This report reflects the major activities and accomplishments of the Virginia Institute for Developmental Disabilities (VIDD) for the second half of Year 4 (January — June 2002) of our five-year cycle of core grant funding. The first section of this report includes institute-wide activities and accomplishments, followed by activities from a variety of projects that address systems change, capacity building, advocacy, support to individuals with disabilities other than developmental disabilities, unserved and underserved populations, and the effects of federal policies.

A. Institute-Wide Activities

Organationally, VIDD continued its team structure with three program teams—Early Childhood, Children and Youth, and Adult—and two organizational teams: Business and Marketing, and Public Policy and Operations. Leaders of each team and members of the Public Policy and Operations Team meet every two or three weeks as part of a Leadership Team to discuss areas of mutual concern and to make decisions on items that require VIDD-wide discussion. Organizational concerns that continue to be explored include: how to strengthen teams and their functions, how to ensure that core functions of a University Center for Excellence on Developmental Disabilities are addressed within the organizational structure, ways to integrate program development into the work of each of the teams, and strategies for increasing the core financial support to VIDD. During the past six months VIDD hired a specialist in evaluation and continues to search for a specialist to fill the research position.

As of September 1, 2002, VIDD will undergo a significant transformation by adopting a new name, “Partnership for People with Disabilities.” This new “brand” was developed during the past six months with the assistance of focus groups that included
people with disabilities, service providers, VIDD staff, and policy makers from state agencies. It is believed that “Partnership for People with Disabilities” better reflects the broad-based nature of the work that we conduct and the collaborations and connections that are key to all initiatives.

The following grants and contracts were received during this time period:

- “Building Inclusive Child Care Services: A Demonstration Project,” Virginia Board for People with Disabilities (DD Planning Council)
- “Youth with Hidden Disabilities in Virginia’s Juvenile Justice System,” Virginia Department of Criminal Justice Services
- “Real Choice Systems Change Grant for Community Living: Training in Consumer Direction,” Virginia Department of Medical Assistance Services

The following proposals were submitted during this reporting period and are pending funding decisions:

- “School Nurses as Professional Partners: Supporting Outcomes for Students with Low Incidence Disabilities,” submitted to the Office of Special Education Programs, USDOE (January 2002)
- “Positive Behavioral Supports for People with Disabilities: Enriching Lives in Community Settings,” submitted to the Virginia Board for People with Disabilities

VIDD staff conducted training events, provided technical assistance, developed materials, presented at conferences, and participated in planning and policy meetings. These include the following:

