



Feature...

Director's Message

Fred Orelove
Executive Director



"Let there be peace on Earth, and let it begin with me." A worthy ambition, certainly, one given special weight this time of year. The holiday season often causes us to aspire to loftier goals. Many of us also have a tendency to use year's end to reflect on the events of the recent past.

Has 2004 felt particularly sobering? Deaths and injuries in Iraq and elsewhere, mass starvation, hurricanes, floods.... The list, unfortunately, can go on. Even some events that were not inherently all bad—the national elections come to mind—were characterized by tremendous negativity.

And yet, when you sit down in December to write a letter to friends and family, summing up an entire year's worth of accomplishments and disappointments, what comes most readily to mind? First, you tend to emphasize the highlights—the happy moments and positive outcomes. Second, you focus on the individual people in your family and in the other parts of your life.

It is all about relationships, about connecting and caring for the person. We can make a difference if we bother to listen—to communicate across the often invisible divides that separate us. World peace is not the Partnership's stated mission. But linking people and connecting with people certainly is. Helping others find a place of personal peace is not a bad beginning.

May your holidays be fulfilling and peaceful.

CHRISTINA DRAPER: CHANGING OBSTACLES TO OPPORTUNITIES

"I want so much to be able to visit my best friend in San Diego, but because I would need a personal attendant to assist me when I arrive, there is little hope that I will ever get to make the trip," sighed Christina Draper, her voice trailing away wistfully.



Christina Draper was born in Fieldale, a small rural community near Martinsville in Southwest Virginia. Born three months premature, it was a very difficult beginning for Christina, who was diagnosed with cerebral palsy at 18 months of age. As a result, she has only limited movement of her arms and hands.

While her motor functions were severely limited by her disability, it did not dull her mind, nor her spirit. Additionally, she had devoted parents who were determined that she would have the same opportunities as other children her age.

Draper began her quest for education at Mary Hunter Elementary School (K-3), transferred to Stanley Town Elementary School (grades 4-5), and finished her middle school requirements at Bassett Middle School. She graduated from Bassett High School in 1997.

Inspired by her accomplishments and urged by family and friends to continue her education, she enrolled at Patrick Henry Community College (PHCC) in Southwest Virginia and earned an associate's degree in general studies in 2001. Upon graduation, she was introduced to TELETECHNET, Old Dominion University's (ODU) distance learning program at PHCC, which provided an

opportunity for her to earn a degree from a four-year college. Again, hard work and persistence paid off and Draper graduated with a bachelor's degree in human services counseling in August of 2004.

"I did not participate in the graduation ceremonies at ODU because the expense of traveling six

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Supporting Virginians with Disabilities in their Communities

The three developmental disabilities agencies in Virginia—the Virginia Board for People with Disabilities, the Virginia Office for Protection and Advocacy, and the Partnership for People with Disabilities—are authorized through the federal Developmental Disabilities Assistance and Bill of Rights Act. That law has as its purpose "to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life...."

Indeed, the past quarter century has seen a widespread shift in this country from institutional to community provision of services to individuals with disabilities (Prouty, Lakin, & Bruininks, 2003). Nationally, there was a 59% decrease in public and private institution residents between 1982 and 2002, accompanied by a 696% increase in community residences housing six or fewer people (Stancliffe & Lakin, 2005).

This same period has seen other dramatic shifts, as well, including a change from state financing of community services to federal-state cost sharing, a substantial proportional growth in the total number of people with developmental disabilities receiving services, and major growth in Home and Community Based Services waiver funding (Stancliffe & Lakin, 2005). Moreover, there has been a move away from program funding and rate setting toward individualized funding and individualized budgets, resulting in greater control of decisions by persons

with disabilities. Finally, the U.S. Supreme Court determined in *Olmstead et al. v. L.C. et al.* that unnecessary segregation of people with disabilities represents discrimination and that states are required to provide services, programs, and activities developed for people with disabilities in the "most integrated setting appropriate."

