing to them and makes it difficult to keep themselves, as well as individuals with disabilities and their families, informed. For example, CD services facilitators are approved to work with individuals on all three Waivers. CD services facilitators reported that the differences across the regulations for the Waivers are confusing, limiting their involvement to individuals on one Waiver. Participants agreed that the diversity in the Waivers' regulations for CD services is

confusing to individuals with disabilities, their family members, case managers, support coordinators, and CD employees. It is almost impossible to remember all the differences in CD services across the Waivers, according to participants.

“ I want to say thank you, thank you to all who have anything to do with this very outstanding program (CD services) because it has been such a blessing to not only me but many others who have benefited from it.”

Comment from a CD services recipient

Finally, the suggestion was made that all Waiver services in Virginia be provided under both CD and agency-directed options. Individuals who receive CD services were thankful for the opportunities to be more flexible in their support and to truly meet their needs through CD services. However, they felt expansion of consumer choice was the most important principle and thought that all individuals receiving Medicaid Waiver services should have available the options of agency-directed or CD for all services, or a combination of both if needed.

The following four sections organize comments according to themes from the ADA: opportunity, participation, independence, and financial security. While some comments could easily be included in more than one theme, comments are included based on the “best fit.”

OPPORTUNITY

The ADA goal addressing opportunity promotes the belief that individuals with disabilities should be able to live, work, and have relationships in their chosen communities. A component of opportunity is receiving accurate information on CD services and the process for application and implementation. It was reported at the Listening Posts that individuals and families have received very little information on CD services and do not have a complete view of their options or responsibilities. Participants stated that currently too many aspects of the Waivers are in draft form (manuals, regulations, forms, etc.) and they cannot find accurate, permanent information. Many participants felt there is a lot of work to do in promoting and explaining CD services, and thought this process would be easier with one set of regulations.

Participants suggested that information be user-friendly, but comprehensive for individuals, families, case managers, support coordinators, CD services facilitators and CD employees. A variety of formats for information were suggested (brochures, flyers, training events, videos, and manuals), ensuring all materials are in alternative formats for individuals with disabilities. Several participants stated the *Employee Management Manual* for the MR Waiver is very user-friendly and should be used as the prototype for any manual that is created to provide information on CD services. Information should be created that educates individuals and families about what CD services are and how to determine what works for them, according to participants. In several Listening Posts, participants suggested a *Procedural Safeguard Document* for individuals and families be created that explains CD services and individual/family rights and responsibilities. Participants also stated that the *Employee Management Manual* and the regulations should not focus on what supports CD employees cannot provide; rather individuals with disabilities and their families should have the flexibility to decide what they need.

A concern for some participants was that eligibility criteria for CD services vary from one Waiver to another. For example, the MR and DD Waivers allow individuals to manage CD services with help from others (e.g., legally authorized representatives, family members), but the CD PAS Waiver does not, according to participants. Participants stated that individuals needing help managing their CD services are found ineligible for CD services in the CD PAS Waiver. Most participants agreed that all individuals who choose CD services should be eligible for them, even if they need assistance. Participants also suggested training all individuals responsible for determining eligibility or participating in the process (screeners, eligibility committees, support coordinators, and case managers, etc.) to make them aware of the eligibility criterion that allows assistance in managing CD services. It was also suggested that the application process for CD services be made user-friendly, streamlining paperwork and the timeline. It was also suggested that CD services regulations be amended to provide emergency access to Waivers to individuals in institutions. Currently in Virginia, individuals in institutions (state facilities and nursing homes) have no access to CD services, according to participants. Finally, participants stated a uniform eligibility process for CD services should enable a smooth transition from one Waiver to another to ensure individuals find the best fit for them (and are able to move money from one Waiver to another).

PARTICIPATION

Participation is defined as the ability of individuals with disabilities and their families to make decisions about their services and supports and to set state policies. The greater individualization of supports through CD services enables individuals to get what they need. CD services allow greater flexibility in the how, where, and when supports are provided to the individual. Individuals and their families can be creative in how they hire and use CD employees.

“CD services foster the sense of dignity, responsibility, and control for people with disabilities.”
Comment from a family member

Many participants stated that CD services have the potential to enable them to make decisions about who provides their support, and where and when it is provided, but many say they need help managing their supports. Some participants stated they appreciate the assistance they receive in finding CD employees, such as the registry of possible employees maintained by the support coordinator or CD services facilitator, and the training and individual support provided in learning to be an employer. One individual stated “being an employer was a new experience, but with support and guidance the rewards are worth the work.” Participants suggested that all CD services facilitators, case managers, and support coordinators be responsible for coordinating and maintaining an updated registry of potential CD employees. They believe the registry will help ease the pressure that individuals and families say they have looking for CD employees by giving accurate information on what a CD employee can and will do. A good example is the registry developed by the Center for Independent Living (CIL) in Lynchburg. According to participants, individuals and families can waste a lot of time calling people on a registry that is not current or gives limited information.

