



Partnership for People
with Disabilities

PARTNERSHIP CONNECTION

Linking People. Changing Lives.

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Director's Message

Fred Orelove
Executive Director



"If you have your health, you have everything." How often have you heard that saying? Unfortunately, many people with disabilities not only deal with significant health problems, but also lack access to the basic health care they need. A national report released April 24, 2007 estimates that over 40 million U.S. residents are disabled in some way. Aging baby boomers are likely to increase this number. Moreover, younger generations will contribute to the disabled population due to declines in physical activity and increases in obesity and diabetes.

The report recommends that Congress and federal agencies:

- Increase funding for research into clinical health services and disability problems,
- Strengthen the Americans with Disabilities Act to ensure accessibility at health care facilities for people with disabilities, and
- Increase educational programs for health professionals who care for people with disabilities.

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HEALTH AND DISABILITIES – A CALL TO ACTION



A consensus is building around the need to improve the health and wellness of persons with disabilities. This is evident in the U. S. Surgeon General's recent call to action aimed at focusing national attention on this important issue. Specifically, the Surgeon General's goals are:

- Increased understanding nationwide that people with disabilities can lead long, healthy, and productive lives
- Increased knowledge among health care professionals, including giving them tools to screen, diagnose, and treat the whole person with a disability with dignity
- Increased awareness among people with disabilities of the steps they can take to develop and maintain a healthy lifestyle
- Increased accessible health care and support services to promote independence for people with disabilities

Why the sudden shift in attention to health issues surrounding persons with disabilities? Some of the answers seem to be related to important trends emerging in our society. People with disabilities have worse overall health and less access to health promotion programs than the general population. Data from Virginia's Behavioral Risk factor survey, conducted in 2006, document that compared to Virginians without disabilities,

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“Guide By Your Side” Brings Help to Families



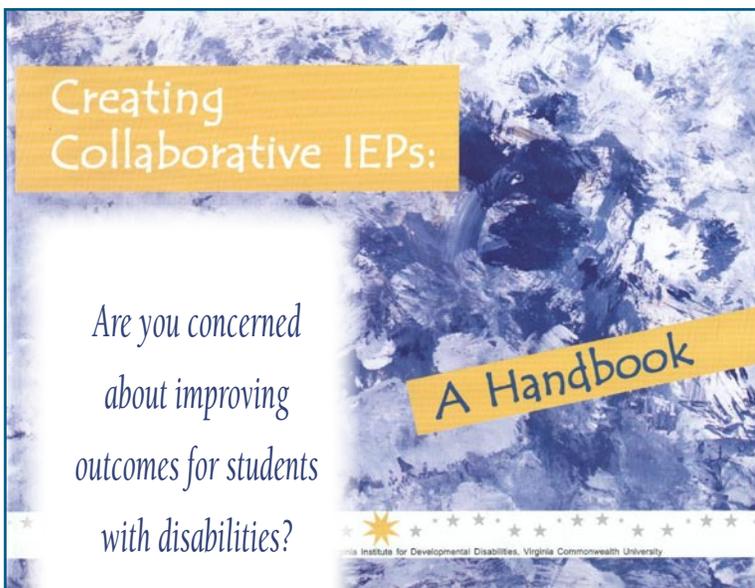
Guide By Your Side is a parent to parent initiative in Virginia that supports families with children who are deaf or hard of hearing. Approximately 100 children are identified as deaf or hard of hearing each year through newborn screenings. Virginia’s Early Hearing Detection and Intervention (EHDI) Program is identifying children with hearing loss at a median age of 3.8 months. However, only 70% of infants with permanent hearing loss are reported enrolled in early intervention services before six months. Through the Guide By Your Side program, trained family guides are matched with families of children diagnosed through the EHDI Program to provide emotional and informational support and to ensure families are aware of the supports and services offered by Virginia’s early intervention system.

The role of the family guide is to provide timely, unbiased, and complete information regarding communication options and available resources to families of children who have recently been diagnosed with a hearing loss. Family guides:

- have a child who is deaf or hard of hearing or deafblind of any age
- are able to share information effectively
- are willing to present information in an unbiased manner
- are open minded to the various communication options available to children who are deaf or hard of hearing and their families
- believe that families should be educated regarding all of their options and allowed to make the best choice for their child and family
- have a vehicle and a valid driver’s license
- can spend a few hours a month making visits
- are able to attend a training session for one or two days

Training for Family Guides is provided and criminal background checks are completed on each applicant. Guides are asked to be available to families in their geographical area and are compensated for time and mileage.

Individuals interested in becoming Family Guides should contact Dana Yarbrough for an application at the following: dvyarbrough@vcu.edu or (804) 828-0352.