- Completed the annual report (a copy is included with this report)
- Published a Summer 2002 edition of the VIDD newsletter (a copy is included with this report)
- “Understanding Self-Determination,” a workshop at VIDD (January 9)
A celebratory and sharing dinner for Roanoke County Schools as part of the School By School initiative; Hollins College in Roanoke (January 21)
“Creating Collaborative IEPs: A train-the-trainer session; Richmond (January 25)
School Nurse Institute Partnership quarterly meetings were held (January, March, June)
Presentation on Virginia Consortium for Teacher Preparation in Severe Disabilities (January)
“Circle of Friends,” a workshop on establishing Circle of Friends; Richmond, (February 1)
“PATH Facilitation: A Techniques Workshop,” a training session for individuals interested in practicing the essentials of PATH facilitation; Richmond, (February 2)
“Consumer-Directed Services,” series of two-day workshops sponsored by the Office of Mental Retardation, with VIDD providing portions of the training. Held in Virginia Beach, Abingdon, Fairfax, Roanoke, and Richmond (January and February)
“Kaleidoscope: New Perspectives in Service Coordination,” two session training event for early intervention service coordinators; Staunton (February 11-12 and March 26-27)
Policy and Legislative Council of the Virginia is for Families initiative meeting in Richmond (February 14)
Pediatric Grand Rounds, Medical College of Virginia at Virginia Commonwealth University and surrounding community hospitals, “Multidisciplinary Issues in Identifying and Responding to Needs of Children with Down Syndrome” (February 19)
Pediatric Noon Conference for VCU School of Medicine: “Down Syndrome” (February 21)
Poster presentations and assistance with sessions at the “Families Are Special, Too” conference held in Richmond (February 22-23)
“Investigating Maltreatment of Children with Disabilities: A Collaborative Approach” (Parts I and II). Workshop at Eighth National and First International Conference on Abuse of Children and Adults with Disabilities, Riverside, California (February 26)
Design Team of the School By School initiative meeting in Roanoke (February 28)
“Educating Primary Care Providers: The Lead Physician Education Module,” invited presentation at Health Educators meeting, Centers for Disease Control, Atlanta (February)
Poster presentation on lead poisoning education at the Virginia Council for Nurse Practitioners, Norfolk (March 17-18)
“Self-Directed Support Corporations,” forum sponsored by Virginia is for Families initiative, Charlottesville (March 19)
“Educating Early Interventionists and School Personnel to Serve Young Children who are Deaf and Hard of Hearing” (PREP Project) training (Richmond: March 19, May 22; Manassas: May 30)
Statewide meeting of Positive Behavior Support Trainers; coordinated through the Matchmaker-Together We Can initiative, Charlottesville (March 27)
Initial meetings of the statewide Training Advisory Committee of the Real Choice Systems Change Grant, Richmond (March 28, May 21)
Design Team meeting for the School by School initiative, Roanoke (April 12)
Nutrition Update: Children With Special Health Care Needs, Washington DC (April 15-16)
“Maximizing Potentials Conference,” several staff-conducted presentations, Virginia Beach (April 17-19)
“Person Centered Planning Strategies,” TTAC training, John Tyler Community College (April 18, 23)
“Abuse and Neglect of Children with Disabilities” training in Keysville (April 18-19), Abingdon (April 29-30), Prince George (May 13-14), Cumberland County Schools (June 19-20), and Stafford County Public Schools (June 24-24)
“Functional Behavior Assessment Seminar,” Roanoke (April 19)
“Advocacy in Action: Health Professionals Response to the Abuse and Neglect of Children with Disabilities” awareness training, National Teleconference (April 25)
Poster presented on the “School Nurse Institute Partnership” at the Southern Regional Education Board’s Council for Collegiate Education in Nursing Conference (April 28)
“Managing School Emergencies III Series,” School Nurse Institute Partnership, Salem (May 4)
“Team Building and Leadership for the Virginia Care Connections for Children Network,” Charlottesville (May 10)
Together We Can Advisory Committee, Richmond (May 15)
Infant and Toddler Connection of Richmond, Annual Picnic, Richmond (May 17)
“Individual Family Service Plan Development,” TTAC training, Richmond (May 20)
“Kaleidoscope: New Perspectives in Service Coordination,” two-session training event for early intervention service coordinators, Norfolk (May-June)
“Writing Effective Waivers that Include Self-Determination,” Jean Tuller, sponsored by Virginia is for Families, Charlottesville (June 8)
Virginia Consortium for Teacher Preparation in Severe Disabilities presented a poster at the “Access for All” conference (June).

Developed and disseminated “Adoptive Family Resource” packets to AFP regional teams. Over 400 families were reached through this effort.

The Year 2002 “Summer Camps in Virginia” booklet was disseminated by the Respite Resource Project.

Five courses taught to students enrolled at Virginia Commonwealth University, University of Virginia, George Mason University, and Lynchburg College by the Virginia Consortium for Teacher Preparation in Severe Disabilities.

The PREP Project disseminated information on the project at the Speech, Language, and Hearing Association of Virginia Conference, the VA Council of Administrators Conference, and the Virginia Beach Severe Disabilities Conference.

A chapter entitled, “Assistive Technology and Developmental Disabilities” written by the director of the Assistive Technology Project was published within the text, Down Syndrome: Vision for the 21st Century.

