



PARTNERSHIP CONNECTION

Linking people. Changing lives.

Partnership for People
with Disabilities

Volume 2

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Director's Message



Fred Orelove
Executive Director

"Swing your partner!" One need not be an accomplished square dancer to be familiar with the expression. Square dancing involves partners, and dancing well requires the partners to execute a series of often-complex steps. Moreover, the maneuvers happen quickly, while the music continues to play. One move in the wrong direction can create chaos for the other dancers in the square. It takes practice, trust, and communication to create a smoothly orchestrated dance.

The parallels for the Partnership and other organizations who work in human services are unmistakable. When the organizations misstep, however, it is often individuals with disabilities and their families who fall. Fortunately for us, we have a bit more time than square dancers to decide on the next move.

Even more fortunately, our partners in Virginia are people representing agencies and organizations with whom we do have substantial experience. These are individuals with whom we communicate frequently, openly, and with trust.

Shortly, the Partnership undergoes a federal review with our two sister developmental disability agencies (see "MTARS is Coming" page 2, for details). We have been practicing some of the dance steps, but, more importantly, the tune we dance to is the same. The music is played by individuals and communities who look to us for support and advocacy. We dance as if people's lives depend on us—because they do.

Feature Story

Children with Dual Sensory Impairments

This feature is about love, effective parenting and being strong advocates for the educational and health needs of children. This story belongs to Robert and Andrea Borum of Virginia Beach, Va. The Borums have two children, Chelsea, 10 and Olivia, 6, each of whom has dual sensory impairments. Their disabilities are part of a broader diagnosis called CHARGE Syndrome.

"Chelsea was born February 21, 1994," said Andrea Borum. "She was born one month early and weighed 4 lbs. 12 1/2 oz. She immediately went into respiratory distress and had to be intubated at Va. Beach General Hospital. We were told that she was a very sick baby and that they needed to run tests to figure out why she went into respiratory distress. At the end of the first week, the doctors found that Chelsea was unable to breathe through her nose. (Babies are avid nose breathers.) Therefore, she would need to be sent to Kings Daughters Hospital in Norfolk, Va., so she could have tracheotomy surgery. This is where our introduction to caring for a child with dual sensory impairments began in earnest."

Chelsea was diagnosed with CHARGE Syndrome and spent the next five weeks in the hospital. Following a six month struggle, highlighted by the difficulty of caring for a baby with a tracheotomy, Chelsea was able to qualify for 40 hours of nursing care through Robert's employer's insurance, to be used at the parent's discretion in the home. This proved to be a life saver for the parents, because Chelsea had been fitted with an apnea monitor due to the tracheotomy and the false alarms were numerous at all hours of the day and night. Shortly past her first birthday, she began to participate in the Infant Stimulation Program



Chelsea Borum

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MTARS is Coming

The week of June 21st, the Virginia DD Network will undergo a federal Monitoring and Technical Assistance Review (MTARS) by its mutual funding agency, the Administration on Developmental Disabilities (ADD). The MTARS process was developed jointly by federal officials, program representatives, and consumers in response to a shift in focus of federal policy from process to outcomes. MTARS is an administrative tool designed to institute change in ADD program monitoring by fostering partnerships and collaboration, involving consumers and peers, using measurable outcomes, and emphasizing and enhancing technical assistance. It increases opportunities for consumers and peers to participate in their review and assessment of each program. The simultaneous review of the entire DD Network is designed to provide a more comprehensive picture of the Developmental Disabilities program in the Commonwealth than would generally be afforded through site visits focusing on an individual program.

Virginia's site visit will involve interviews with the director of each program, representatives from each agency's staff, Board members and Advisory Councils; review of fiscal and other records as appropriate and an assessment of the extent of collaboration among the DD Partners. In addition, a Public Forum will be held on June 21 to ensure public participation in the review process. The overall goals for MTARS will be to answer the following questions: (1) Are Virginia's DD network programs doing what the law requires? (2) Are our programs making a difference in the lives of people with disabilities? and (3) What kind of technical assistance, if any, do Virginia's DD Network agencies need to improve performance or compliance? For more information on the Forum, go to our website: <http://www.vcu.edu/partnership>.

Virginia's DD network partners look forward to the MTARS review being a positive and productive experience. The review will provide each agency an opportunity to highlight its accomplishments and to proactively and positively address any concerns that may be identified through the technical assistance and review process.