This popular handbook, developed jointly by a group of parents and professionals, provides quick tips for developing IEP’s collaboratively to achieve better outcomes and positive futures for students with disabilities.

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www.vcu.edu/partnership

Director’s message continued...

The chair of the committee that prepared the report, Alan Jette, said “If one considers people who now are disabled, those likely to develop a future disability and people who are or will be affected by the disabilities of family members or others close to them, it becomes clear that disability will eventually affect the lives of most” U.S. residents.

The Partnership is committed to doing its part to conduct research and training to inform and help lessen the impact of health problems of individuals with disabilities. This issue includes coverage of some of the Partnership’s activities in the area of health.

We know that no one can have it all—but we do believe that people with disabilities deserve access to competent, affordable, health care.

¹ THE FUTURE OF DISABILITY IN AMERICA, NATIONAL ACADEMIES PRESS, 500 FIFTH ST., NW, LOCKBOX 285, WASHINGTON, DC 20055. FULL TEXT AVAILABLE AT [HTTP://WWW.NAP.EDU](http://WWW.NAP.EDU)



Promising Practices in Family Mentorship:

A Guidebook for MCHB-LEND Training Programs

The guidebook targets family mentorship as a means to improve the quality of care model. Family mentorship is one way to incorporate the life experience and expertise of families into professional training programs. It provides the kind of hands-on sharing of experiences that no classroom or textbook can offer.

The guidebook was created

by a dedicated workgroup that included Elaine Ogburn, workgroup co-chair, and member of the Va-LEND staff at the Partnership for People with Disabilities.

LEND programs provide long-term interdisciplinary leadership training to graduate-level health professionals at universities and schools of medicine. The purpose is to improve the health of infants,

children, and adolescents who have or are at risk for developing neurodevelopmental and other related disabilities.

The guidebook and its appendices can be viewed on the Association of University Centers on Disabilities (AUCD) Web site at www.aucd.org. (Click on LEND, click on Directory, click on Family, and scroll down to Publications.)

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individuals with disabilities are more likely to be overweight as measured by body mass index (66% vs. 56%), more likely to have high cholesterol (45% vs. 29%), and high blood pressure (40% vs. 23%), and more likely to be diagnosed with diabetes (13% vs. 5%).

Virginia Responds

Virginia has taken an important step towards improving health care services for persons with disabilities through the development of a five-year plan for health promotion that emphasizes increased awareness and outreach. The plan focuses on five key areas of influence:

- Access to health care
- Nutrition and physical activity
- Health promotion and outreach
- Data gathering and surveillance
- Interacting with existing initiatives

The Virginia Department of Health's Health Promotion for People with Disabilities (HPPD) Project was established in 2002 with a grant from the Centers for Disease Control and Prevention (CDC). Since its establishment staff have practiced outreach to people with disabilities, and to service providers and caregivers who support people with disabilities. A main focus of the HPPD Project is to raise awareness within the Virginia Department of Health (VDH) and partner organizations to put people with disabilities in the forefront when planning events, activities, and outreach.

In 2005, the HPPD Project and Task Force completed the first Health Promotion for People with Disabilities State Plan, The Commonwealth of Virginia Five Year State Plan for Health Promotion for People with Disabilities. Several Task Force members contributed to writing this plan, including Partnership for People with Disabilities staff, who have been members since 2002. The state plan was written broadly so that anyone in Virginia could use it as a guide for health promotion and disease prevention activities. The five goals were decided upon by the Task Force as the areas of greatest importance that the group could work on to improve the lifestyles of people with disabilities.

"The key objective of Virginia's plan is to promote the health of individuals with disabilities, prevent secondary conditions, and eliminate the health disparities between people with disabilities and those without disabilities," said Holly Tiller, project coordinator.

The Partnership Expands its Outreach Effort

The Partnership for People with Disabilities is responding to the need for increased awareness, education and methodology by seeking partners and funding to implement health promotion projects in targeted communities.

"Activities that promote positive changes in lifestyle can begin to reverse negative trends and provide significant cost savings by preventing hospitalizations and crisis care. Therefore, the Partnership's Health Program Group considers health promotion for people with disabilities a priority for future initiatives," said Bernice Allen, director of the Health Program Group for the Partnership.



John Randolph Foundation Grant Expands “Include Me” Project to Hopewell

The Partnership for People with Disabilities at Virginia Commonwealth University has been awarded a \$20,000 grant from the John Randolph Foundation to provide training and technical assistance to child care centers in Hopewell, Va. to help them include children with disabilities in their programs. The “Include Me” project, active in Greater Richmond for more than a year, provides training and consultation to child care providers so that they can fully include children with disabilities in their classrooms.