Despite these national trends, there continues to be wide variation among states in fiscal effort and in service provision, including progress towards deinstitutionalization. How does Virginia stack up? Like other states, Virginia has downsized its institutions. As of 2002, there were 1,619 individuals residing in Virginia's state-operated MR/DD institutions (Rizzolo, Hemp, Braddock, & Pomeranz-Essley, 2004). Unlike the majority (36) of states, however, which have closed one or more state-operated institutions, Virginia's facilities all remain open. An additional 1,012 individuals with MR/DD were residents of nursing facilities in 2002. The annual cost of care per resident in public institutions in Virginia in 2002 was \$115,822 (Rizzolo et al., 2004).

At the same time, utilization rates (per 100,000 of state general population) in community residences for 1 to 15 persons in 2002 averaged 123. Virginia's rate was 54, which ranked 47th nationally. Virginia's ranking in terms of small (1-6 person) publicly funded residences was even lower, at 49. Looking at the percentage of MR/DD spending allocated for all community services (including residential settings for 6 or fewer person, related day programs, and individual and family support), Virginia's percentage is 48%, for a ranking of 50th nationally (Rizzolo et al., 2004).

According to Stancliffe and Lakin (2005), "available studies of costs and outcomes of deinstitutionalization

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FEDERAL AGENCY LAUDS PARTNERSHIP & VIRGINIA'S DD NETWORK

During the week of June 21-25, 2004, the Administration on Developmental Disabilities conducted a Monitoring and Technical Assistance Review of the Virginia DD Network. The network is comprised of the Partnership for People with Disabilities, the Virginia Board for People with Disabilities, and the Virginia Office for Protection and Advocacy. The review was designed to evaluate the members of the network on their ability to support and promote self-determination, independence, productivity, and integration and inclusion of persons with developmental disabilities in all facets of community life.

The MTARS team identified no compliance issues. The team noted a myriad of successful projects for individuals of all ages administered by the Partnership. Also noted was the close working relationship among the members of the network.



Program Notes:

Children and Youth

The Continuing Education Collaborative Office Rounds (CECOR) grant supported monthly meetings of 13 community pediatricians, one family practice physician, one nurse practitioner, and two community mental health clinic psychiatrists to discuss cases and participate in continuing medical education on childhood mental health issues.

The Model for Integrating Research Knowledge and Skills (MIRKS) project provided enhanced research training for eight Va-LEND trainees. The training included eight workshops to provide them with hands-on participation in a research study. The group used data from the National Survey on Children with Special Health Care Needs (CSHCN) to examine underinsurance in CSHCN in Virginia. A journal article is planned to report the results of the workshops.

For the fifth consecutive year, the Partnership offered the 2-day training titled: *Abuse and Neglect of Children with Disabilities: A Collaborative Response*. The author of the course, Peggy O'Neill of the Partnership, and two trainers, Vernon Simmons, Chesterfield/Colonial Heights Social Services, and Detective Brian Colligan, Fairfax County Police Department, presented a workshop at the Children's Justice Conference in Seattle, WA, in March 2004.

Adult

The Consortium for Handheld Technology (CHT), a community-based service project for individuals with acquired brain injury or autism, has expanded its work to include 15 individuals with acquired brain injury and 15 with

autism spectrum disorder. Additionally, training presentations are being made to conferences, disability service groups and support groups.

The Positive Behavioral Support Project, funded by the Virginia Board for People with Disabilities, developed a report entitled "Recommendations for Implementing a Best Practice Model for Positive Behavioral Support Services in Virginia."

The Community-Integrated Personal Assistance Support and Services project developed and is piloting a survey instrument that will be administered to individuals who are using consumer-directed personal assistance services in Virginia's waivers.

Early Childhood

The Virginia Department of Education's Early Childhood Priority Project convened a "Shining Stars" conference that was attended by 300 early childhood practitioners from across the state.

As part of the Integrated Training Collaborative, the Partnership pilot tested three training modules with early intervention personnel as a means of meeting personnel standards in Virginia. The modules are: Child Development, Orientation to Part C, and Knowledge of Developmental Delays and Disabilities in Early Intervention.

The Including All Children project trained 28 home and center providers in two training sessions. The two-hour sessions covered the benefits of including children with disabilities in early childhood programs along with training on how to work with parents.

New Grants:

Virginia Leadership Excellence in Neurodevelopmental Disabilities (Va-LEND)

Va-LEND provides interdisciplinary leadership training, continuing education, and technical assistance in childhood neurodevelopmental disabilities. The five-year award of \$460,000 annually from the Maternal and Child Health Bureau, Health Resources and Services Administration, will help expand the training program to support more trainees and fellows, incorporate new core disciplines, including genetic counseling and pediatric physical medicine and rehabilitation, and support continuing education programs with collaborators in the state and region.