Participants in all areas of the state agreed that they need assistance at times in being effective employers. Some participants at the Listening Posts suggested that consultants be available to provide information and technical assistance to individuals and their families, similar to the MR consultants (regional) for the MR Waiver. Individuals and family members often have questions about the Waivers in general and CD services in particular but do not know where to get the answers. Most participants

stated they are pleased with the opportunity to train their own CD employees, but some of them said they need help with training. One participant stated that the Centers for Independent Living (CILs) are helping individuals recruit and train potential CD employees, and this has proven successful in several areas of the state. Maintaining a reliable fiscal agent (DMAS) has also helped participants be successful as employers, by ensuring that providers are compensated for their services.

In developing uniform regulations, participants suggested always looking at ways to make the process more user-friendly, making it easier for individuals with disabilities to manage CD services. Too many rules can limit flexibility and defeat the purpose of CD services, according to participants. Participants stated existing rules are hindering individuals with disabilities and their families from hiring whom they want and getting what they need when they need it. Limiting paperwork and bureaucracy to encourage the choice and control of individuals with disabilities and their families using CD services in Virginia's Waivers, was suggested by participants.

"It's nice to know everyday I have someone come in around the same time for me to get my bath and cook my breakfast and lunch and take care of me and my surrounding.

I do hope this can continue."

Comment from a CD PAS recipient

Participants expressed their appreciation for some of the other Medicaid services that support their lives in the community and CD services. Making behavioral support available for individuals with disabilities, especially children, has assisted in keeping individuals in their homes, work, and schools. Several participants stated that an individual's behavioral issues often threaten community participation. Behavioral intervention is limited (limited providers in some areas of the state), which increases the risk of institutionalization, according to participants. Individuals also greatly appreciate the Medicaid services (insurance, medication, etc.) that are connected to receiving Waiver services, and the funding for assistive technology, which enables families to obtain technology that their children need, but that the family could not afford.

"Put disability advocates on all the screening teams statewide."

Suggestion made by a CD PAS recipient and CD services facilitator

Throughout the state, participants stated they wanted more control over the systemic decisions being made. Many participants expressed concerns about the screening teams for the CD PAS Waiver. It was suggested that all screening teams have at least two members with disabilities. Participants believe this addition of individuals with disabilities to the screening teams will provide first hand knowledge and experience to the process. Participants stated that individuals with disabilities will help the screening teams in several areas: assisting teams in knowing all the options and resources, simplifying and therefore streamlining the enrollment process, and promoting community as opposed to institutional (including nursing home) placements. Many participants, statewide, complained about the cumbersome and lengthy process for eligibility in the CD PAS Waiver, and the barriers to community living created by its regulations. Individuals leaving nursing homes wait six to eight weeks from the determination of eligibility for the CD PAS Waiver to the start date for services, which makes discharge extremely difficult, sometimes impossible, according to participants. The MR Waiver, in comparison, has the effective date of services the same as the start of the plan, but the CD PAS and the DD Waivers do not.

“CD services give Americans with disabilities their constitutional right to live life to the best of their abilities. Life, liberty and justice are what you, the government, preaches to the world.”

Comment from a CD service recipient

The suggestion was also made that DMAS be required to have 50% of its Board’s membership be individuals with disabilities, and that all Board members have expertise that qualifies them to make decisions about Medicaid/Medicare. Participants stated that individuals with disabilities on the DMAS Board would bring real-life experience and information to the decision making process. Individuals with disabilities can provide feedback on the impact of policy decisions on the individuals receiving services, and give a realistic view of the level of success in implementing change, according to participants. Participants were adamant that individuals with disabilities want a voice in shaping the Medicaid system and policy in Virginia.

INDEPENDENCE

Independence is described in the ADA as the right to control one’s life. It is having the freedom to decide where and how one will live. CD services promote community participation, according to the participants in the Listening Posts. Individuals stated they have been able to stay in their homes, with loved ones, through CD services. Some fear that without CD services they would be institutionalized (nursing home). Because individuals and families are able to control the hours of support, it is easier to work out a schedule that accommodates individuals’ work and school, according to participants. Individuals can stay in their homes, schools, places of employment, and remain productive through CD services. Participants would like to see all CD regulations promote community living and independence, and not make a facility or an agency the first choice put forth to individuals.

“CD services lead to creative solutions.”

Comment from a Support Coordinator

Participants stated that before CD services were available, individuals with disabilities and their families were dependent upon agencies’ hours, staff, and types of supports. They did not have input into who provided their care, and they were concerned that they might be supported by providers they did not “like or trust.” Some participants stated that prior to CD services they could not get the support they needed because there was not an agency to provide the care. Participants stated that the ability to be the employer, and to hire friends, neighbors, family members, and others through CD services, gives individuals a greater level of comfort because they know their CD employees and they have control over how and when they are supported. Individuals stated they can match their needs with the skills and willingness of CD employees to do certain tasks and work certain times.