The “Include Me” project, based at the Partnership, serves as a clearinghouse for resources, training, and technical assistance

for child care providers, families, and local school personnel working with children with disabilities. Training is offered on critical topics related to the inclusion of children with disabilities, especially sensory, developmental, and behavioral challenges. The project also helps providers modify the environment and tailor materials in ways that best meet the needs of all children.

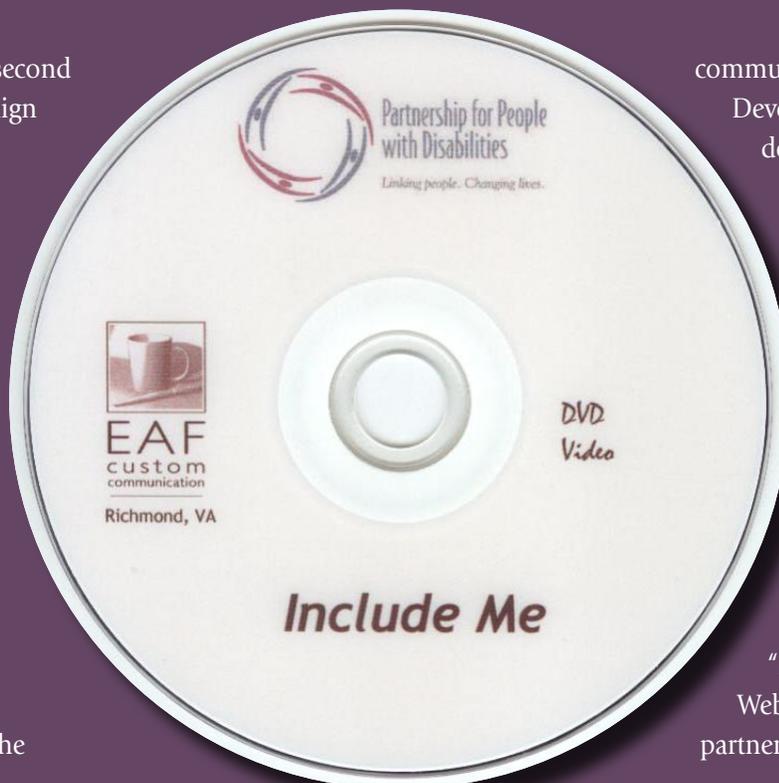
The John Randolph Foundation is a not-for-profit 501 (c) (3) organization governed by a board of trustees and supports health programs and services that improve the quality of life in Hopewell and surrounding areas. The United Way of Hopewell/Prince George contributed the community match that made this grant award possible.

“This grant award is an important milestone in our efforts to give parents of children with special needs more options for quality early childhood education. This is especially important in growing communities, such as Hopewell, where the emphasis is on quality family services in the local area,” said Dr. Fred Orelove, executive director of the Partnership for People with Disabilities.

“Include Me” Campaign Gets Boost from Promotional Video

The Partnership is in the second year of a \$600,000 campaign to raise funding for a program that addresses the shortage of preschools and child care centers in the Richmond area that provide quality education settings for children with special needs.

To facilitate the distribution of information about the “Include Me” project, its goals and the impact on the



community, the Partnership’s Resource Development Board funded the development of a 10-minute video. The production features family members, providers, and educators who offer compelling testimony to the beneficial effects of quality early education for all children, and especially children with special needs.

The video can be viewed online at the Partnership’s Web site under the heading of “Early Childhood” programs. The Web address is: <http://www.vcu.edu/partnership>



The Lifespan Respite Care Act (HR 3248) was signed into law by the President on December 21, 2006. This bill authorizes competitive grants to states to make quality respite available and accessible to family caregivers, regardless of age, disability, or family situation. Virginia was instrumental in the passage of this legislation: Senator John Warner was one of the key cosponsors, and Partnership staff (Fred Orelove, Monica Uhl) have been involved in Association of University Centers on Disability (AUCD) and National Respite Coalition legislative advocacy activities over the last 5 years. Work now begins on the funding and implementation process of this important legislation with anticipated implementation in 2008. Evidence supporting this important legislation revealed that



Senator John Warner (3-l) Monica Uhl (3-r)

Lifespan Respite Care Act Signed into Law by President Bush

family caregivers are providing 80% of long-term care in the United States, a level of care valued at \$306 billion a year. Even though most families are content to provide care to loved ones so they can remain at home, the physical, emotional, and financial consequences can be overwhelming without some support, such as respite. Respite provides the much needed temporary break from the often exhausting challenges brought

about by constant and prolonged caregiving. Lifespan respite programs are defined in the new law as "coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with special needs."



Research Poster Fair Highlights Va-LEND Trainees

Research topics promoted at the event included the following :

- Complementary and alternative therapies and autism
- Early predictors of ADHD in infants

- Cultural issues related to health care for children with disabilities
- Issues for siblings of children with special health care needs
- Strategies for involving children with neuro-developmental disabilities in their own health care

On March 28-29, 2007, graduate level health professionals participating in leadership development training with the Va-LEND program at Virginia Commonwealth University hosted the annual Research Poster Fair to highlight research topics related to childhood disabilities.