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CORPORATE PARTNERSHIPS EXPAND



Ride-Away Corporation of New Hampshire, the nation's largest modifier of vehicles for people with disabilities, has joined the Partnership's Corporate Partner Program. The company will support the activities of the Partnership through contributions and other activities to support the needs of Virginians with disabilities. The company's Virginia offices are located in Richmond and Norfolk.



Community and Business Leaders Join to Form a Resource Development Board

The Partnership has formed a Resource Development Board (RDB) to assist with the acquisition of individual, corporate, and private foundation funding to meet the growing needs of individuals with disabilities and their families in Virginia. The Board held its initial meeting on October 20, 2004 and elected five Board members. Current members are: Paul G. Blair, Vice President, Strategic Planning & Development, Owens & Minor, Inc.; Steve Fitchett, Vice President, Imaging Solutions, Inc.; James D. Rorrer, Managing Director, Capital Advisory Group; J. Durwood Usry, President, Usry, Inc.; and Cheryl Yancey, former Associate VP for Advancement, Virginia Commonwealth University. The Partnership extends a warm welcome to each new Board member.

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New Grants:

School Nurses as Professional Partners

The U. S. Department of Education funded "School Nurses as Professional Partners: Supporting Educational Outcomes for Students with Low Incidence Disabilities (SNAPP)," at \$250,000 per year for five years. The SNAPP project will develop and deliver a specialty component to 28 pre- and post-professional school nurses enrolled in baccalaureate education programs annually. It will use distance education technology, combined with a specialty clinical practicum with six partnering institutions of higher education.

Effectiveness Training for Local Special Education Advisory Committees

The Virginia Department of Education (VDOE) joined with the Virginia Board for People with Disabilities (VBPD) to awarded a \$348,000 grant to the Partnership to be used over a 24-month period. The funding will be used to provide local Special Education Advisory Committees (SEACs) with increased direction on meeting the unmet educational needs of students with disabilities, advising school divisions on those needs, and assisting school divisions with the development of strategies and plans to meet those needs. SEACs are comprised of volunteers from

the community and are appointed by local school boards.

Increasing Informed Choices and Self-Direction for Individuals with Disabilities: A Rebalancing Initiative

This award, totaling \$300,000, from the U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, will assist the Partnership in its work on strategies to help individuals with disabilities increase access to the diversity of home and community-based long term services and supports.

Positive Behavioral Supports Training and Services

The Virginia Board for People with Disabilities awarded a \$150,000 grant to the Partnership to increase the number of qualified facilitators who can provide Positive Behavioral Support (PBS) services to individuals with disabilities. During the past seven years, the number of professionals who have received training in PBS strategies has declined significantly. The lack of adequate opportunities for training for professionals to become proficient in PBS has affected the complement of services and supports available to individuals with disabilities, who also present challenging behaviors. The effort will include a certification component for individuals who have received the appropriate training.



Continued from page 1

hours to the Norfolk campus was just too great. Nonetheless, I am proud of my accomplishment and the joy that it brought to my mom and my great-aunt who helped to make it all possible," Draper said. "A lot of people have suggested that I pursue a master's degree, but there isn't much incentive for me because of the strict limits on what I can earn without losing all or part of my Social Security (SSI) benefits. And of course, when the check stops, the Medicaid assistance also stops. It's very discouraging. I will probably never get a pay raise because it will affect the benefits that I receive," she added.

However, she quickly points to the fact that she considers herself fortunate to be one of relatively few individuals in Virginia with a major disability to have part-time meaningful employment in a position commensurate with their education and training. She presently works for the Piedmont Independent Living Center as an Outreach Coordinator for individuals with disabilities. Her supervisor, Clarence Dickerson, Director of the Piedmont Center for Independent Living, offered this assessment of Draper. "She does not allow her disability to get in her way. Christina is one of those rare individuals who is able to accept her condition and get on with what needs to be done. She is thorough, competent, and enthusiastic about her work. She knows how important it is to be independent; consequently, she will often go beyond her job requirements to help individuals get the help they need."