“ When I had to hire an agency to find help for me (before I was on the CD PAS Waiver), it often took weeks to find someone who was usually unqualified to help me. Agencies often assigned non-English speaking, sometimes physically unfit, people to help me.

I had no real say in who was sent to my home.”

Comment from a CD PAS recipient

Participants expressed their concerns that the current screening processes for CD services in the three Waivers has at times hindered the independence of individuals with disabilities. The concerns expressed about the CD PAS Waiver included: screening teams giving no or incorrect information on eligibility and types of support available, the difficulty in leaving an institution (nursing home) after a short-term crisis, the lag time between leaving a nursing home (returning home) and receiving Waiver services, and prohibiting individuals who need skilled nursing care from being eligible to receive CD PAS Waiver services. More short-term crisis care should be made available in facilities as needed, ensuring a return home as soon as possible, according to participants. Concerns about the MR Waiver were also expressed at the Listening Posts. The concerns from some participants included control of the process by Community Services Boards and case managers who are limiting referrals to CD services, not responding to CD service facilitators, and delaying the process. Some participants do not like that they do not have a choice of case managers on the MR Waiver. Other participants were appreciative of the MR case management services they receive, which included information on and support for their CD services.

"Better training for all CD services facilitators, case managers and support coordinators."
Quote from a family member

A major issue heard statewide was the limited number of providers, especially CD services facilitators. In all three Waivers, individuals must have a CD services facilitator before they can receive CD services. Participants stated that some regions of the state have no CD services facilitators, with the closest providers being hours away. In areas where CD services facilitators are not easily accessible, the families stated they are doing most of the work themselves because their CD services facilitators do not know local resources. Several of these individuals and families, who have long distance CD services facilitators, say they have not found CD employees, although they have been approved for CD services months before. Participants suggested that provider development is needed to ensure all interested individuals and families, in all regions of Virginia, have accessible CD services facilitators to help them recruit, hire, and maintain their employees. Support coordinators are also limited in some areas, according to participants. Several participants stated they do not have the option to change support coordinators or CD services facilitators if they are not happy with their services. Participants stated that individuals do not want to be in the position of having to work with CD services providers who are not doing their jobs, but this is happening in areas where there are limited choices or no choice.

The lack of qualified, competent CD employees and the current limit on the number of CD employees an individual or family can hire can greatly hinder independence, according to participants. Several suggestions were made by participants on ways to address the shortage of employees. It was suggested that CD employees, who are currently working for one individual, be allowed to also work for another individual, without going through the full hiring process and paperwork. Participants also stated that CD employees who provide services to multiple family members should be allowed to bill for the multiple services. An example given was a family with twins who are receiving CD services and must have two CD employees for the two children. Several participants suggested that CD employees be allowed to perform tasks such as tube feeding, giving medication, nebulizing, and basic first aid. Sometimes the person hired has been performing the health care for the individual, but once hired as a CD personal assistant, he/she cannot perform the same tasks, according to participants. Participants stated that restrictions on hiring family members should reflect federal regulations and not be more restrictive in Virginia. Another suggestion for addressing the shortage of providers was to work with

higher education to develop a pool of CD employees among college students, as a way of addressing the shortage of CD employees.

Additional suggestions to ease the shortage of CD employees include lowering the age restriction (to 16 years of age), covering startup costs for all CD employees (current amount is not sufficient for allowable number of employees), and simplifying the application process. According to participants, the funding available for training, background checks, and shots does not cover all their CD employees. Participants would like to see more equity in services and employee qualifications, and consistency in who can and cannot work for an individual. Where an individual lives in Virginia can determine what supports are available and how difficult it is to find a CD employee, according to participants. In some areas of Virginia, participants reported that individuals with disabilities have been approved for CD services and cannot receive them because they cannot find CD employees. Some participants stated they have been looking for CD employees for almost a year.

“CD providers should be trained to provide CD services the way individuals with disabilities and their families want them.”

Comment from a CD services recipient

Training and technical assistance are key issues for individuals and families using CD services to succeed, according to participants. Participants agreed that training is needed that promotes the goals, values, successes, and opportunities of CD services. Accurate, basic information on CD services through training and materials (i.e., brochures on most frequently asked questions, overviews, and resources for additional information, etc.) that are clear and concise, using simple language are needed. Activities are also needed in provider development and creating more CD services facilitators and CD employees in localities so families can use and have real choices, according to participants. Participants suggested training existing CD employees, teaching them the process and their responsibilities in making the process work. Family members specifically expressed the need for creating training and technical assistance for schools, educating school personnel and families about CD services, including benefits, process, options, and responsibilities. Training areas suggested by participants included: teaching how to improve community participation for individuals with disabilities, specialized training and mentoring of CD services facilitators, training for individuals responsible for determining eligibility for CD services, and technical support and training to enhance the CD services process, for example working together, meeting timelines, responsibilities, resources, maintaining flexibility, and streamlining paperwork.