Several trainings were conducted by the Assistive Technology Project including “Including AT Throughout Your Child’s Life,” at the Families are Special Too conference; “AT: Selection, Acquisition and Funding,” at a Virginia Partners in Policymaking session; “AT Across the Lifespan” at the Children’s Spina Bifida conference; “AT and Loan Financing,” at the RESNA conference; “AT and Augmentative Communication,” at the CLAMR conference; and “Funding AT,” at the Severe Disabilities conference.

The UpLink project trained 30 students in interdisciplinary teamwork.

The UpLink project presented a poster at the Tapestry of Learning conference and the VA-CEC conference.

UpLink community partners meeting convened

Newborn Hearing Screening Training Program Advisory Panel convened

PREP Project Statewide Advisory Committee convened

B. VI/DD Activities Addressing ADD Categories

(Systems change, capacity building, advocacy, support to individuals with disabilities other than developmental disabilities, unserved and underserved populations, and the effects of federal policy)
1 Systems Change

Activities of various projects that have had an impact on systemic change during the past six months include:

- The Respite Resource Project provides ongoing technical assistance and dissemination of resources to families and professionals. Through an adoptive initiative, technical assistance and statewide dissemination of resources was provided to regional adoptive family preservation teams.

- The Va-LEND
  - was accepted as a participating site to conduct up to 15 chart reviews and/or assessments of school-aged children ages 6-18 years for this year. These data will be used to revise the national SSA criteria for disability determinations.
  - downlinked the “Advocacy in Action” training program. This program educates health professionals on recognizing and assessing abuse and neglect in children with disabilities.
  - served on a planning committee for the “Medical Home Initiative,” a statewide conference for pediatricians and physicians to promote medical homes for children with special needs.

- The Abuse for People with Disabilities initiative conducted a presentation session for the 8th National Conference on Abuse and Disabilities. Additionally, 3 sets of the 2-day training “Abuse and Neglect of Children with Disabilities: A Collaborative Response” were held in May and June of this year.

- The VCU Training and Technical Assistance Center T/TAC partnered with schools and school divisions offering long-term technical assistance on school-wide positive behavior supports, instructional support teams, secondary transition, and inclusion. The VCU T/TAC promoted systems change in 20 schools during this reporting period.

- The Together We Can project co-sponsored the “Tapestry of Learning,” statewide special education conference. This conference provided information to a statewide
audience on TWC. Additionally, the conference helped to promote the unique needs of learners with dual sensory impairments.

The director of the Assistive Technology project served on the AT and Education Advisory Task force. This group is piloting the sharing/purchasing of AT devices between designated school districts and the Vocational Rehabilitation program for transition age students with disabilities.

The UP Link project accepted a new cohort of related services and early childhood special education students into the program. This will increase the number of personnel (especially from traditionally underrepresented groups) qualified to provide services to young children with low incidence disabilities.

VIFF held two statewide forums on self-determination. Jackie Golden presented on micro-boards and Jean Tuller spoke about waivers.

The Real Choice Systems Change project held training advisory team meetings to evaluate Virginia’s consumer directed services using a consumer direction tool developed by Home and Community-Based Services.

The School By School initiative completed a planning process with three schools involved in developing and implementing school-wide reform.

The Richmond Infant and Toddler Connection worked closely with multiple providers including physicians in training at the Medical College of Virginia at VCU to facilitate coordinated care and early referrals for early intervention.

The Virginia Lead Poisoning Education Project collaborated with the Division of Chronic Diseases and Nutrition at the Virginia Department of Health to increase awareness of childhood lead poisoning among WIC (a special supplemental nutrition program for women, infants, and children) families. The project developed and disseminated information and designed an educational model (CD format) on effects of lead poisoning, sources of lead, prevention tips, and a nutrition component.

The Integrated Training Collaborative refined the service coordination curriculum and began to examine core skills for early intervention providers across the state.
VIDD's Project of National Significance, Educating Health Professionals about Maltreatment of Individuals with Disabilities: A National Developmental Disabilities Training Consortium, held an awareness training, National Teleconference.