Draper eagerly shares her gifts and advocacy for individuals with disabilities through service with three disability organizations. She supports the Partnership for People with Disabilities with enthusiastic participation in the "New Voices" project. This important program, funded by the Virginia Board for People with Disabilities, brings together a small group of individuals from across the state to plan a conference that will be held in the fall of 2005. As part of the planning process, the New Voices members build relationships, share challenges, and discover ways to let others know about the needs of individuals with disabilities. When asked to comment on her work with New Voices, she offered the following assessment: "New Voices is a special project because until I joined the work

group, I thought that I was the only one having problems with attendants and transportation. Now, I feel like we have an opportunity to get legislators and individuals without disabilities to see things from our point of view."

In September 2004, Draper joined Partners in Policymaking, an advisory group that provides direction, feedback, and recommendations for change to the Virginia Board for People with Disabilities. Participants like Draper and others also attend classes where they learn about trends in effective practices for people with disabilities, the history of independent living in Virginia, how various bills are processed into laws by Virginia's General Assembly, and other topics that encourage involvement in advocacy and service.

Draper also serves as a governing board member of the National Youth Leadership Network for Persons with Disabilities, which meets twice a year in the Washington, D.C. area. This national organization promotes leadership development, education, employment, independent living, and health and wellness among young leaders representing diversity of race, ethnicity, and disability in the United States. This requires her to board a plane and travel to Washington where she is met by an attendant provided by the Network.

Meanwhile, Draper continues to face much of the uncertainty that is never far from individuals with disabilities. The most significant issue at this moment is the loss of her personal attendant. "I am really anxious about my attendant at this time because she is 25 years old and will leave the area to go to college soon," she said. "I have been advertising and interviewing for a while now, but most do not show up or call back. It's very difficult to get someone because of low hourly rates and no benefits."

Still a work in progress, Draper is an excellent example of the power of persistence, especially when it is fueled by family and friends, and supported by a compassionate community.

Next to visiting her girlfriend in San Diego, Draper says that she has another wish that she hopes to fulfill soon. "I want to go to a concert. I have never been able to do that. My preference would be to see and hear my favorite singer, Usher, but I would settle for a good gospel concert."

Publications:

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New Products

• Consumer-directed Services

Introduction to Consumer-Directed Services in Virginia's Mental Retardation and Developmental Disabilities Waivers helps consumers with cognitive disabilities learn more about CD services in Virginia's MR and DD waivers. Three training modules cover topics that include the basics of CD services, the process for obtaining them, and how to be an employer.

Consumer-Directed Services in Virginia's Mental Retardation Home and Community Based Services Waiver is a well organized, user-friendly workbook that provides step-by-step guidance on how to obtain and use CD services in Virginia's MR Waiver. This is a must-have tool for individuals with disabilities, their families, and the professionals who support them. For more information, call Dawn Machonis, 804-828-1335 (dmmachonis@vcu.edu) to order, or to get information on ordering multiple copies of materials or materials in alternative formats.

• Self-direction for Individuals with Cognitive Disabilities

Introduction to Self-Direction includes four training modules, one geared toward families and professionals, and three geared toward people with cognitive disabilities. The modules promote the importance of having dreams, making responsible choices, and exercising control over one's life.

"Person-Centered Planning - Renewed Interest" and "Person-Centered Planning - Centers for Medicare and Medicaid Services Definition" are colorful and easy to read brochures to introduce the topic of person-centered planning to families, professionals, and others who support someone with a disability. For more information, call Dawn Machonis, 804-828-1335 (dmmachonis@vcu.edu) to order, or to get information on ordering multiple copies of materials or materials in alternative formats.

• Virginia Respite Resources Directory

The Respite Resource Project is updating and expanding the "Virginia Respite Services Directory." If you know of any respite programs in your area for families of children with special needs, please call or email us to be sure they are included. Once completed, the respite directory will be posted on the Partnership website and updated quarterly. You can access our Year 2004 Summer Camps in Virginia on the Partnership website at www.vcu.edu/partnership. For more information, please contact Monica Uhl, Project Director, at 804-828-8587, muhl@mail1.vcu.edu.