FINANCIAL SECURITY

“The focus on the individual and off the bureaucracy provides a more economical option.”

Comment from a CD services provider

Financial security and other safeguards relate to the assurance that individuals with disabilities have enough money to support themselves and secure the support they need. Having enough resources to meet expenses includes, in CD services, having the ability to pay employees adequately, having sufficient billable hours of support, and maintaining their health and welfare. Participants had many suggestions about the financial security issues in CD services.

“ Salaries for CD employees are too low and are never increased.”
Comment representative of comments made by majority of participants

Most participants agreed that they are unable to pay their CD employees a reasonable salary. The hourly rate for CD services is less than many jobs held by teenagers in their areas, according to participants. Participants recommended that the hourly rate be comparable to agency rates (which is sometimes double the CD rate). One participant suggested creating a salary range of pay for CD employees, allowing employers to raise the rate for CD employees for experience and education, performance, and length of employment. CD services rates have no mechanism for individuals to offer raises, and it is difficult to keep good employees, according to participants, when they are unable to increase their CD employees' pay. Other suggestions for improving the financial security of individuals' employees, once rates are raised, included withholding state and federal taxes from the CD employees' paycheck, providing health insurance (even if it is just a group into which employees can buy), providing annual cost of living raises, and reimbursing employees for transportation.

Participants also see training as a way to help their CD employees. For example, training and information on tax deductions for CD employees is needed, according to participants. Participants stated that they did not know that CD employees can keep a journal of miles traveled transporting individuals and can file a non-reimbursed work expense form, even if they file a short tax form, and get a tax break. They also did not know that CD employees can file for depreciation of their vehicles. Employees should receive this type of tax information, according to participants.

Across Virginia, participants receiving CD PAS Waiver services stated they are struggling with too few hours of support, and suggested extending the hours of support for individuals using CD services. Some participants suggested letting individuals decide how much support they need and eliminating arbitrary caps for hours. Allow more hours for attendant care, up to 24 hours a day if necessary, was the suggestion from many participants. Some participants stated it is too difficult to track the hours they have used as their needs change or CD employees change. It was recommended that DMAS create a computerized voice line, from which individuals and families could access information with a code to check the balance of their hours. Another suggestion was to have DMAS send quarterly, computerized reports to individuals and families on expended hours to date. Participants asked that individuals in congregate living stop being penalized by limiting their hours. An individual does not always need fewer hours as a member of a group, according to participants.

Finally, participants are discouraged with the lack of funds and “slots” in the Medicaid system. They are unsure how to remedy this problem, but the number of individuals waiting for services discourages them. Participants see an unfair distribution of services with the limit on Waiver “slots” when no one is stopping the increase in nursing home beds. One participant summarized his view of the unfairness of the situation by stating “ because individuals use CD employees only when and how they are needed, CD services provide a more economical option. For example, it costs less to give 24 hours of attendant care on the CD PAS Waiver than it does to go to a nursing home. Why then are we increasing nursing [home] beds, and limiting a more economical option, [like] CD services?”

SUMMARY STATEMENT

The Listening Posts provided a wealth of information on how CD services are working in Virginia and many suggestions for improvement. The experiences and suggestions from individuals who depend upon or provide CD services on a daily basis are invaluable. The participants' suggestions pinpoint areas for improvement, some of which can be remedied through training and technical assistance, others of which need systemic attention and change. CD services are an evolving option, which will require ongoing discussion among individuals with disabilities, their families, CD employees, and providers as to how CD services are working and what improvements are needed. The Listening Posts have served as a good starting point for the Partnership and others to open up and continue this discussion. The implications for training and technical assistance have been extracted from the numerous comments and will be used to guide the ongoing work of the Training Advisory Team and the Partnership for People with Disabilities.

For more information, please contact the Partnership for People with Disabilities at (804) 828-3876.

The Partnership for People with Disabilities is a university center for excellence in developmental disabilities at Virginia Commonwealth University. VCU is an equal opportunity/affirmative action institution providing access to education and employment without regards to age, race, color, national origin, gender, religion, sexual orientation, veteran's status, political affiliation or disability. If alternative formats of this document are needed, please contact the Partnership for People with Disabilities at 804/ 828-3876 or 800/ 828-1120 (TDD Relay). Support for this initiative was provided through a contract with the Virginia Department of Medical Assistance Services (DMAS) with funding from the Centers for Medicare and Medicaid Services.

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