The Future Planning: Helping Communities to Welcome People with Disabilities initiative provided workshops on individual facilitation techniques including PATH, Circles, and other methods of supporting individuals in communities. The project partnered with a southwest community to promote individualized planning and support.

2. Capacity Building

Activities of projects that helped to expand the capacity of services and supports to individuals and families include:

- Representatives from Lynchburg College and Marymount University were added to the School Nurse Institute Partnership.
- Educating Health Professionals about the Maltreatment of Individuals with Disabilities: A National Training Consortium formed a local planning committee and a national training consortium to provide advice on the development of content and review of web-based materials.
- The Va-LEND initiative participated in several activities that were capacity building:
  - It received funding from KOVAR ($9,000) to support leadership training of special educators, genetic counselors, and therapists who work with children with developmental delays in VA.
  - It continues to have a collaborative relationship with the Virginia Lead Education Project and the VCU Autism Project.
  - The NationalSSI Project provided additional funding and training opportunities for Va-LEND.
- The Together We Can project provided long-term technical assistance to an elementary school team on inclusion for a child who is Deaf-Blind. Team members
were provided with a host of techniques and methods aimed at increasing positive outcomes.

- The **Respite Resource Project** disseminated “Early Intervention TOOL KITS for Respite and Family Support” to 40 local interagency coordinating councils. This activity was funded through the Family Support and Advocacy Committee of the Virginia Interagency Coordinating Council through the Infant and Toddler Connection of Virginia. Additionally, the directories of summer camps and respite services (2002) were updated and distributed.

- The **Abuse for People with Disabilities** initiative conducted a presentation session for the 8th National Conference on Abuse and Disabilities. Additionally, 3 sets of the 2-day training, “Abuse and Neglect of Children with Disabilities: A Collaborative Response,” were held in May and June of this year.

- Norfolk State University has been added to the **Consortium for Teacher Preparation in Severe Disabilities**. This expands the program to the entire Virginia Tidewater area.

- The **PREP Project of Virginia** conducted a training event entitled, “Educating Early Interventionists and School Personnel to Serve Young Children who are Deaf and Hard of Hearing” in Richmond.

- The **Assistive Technology** project is pursuing a collaborative venture to pilot Personal Digital Assistants with transitioning youth with traumatic brain injury and autism. Partners in this project include various Virginia Commonwealth University/Medical College of Virginia departments, the Virginia Department of Rehabilitative Services, consumers, and family members.

- The **UpLink** faculty continues to build capacity through partnering with local service providers. In January, the project held its first Community Partnership Meeting. In addition, the project continued to develop its website where on-line forums will be available for UpLink students and community professionals and families will be able to discuss current issues, ask questions, and share experiences.
Real Choice Systems Change sponsored five training events for individuals, family members, and advocates on consumer-directed services under Medicaid waivers throughout the state.

The Virginia Partnership for Education in Lead Poisoning Prevention presented two sessions at the National Lead Education Conference in Atlanta. One presentation focused on reaching primary health care providers and the second on reaching pregnant women.

Through the Kaleidoscope training curriculum, in-depth information is provided to service coordinators. The four days of training bring together 30 service coordinators to learn and discuss the role of the service coordinator in the early intervention system in an interactive and informal atmosphere.

The Newborn Hearing Screening Statewide Training initiative developed core content specific to the needs of hospitals, physicians, and audiologists focusing on the roles and responsibilities of stakeholders to full implementation of newborn hearing screening programs in Virginia.

3. Advocacy

Advocacy was addressed in the following ways:

★ The Together We Can project sponsored a family weekend, “Dreamcatchers: Families whose lives have been touched by Deaf-Blindness.” Families were given updates on national and state initiatives, current legislation, and heard a presentation on self-determination from a national speaker. Twenty families participated in the event.

★ The Respite Resource Project provided individualized technical assistance and resource dissemination to families. Additionally, focused technical assistance was given to professionals and agencies in developing local and regional respite services. Through an adoptive initiative, individualized technical assistance and resource dissemination was also provided to families.
VA-Lend participated as a member of the Coalition for Children's Health. This group collectively advocates for the improvement of Virginia's health insurance programs for children and promotes the enrollment of eligible children to these programs.