- Efficacy of constraint induced movement therapy in cerebral palsy
- Life satisfaction in parents of children with Down syndrome
- Physical activity and children with special health care needs
- Educational issues for children with mosaic Down syndrome

Va-LEND graduate trainees use the poster fair to advance their knowledge and skills and to provide public exposure for projects developed to improve health care delivery systems for children with developmental disabilities.

NOW AVAILABLE



Events & Training

Abuse and Neglect of Children and Adults with Developmental Disabilities:

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A Comprehensive Web Course for
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Continuing Education Credits Pre-Approved

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Nationally Tested, Comprehensive Curriculum

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Complimentary Seminar Discussion Guide for
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This curriculum was developed by the Partnership for People with Disabilities, A University Center for Excellence in Developmental Disabilities (UCEDD), with funding from the Administration on Developmental Disabilities as a Project of National Significance, in collaboration with seven UCEDDs and five Protection and Advocacy agencies across the country. For more information, visit the course website: <http://www.maltreatment.vcu.edu/info> or call the Partnership at (804)828-3876.

SUMMER INSTITUTE: PATHWAYS TO POSSIBILITIES

August 8-10, 2007

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Sponsor: Virginia Project for Children and Youth
with Dual-Sensory Impairments

For information, contact Mark Campano
(804)828-8252 or e-mail: macampano@vcu.edu

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For information, contact Laurie Comer (703)
993-4496 or e-mail: lcomer@gmu.edu

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August 8-9, 2007

Stonewall Jackson Hotel and Conference Center
Staunton, Virginia

For information, contact Ann W. Hughes (804)
828-1342 or e-mail: awhughes@vcu.edu



Rachelle Adams joined the Partnership as an Office Assistant. Her responsibilities include general office support and clerical duties in support of programs and projects.

Jessica Fleenor joined the Partnership as a Project Assistant for the Infant and Toddler Connection of Richmond. She is a junior majoring in Mass Communications at Virginia Commonwealth University.

Malinda Macon joined the Partnership as a Senior Fiscal Technician. She was employed previously as a Financial Services Specialist for Grants and Contracts at Virginia Commonwealth University.

Jennifer Harris joined the Partnership as an Evaluation Associate. She was employed previously at the VA Department of Mental Health, Mental Retardation and Substance Abuse Services.

Marilyn Rice joined the Partnership as an Inclusion Program Specialist for the "Include Me" project in 3 child care centers in Hopewell through the John Randolph Foundation. She was the Director of Curriculum & Training for the 5 Tuckaway Child Development Centers in Richmond for over 20 years. She is also Adjunct Faculty at VCU and J. Sargeant Reynolds Community College.

Joan Lovegren-O'Brien joined the VDOE Training and Technical Assistance Center at the Partnership as a Program Specialist in Secondary Education. She served previously as a Transition Specialist in the Newport News Public School System, Newport News, Va.

Laura Peters joined the VDOE Training and Technical Assistance Center at the Partnership as a Program Specialist in Positive Behavior Supports. She served previously as the principal of the Pathways School in Maryland, a special education facility for students with emotional and behavioral disabilities.

Linda Lundin-Seidel joined the VDOE Training and Technical Assistance Center at the Partnership as a Program Specialist in Inclusion and Behavior. She served previously as the Director of Special Services for Greene County Public Schools, Stanardsville, Va.

Jen Hines joined the VDOE Training and Technical Assistance Center at the Partnership as the Library Assistant/Office Support Technician. Before joining TTAC she worked as an actor and arts administrator in Chicago, IL.



Bernice Allen, Ph.D. successfully defended her dissertation, titled "The Experience of Decision Making In Self- Management in Adolescent Females and Young Women With Mobility Limiting Disorders" (VCU School of Nursing). Dr. Allen is the Health Group Program leader at the Partnership.



Ann W. Cox Ph.D., former associate director, Partnership for People with Disabilities received the Association for University Centers on Disability (AUCD) Meritorious Service Award at its annual meeting in November 2006. She was honored for two decades of work at the Partnership and support of its Leadership Excellence in Neurodevelopmental Disabilities (LEND) program.



Susan Murdock, a program evaluator at the Partnership, recently defended her dissertation entitled "Conceptualizing Hoarding Behavior Among Elderly Women: A Mixed-Methods Approach." The dissertation research revealed that hoarding is a serious and pervasive social problem for elderly women throughout Virginia, often coming to the attention of adult protective service workers. Sue's doctorate is from the VCU School of Social Work at the fall commencement.



Partnership Connection

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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 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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