Note: The DD Network agencies include: the Virginia Board for People with Disabilities (Heidi Lawyer, Director), the Virginia Office for Protection and Advocacy (Colleen Miller, Director), and the Partnership for People with Disabilities (Fred Orelove, Director)

Feature Story *(continued from page 1)*

which helped with gross and fine motor skills. This continued until age 2 ½, when she was accepted into the Early Childhood Special Education program at Red Mill Elementary School in Va. Beach. This placement was deemed to be cross-categorical which provided access to occupational therapy, physical therapy and some speech therapy during her two years at Red Mill.

Because she was not ambulatory and had been diagnosed with vision

and hearing impairments, Chelsea's stay at Red Mill proved challenging which led to an expedited placement in a class for children with severe disabilities at Princess Anne Elementary School.

The term CHARGE Syndrome refers to children with a specific set of birth defects. "CHARGE" originally came from the initial letter of some of the most common features seen in these children: C = coloboma (vision impairment), H = heart defects, A = atresia of the choanae (blocked nasal passages), R = retardation

of growth and development, G = genital and urinary abnormalities, E = ear abnormalities and/or hearing loss.

CHARGE Syndrome occurs in about 1/10,000-1/12,000 births, but is probably underdiagnosed. The frequency is the same in males and females and affects people of all races. CHARGE Syndrome is usually sporadic with no other affected individuals in the family. There are rare reports of multiple affected individuals in a family.

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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.

Contact

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:

Phone: (804) 828-8243 • E-mail: watinsley@vcu.edu • Web: www.vcu.edu/partnership



Feature Story

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The Partnership for People with Disabilities enters the picture

In July 1997, the Borums continued their search for information and solutions and decided to attend the CHARGE Syndrome Convention in Boston. They were befriended there by three members of Together We Can, a program administered by the Partnership. "I will never forget that moment when Gwen Williams, Anne Malatchi and Susan Olson came up to us at the convention and stated, 'So you are the Borums from Virginia Beach. We have been looking all over for you.' We could not have known at the time how important that alliance would become in the years ahead," Andrea said with a smile.

More on the Borum family

"Olivia Dawn was born June 19, 1998," Robert Borum shared. "She was born two months early and weighed 3lbs. 14 oz. and 16 ½ inches long. She was delivered by C-section on an emergency basis with Robert at my side, because she was starting to go into distress. When she was born, her main problem was (or seemed to be)



Olivia Borum

her prematurity, so she had to be placed in an incubator. She also had other tests performed during her stay. We were told that she needed to be 5 lbs. before they would release her. Olivia also failed three different hearing tests before leaving the hospital. And this is where her story begins."

During her hospital stay, Olivia was diagnosed as having agenesis of the corpus callosum, a condition that affects the pathways of the brain, along with a major hearing impairment. Within a short period, she was accepted in the Infant Stimulation program at a center in Virginia Beach. The experience gained by the Borums from previous experiences, along with their enthusiastic advocates, allowed for placement in a program for hearing impaired children at Corporate Landing Elementary School in Va. Beach. During this period,

her vision also began to deteriorate, making learning difficult, according to her parents. Olivia enrolled in preschool classes at Princess Anne Elementary and now attends kindergarten for half of the day and classes for children with severe disabilities the remainder of the day.

Chelsea Borum update

Chelsea left Princess Anne Elementary two years ago and now attends Linkhorn Park Elementary as part of the Southeastern Cooperative Education Program. Because she is non-verbal, her education remains a challenge for all concerned.

Fast forward to Together We Can and the Partnership

The Borums and other families in Virginia remain under the watchful eye of the "Together We Can" initiative sponsored by the Partnership for People with Disabilities. Together We Can (TWC) is a deaf-blind project federally funded under the Individuals with Disabilities Education Act (IDEA, Part D) and is part of the Partnership for People with Disabilities TWC's commitment to:

- Promote systemic change and school reform to facilitate improved outcomes for learners with dual sensory impairments.
- Collaborate with state agencies to provide training and technical assistance to support individuals with hearing and vision impairments.
- Raise awareness of the unique needs of children and youth with dual sensory impairments.