The Assistive Technology project provided direct technical assistance to consumers, their families and service providers in their search for assistive technology. This involves providing information materials on policies, procedures and rights information. All training workshops presented by the project are intended to build participants’ self-advocacy skills.

In the Spring, Uplink invited a number of community professionals, families, and their children with disabilities to speak to students. The students were thrilled and participants found this an important and enjoyable experience.

VIFF's Policy and Legislative Council has developed a proposal for VA to submit a new Independence Plus Model Waiver and is enlisting advocates to support the proposal.

Project PREP increases the knowledge of professionals so that they can become more efficient advocates for infants and children and their families.

The Richmond Infant Council distributed user-friendly materials for potential referral sources, including a brochure written by parents for other parents who are just getting started in early intervention.

VIDD continued the distribution of the Creating Collaborative IEPs: A Handbook publication to families and advocacy organizations.

Staff members continued to serve on state, regional, and local advisory committees and work groups.

Through several projects, VIDD provided direct technical assistance to individuals and their families. This often involves helping with strategies to assist in more effectively advocating for services and supports for themselves and their families.
4. Support to Individuals with Disabilities Other Than Developmental Disabilities

Many projects and services are not specific to disability. Therefore, services and supports are provided to individuals who need the service rather than by disability definition. Many of these examples have not changed in the last six months; thus this section includes categories from the previous report:

- VIDD collaborates with Virginia assistive technology efforts and both the policy analysis and loan financing programs support people with all types of disabilities.
- The Lead Poisoning Education project screens children at risk due to exposure to lead.
- The School Nurse Institute Partnership prepares nurses to plan for students with chronic health care conditions and other physical limitations in addition to students with developmental disabilities.
- The Richmond Behavioral Intervention Program serves children and youth with a range of delays and disabilities including mental illnesses, traumatic brain injury, attention deficit disorder, and Tourette’s syndrome.
- The Richmond Infant Council provides assistance to infants with delays and their families; the children are not labeled by disability.
- The VCU Training and Technical Assistance Center serves the at-risk school aged population and individuals with all types of disabilities ages 0-22.
- The Va-LEND program targets children with neurodevelopmental disabilities and their families. The program works closely with families in community-based clinics to provide interdisciplinary evaluations and to help families gain access to services.
- The Respite Resource Project provides technical assistance regarding eldercare needs; children with mental health needs, short-term disabilities and healthcare issues; and adopted children with ADHD, RAD, depression, and other related emotional and mental health issues.
- The School By School project provides support to whole school reform efforts, thus influencing all students.
- The Youth with Disabilities in the Juvenile Justice System project provides indirect support to youth with all disabilities through increased awareness and staff training.
- In providing support to children with deaf-blindness in schools, other children also benefit from the practices and resources.

5. Unserved and Underserved Populations

Some of this information has been noted in previous reports and additions have been included as new initiatives highlight groups and populations that are underserved. Virginia continues to struggle with a severely under-funded community services system with limited funding for creative options. There are also discrepancies in the availability of support depending on relative wealth of a community, the factors of urban and rural needs, and the eligibility based on labels and categories. The continued reliance on an institutional model and outdated paradigms for providing services and supports impedes the innovative efforts that do occur. Support and service options are not comprehensive; residential options are lacking in most communities, and employment services are often not designed to fully integrate individuals in communities. There are waiting lists for people needing assistance with long-term care needs. Thus, populations and individuals remain unserved and underserved in many areas.

Several projects have noted specific gaps in the provision of supports:

- Many students with chronic health conditions are unable to regularly attend school because health conditions cannot be managed. Better preparation of school nurses helps to address this need.
The assistive technology events offered training in areas that are underserved; in particular, the southwestern area, the south central area, and the Eastern Shore of Virginia.

The number of children identified in Richmond City as needing early intervention services falls below the projected target number of children. In addition, according to the Part C definition, “underserved” includes urban communities.