• Web-Based Abuse and Neglect Training

Recording of the audio version for the 13-module web-based course, *Abuse and Neglect of Children and Adults with Developmental Disabilities: A Problem of National Significance*,

was recently completed at Audio Images Studio in Richmond. In the photo right, Peggy O'Neill, author of the course, and Irene Zeigler, narrator, review the script for correct pronunciation of medical



terminology. The Partnership will release the course on February 1, 2005. This course is appropriate for health and human services professionals. CEUs are available. Check the latest information on the website, www.vcu.edu/partnership/maltcourse.htm. For more information, call Peggy O'Neill at 804-827-0194, maoneill@vcu.edu or Ann Cox at 804-828-8244, awcox@vcu.edu.



Welcome Aboard

Promoting Quality Through Person-Centered Thinking

Dates: February 10 and 11, 2005

Location: Fredericksburg, VA

Site to be announced

Dates: March 21 and 22, 2005

Location: Roanoke, VA

Site to be announced

Sponsored by The Real Choice Systems Change project,
Partnership for People with Disabilities at VCU.

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Supporting Virginians...

reveal a consistent pattern across states and over time of better outcomes and lower costs in the community. "(p. 11) The issue, however, is not whether institutional or community services are cheaper, but which array of services and supports yields the best outcomes (Eidelman, Pietrangelo, Gardner, Jesien, & Croser, 2003). Regardless of the cost-comparison data, the evidence that community services result in better outcomes than institutions is clear and compelling (Emerson et al., 2000; Kim, Larson, & Lakin, 2001).

The future of Virginians with disabilities and their families will continue to be determined in large part by elected officials. As many other states have determined, as institutional census continues to fall and average daily costs increase, it becomes increasingly difficult to justify maintaining a dual system, from an economic standpoint alone, let alone from a moral or legal perspective. It will be important to see if Virginia can catch up to its peers in supporting this vital group of citizens.

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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 university providing access to education and employment without regard 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 Bill Tinsley at 804.828.8243 (Voice), or 800.828.1120 (TDD Relay). This newsletter is funded in part by a grant from the Administration on Developmental Disabilities, U.S. Department of Health and Human Services.

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The Case for Giving to the Partnership for People with Disabilities



OVERVIEW

Established in 1985, the Partnership for People with Disabilities supports people with disabilities and their families to be active members of their communities throughout the commonwealth. The Partnership is Virginia's only federally designated university center for excellence in developmental disabilities. Partnership staff work with a wide variety of individuals, families and professionals to promote independence and inclusion for infants, children, youth and adults with disabilities.

A HISTORY OF EFFECTIVENESS

The Partnership has accomplished much in its first 18 years. As a small sampling of activities in the recent past, the Partnership:

- provided training and technical assistance to 20,000 individuals in Virginia.
- produced a national teleconference on preventing abuse and neglect of individuals with disabilities.
- provided in-home behavioral intervention services to dozens of individuals and families.
- began to develop strategies for supporting preschoolers with disabilities to be included in their community childcare centers.
- developed leadership skills of health professionals to work with children with neurodevelopmental disabilities and their families.
- prepared personnel to work with infants, toddlers and children with disabilities in early childhood and school programs.
- held Listening Posts around Virginia to solicit feedback from individuals with disabilities, family members and professionals about their need for supports.
- conducted emergency medical services training for school nurses.
- helped increase access to resources for families with children who are deaf-blind.
- worked with school personnel to enable children with disabilities to be taught successfully.

WHY SUPPORT THE PARTNERSHIP?

The Partnership is totally reliant on outside funding to conduct its work. Staff must secure public funds through competitive grants, and those sources of support are becoming increasingly competitive. Moreover, in spite of the Partnership's numerous accomplishments, much remains to be done on behalf of individuals with disabilities and their families.

Donors' gifts go 100 percent to strengthen and secure programs that are critical to the lives of people with disabilities. With these funds, the Partnership will address the following priorities:

- Improve specialized supports individuals need to live in their home communities, including making available additional housing opportunities.
- Improve the identification and assessment of infants and toddlers with disabilities.
- Improve access to special education services for children and families, including availability of assistive technology.
- Improve prevention of abuse and neglect of individuals with disabilities.

For more information about the Partnership and the ways in which you can contribute to a better quality of life for people with disabilities, we invite you to visit our "Ways to Give" online giving center, or contact William Tinsley, director of development for the Partnership for People with Disabilities.