"We are now working with John Eisenberg and Maria Beck [the project directors of Together We Can] almost exclusively," said Mrs. Borum. "I can't begin to tell you how helpful they have been to the families in Virginia. Assistance runs the gamut from information dissemination to classes and retreats. They support us, they advocate for us with school systems, they monitor our IEPs to help us get the special services that we need. I can't say enough about TWC and the assistance that they have provided us since that first meeting in Boston in 1997. In fact, I feel so enthusiastic about the work that they do, that I elected to be the President of the parents group that they formed called 'Dreamcatchers', so that I can use my knowledge and experience to take this program to the next level."



Program Notes

Abuse & Neglect of Children with Disabilities

Peggy O'Neill, and Vernon Simmons of the Chesterfield/Colonial Heights Department of Social Services presented a workshop at the Children's Justice Conference in Seattle, Washington in March 2004, entitled Abuse and



Det. Brian Colligan, Fairfax County Police Dept., Peggy O'Neill, Partnership for People with Disabilities and Vernon Simmons, Chesterfield/Colonial Heights Social Services

Neglect of Children with Disabilities: A Collaborative Response. The workshop was based on the training that has been offered throughout Virginia for 5 years by the Partnership, in collaboration with the Virginia Department of Criminal Justice Services, Virginia Department of Social Services, Virginia Institute for Social Services Training Activities (VISSTA), the Virginia Department of Education, and local school divisions. **For more information contact Peggy O'Neill at maoneill@vcu.edu, 804-827-0194.**

Respite Resource Project

The Respite Resource Project's "Year 2004 Summer Camps in Virginia" resource is now available on the Partnership website at www.vcu.edu/partnership. Copies are also available upon request. This listing includes 37 summer camps from throughout Virginia for families of children with disabilities and chronic illnesses. **For more information, please contact Monica Uhl, Project Director, at 804-828-8587, muhl@vcu.edu.**

EARLY CHILDHOOD

Several new publications were developed for use by early intervention providers, through the work of the Integrated Training Collaborative. These resource materials, funded by the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services, will be used by early intervention personnel in Virginia. Three modules: "Child Development", "Knowledge of Developmental Delays and Disabilities in Early Intervention" and "Orientation to Part C" were developed and field-tested. In addition, the Kaleidoscope curriculum for early intervention service coordinators

was revised and reformatted into two levels. **For more information, contact Deana Buck at 804-827-0198, dbuck@vcu.edu.**

The Training & Technical Assistance Center at VCU (TTAC)

At the direction of the Virginia Department of Education, the T/TACs throughout the state have been involved in academic reviews for schools designated as "accredited with warning." The VCU T/TAC completed reviews for twenty-two schools this year. To date, technical assistance follow-ups are being conducted for fifteen of those schools.

The T/TAC's activities are largely determined by priorities established by the Virginia Department of Education. To achieve maximum effectiveness, the application and coordination of resources has shifted to a state-wide focus rather than the pursuit of unique strategies in each region. Current priority projects are: academic review; enhanced SOL scope and sequence; assistive technology; instructional and learning strategies; Reading First Initiative; early transition and preschool; school-wide discipline; parent involvement; Instructional Support Teams; autism; alternate assessment; and secondary Transition Outcome Project. **For more information, contact Linda Oggel at 804-827-1400, lsoffel@vcu.edu or Sandy Wilberger at 804-827-1405, slwilber@vcu.edu.**

TOGETHER WE CAN

Together We Can, Virginia's Deaf-Blind Project, worked with the Virginia Department of Education to sponsor a two-day training event focusing on the unique needs of individuals with Deaf-Blindness and strategies for improving access to the general curriculum. This training event was one of several collaborative activities between Together We Can and the Virginia Department of Education completed during the 2003-2004 school year and was designed to enhance the capacity of technical assistance providers and staff from a number of school divisions and a state-operated program that provides support to students who have been identified as having Deaf-Blindness. Each office, school division, and agency received a two-volume curriculum on Deaf-Blindness, a DVD that outlines vision and hearing information, and a variety of other resource

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Upcoming Events



Assistive Technology and Augmentative Communications Conference: Making the Connections '04

Dates: June 24-25, 2004

Place: Hotel Roanoke and Conference Center, Roanoke, VA

Who should attend: Teachers; service providers; administrators; parents; and paraprofessionals who want to learn more about using technology to support students with disabilities

For information, contact: T/TAC at 540-231-5167 or e-mail gsgustaf@vt.edu

Families Planning Together

Dates: June 28-29, 2004

Place: Endependence Center, Norfolk, VA

Sponsored by: Partnership for People with Disabilities

Who should attend: Family members and caregivers of persons with disabilities who are actively involved and want to develop a person-centered plan.