Youth in the juvenile justice system, particularly those with learning disabilities and emotional problems, have not received adequate educational services and supports. Many of the youth committed to the Department of Juvenile Justice (39%-42%) were identified as being eligible for special education at the time of commitment. In a recent training needs survey completed by VIDD, close to one-third of detention center personnel and one-half of court services staff report that they have not received adequate training in how to provide support and services to youth with disabilities.

The Virginia Consortium of Teacher Preparation in Severe Disabilities prepares teachers to work with the most underserved populations —children with severe disabilities (including learners with significant cognitive impairment autism, deaf-blindness, special health care needs, and other multiple disabilities).

Because of disability specific criteria, many individuals with developmental disabilities are excluded from funding streams. The developmental disabilities waiver will provide support to only a percentage of those who were projected to need the services.

The T/TAC provides support to infants with vision problems and children with severe disabilities who have been underserved in the past.

In Va-LEND’s community-based clinics, interdisciplinary evaluation is provided for children who have limited resources, and who often “fall through the cracks” in the service delivery system.
Several Va-LEND faculty and trainees provide services to children with special needs in Title V supported specialty clinics in the Richmond area. These services are targeted to children and families with limited incomes.

Due to the low incidence of deaf-blindness, many of the children who are supported are categorized as “multi-handicapped” instead of “Deaf-blind” on their IEPs. When they are not recognized as “Deaf-blind,” they may not receive all the services that a Deaf-blind student would receive, such as orientation and mobility, or interpreter services.

Comprehensive service system for respite and family support does not exist in Virginia.

For adoptive families, there are limited post-adooption services available.

The population that the lead poisoning education project targets includes individuals (children and families) deemed “high-risk” due to social and economic status, age of housing or zip code, or enrollment in a program such as Medicaid, FAMIS, and WIC.

Children with disabilities are typically not included when information and training about child abuse is disseminated.

There are limited post-adoption services for families of children with special needs (RRP is the only statewide initiative to focus on post adoption needs).

6. Effects of Federal Policy

Several federal policy items have a direct impact on state and local programs. Many of these have been mentioned in previous reports and still remain factors in influencing the supports provided to individuals with disabilities and their families. These include:

- The New Freedom Initiative and the Medicaid waiver templates proposed by CMS provided direction to the Policy and Legislative Council in its efforts to address policy issues and promote systems change.
The initiation of the State Children's Health Insurance Program, FAMIS in Virginia, has provided federal support for increased access to care for underinsured children in Virginia.

EPSDT screening requires that lead levels be tested at 12 and 24 months.

The AUCD Assessment Project is in place to examine the policies related to the SSI enrollment criteria and the re-determination process.

CAPTA legislation has been supportive of community based prevention efforts.

Funding for Adoptive Family Preservation has provided some support to help prevent adoption disruption for children with special needs.

Ambiguous CBFRS funding resulted in loss of respite and family support funding.

In course curricula for providing training in severe disabilities, changes in IDEA are reflected in the course content.

The Assistive Technology Act provides matching funds for AT loan programs. Virginia’s loan program receives over 3 million dollars in federal funds.

IDEA promotes inclusion, least restrictive environments, functional behavioral assessment, assistive technology, alternate assessment, and transition and thus is supportive of initiatives that promote implementation of these practices.

Federal policy has played a large part in funding for education surrounding lead poisoning awareness and the policies that include screening and case management and intervention.

We remain hopeful that increased funding will become a part of the family support title, bringing stability and continuance to initiatives begun through ADD in many states to revive the work in family support and to further the work in self-determination.

IDEA provides funding through Part D to specifically address the needs of children with deaf-blindness and the people who provide support to them. Federal policy helps fund this project to provide training and technical assistance to many of the children and youth on the census.
MCHB has placed a high priority on supporting distance education.

When examining issues related to core and other funding, it is hoped that reporting requirements will also be examined in order to maximize the usefulness of programmatic and fiscal information provided by states to federal agencies.