For information, contact: Rachel Valenti at 804-828-1365

Access for All: Supporting Students with Moderate to Significant Disabilities

Dates: June 28-29, 2004

Place: Holiday Inn Select, Lynchburg, VA

Sponsored by: The Training & Technical Assistance Centers; VA Dept. of Education; Virginia's Deaf-Blind Project "Together We Can."

Additional information and registration available at:
<http://www.conted.vt.edu/access4all/>

Shining Stars: Charting the Future of Today's Children

Date: July 13, 2004

Place: The Hotel Roanoke & Conference Center, Roanoke, VA

Date: July 15, 2004

Place: Holiday Inn, Richmond, VA

Sponsored by: The Virginia Dept. of Education; The Partnership for People with Disabilities; Training and Technical Assistance Centers; Child Development Resources

Who should attend: Early Childhood Special Educators; Early Childhood Educators; paraprofessionals; childcare providers; families, etc.

For information, contact: Elizabeth Schroder at 540-231-3144 or Jane Todd at 540-231-2104

Disaster Preparedness for School Nurses

Date: August 3, 2004

Place: North Fork Middle School, Quicksburg, VA

Sponsored by: The Virginia Department of Health; and The School Nurse Institute Partnership (SNIP)

For information, contact: Bernice B. Allen at 804-828-8593.

Kudos



Kathleen Lynch, who recently assumed a new position within the School of Education. She is working half-time as the Project Manager for TrueOutcomes, a web-based assessment system for faculty, students, administrators, and alumni, which supports performance-based assessment and curricula improvement. Kathy will continue to work with the T/TAC and will be finishing up her work with School by School, which concludes at the end of the calendar year.

Valerie Luther and Rachel Valenti, who were members of the 2004 graduating class of Partners in Policymaking, sponsored by the Virginia Board for People with Disabilities.

Connie Kvarfordt, whose proposal for her Ph.D. dissertation was approved. The title: *The Role of Religion and Spirituality in Social Work Practice with Children: A National Survey of Clinical Social Workers*.

Jayne Shepherd, who received an award from The American Occupational Therapy Association Roster of Fellows for making significant contributions to the continuing education and professional development of members of the Association.

Joey Wallace, who served as the keynote speaker at the 10th Annual Guam Conference on Assistive Technology. Joey provided information on outcomes from the Technology Act and what the future holds for Guam and its fellow territories.

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materials. **For more information, contact John Eisenberg at 804-828-8252, jmeisenb@vcu.edu.**

Project of National Significance: Educating Health Professionals about Maltreatment of Children and Adults with Developmental Disabilities

Bernice Allen presented a poster session on the topic of abuse and neglect of children and adults with developmental disabilities at the 128th Annual Meeting of the American Association on Mental Retardation in Philadelphia, Pa., June 1-4, 2004. Peggy O'Neill presented "Abuse and Neglect of Children with Disabilities" for Pediatric Grand Rounds at Seattle Children's Hospital and Regional Medical Center on April 1, 2004.

This project involves collaboration among partners from several states to produce a web-based course for health professionals. The course will be available in the Fall, 2004. **For more information contact Peggy O'Neill at 804-827-0194 or Bernice Allen at 804-828-8593.**

Welcome Aboard

The Partnership for People with Disabilities is proud to announce the following additions to the organization's staff over the past year:

Vicki Beatty – Family Linkage Specialist, Infant & Toddler Connection

Maria Beck – Program Specialist, Together We Can

Belinda Hooper – Training & Technical Assistance Center at VCU

Dawn Machonis – Network Coordinator, Real Choices

Sara-Beth Plummer – Project Evaluator

Rachel Valenti – Training Coordinator, Real Choices and Person-Centered Planning

Latonya White – Fiscal Technician

Mary Lynn White – Project Coordinator

Attention Readers

In response to inquiries from our readers, beginning this fall the Partnership will offer readers the choice of receiving a printed copy of our newsletter or an HTML version via e-mail. If you want to receive the newsletter via e-mail, please go to the Partnership's Web site and sign up today.

Web address: <http://www.vcu.edu/partnership>



PARTNERSHIP CONNECTION

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