



VOICES & VISIONS

A VOICE FOR PEOPLE WITH DISABILITIES: A PROMISING VISION FOR TOMORROW

Housing—Included or Priced Out?

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In Virginia, and nationally, obtaining affordable, accessible housing is one of the biggest barriers to community living faced by people with disabilities. While many can live independently with or without supports if suitable housing options are available, people with disabilities are frequently priced out of the housing market.



Priced Out in 2004, a study by the National Disability Institute's Technical Assistance Collaborative, provides numerous specific scenarios illustrating the problem's severity. For example, under current federal guidelines, housing is considered affordable when the cost of monthly rent, including any tenant paid utilities, does not exceed 30 percent of monthly household income. Using this guideline, a Supplemental Security Income (SSI) recipient receiving \$579 per month can afford monthly rent of no more than \$174. In contrast, Virginia's average fair market rent for a one-bedroom unit is \$741.

Addressing this critical issue in its 2006 *Biennial Assessment of the Disabilities Services System in Virginia*, the Board recommends two key courses of action. To create more affordable housing for people with disabilities and very low incomes, advocates must educate housing officials about both the residential preferences of this population and how housing assistance can facilitate community integration. Further, the disability community must become active-

ly involved in significant state housing planning efforts, such as the Consolidated Plan, Public Housing Agency Plan, Continuum of Care, and Qualified Allocation Plan, to influence the use of federal housing resources. To read more about the Board's housing recommendations, visit the Community Housing section of the *Biennial Assessment* at www.vaboard.org/biennial.

Two related proposals will also be presented during the 2007 General Assembly session that can improve housing options for people with disabilities. In House Bill 92 and Senate Bill 277, the Virginia Housing Coalition proposes that the state's Housing Commission establish a **Virginia Housing Trust Fund** to encourage and facilitate the development of affordable homeownership and rental housing across the Commonwealth. The Fund will promote mixed income communities and workforce housing through initiatives targeted specifically at those needs and will seek to ensure that projects are made possible statewide.

In the second proposal, the Northern Virginia Aging Network (NVAN) calls for amending the *Code of Virginia* (§ 58.1-339.7) to rename the home modifications tax credit the "**Livable Home Tax Credit**" and to make it available to taxpayers who build or purchase newly constructed residences with accessibility features. The current credit provides up to \$500 to homeowners who make accessibility changes in existing homes, with an annual cap of \$1 million. Expansion of the tax credit to newly constructed homes would promote "visitability" and universal design features in Virginia housing. ♾



Letter from the Executive Director

Heidi Lawyer



As we head into 2007, there continue to be many challenges facing people with developmental disabilities. There is also progress. State agency collaboration being fostered by the Governor's Office of Community Integration and agreement by our state Medicaid agency (DMAS) to cover positive behavior supports under the MR and DD waivers are just two examples of important movement forward. Other exciting opportunities include Virginia's receipt of one of eight federal "Real Choice Systems Change Grants for Community Living" (see page seven), the result of a strong collaborative effort, and its application for "Money Follows the Person" grant funds, a \$1.7 billion federal initiative. It is clear that many public and private organizations are working very hard to improve programs, services, and cooperation in a variety of areas covering a diversity of issues. However, there is much work to be done.



With the arrival of 2007, a new General Assembly session will begin to examine the policy and budgetary priorities that come forth, and citizen participation will be crucial. Our policymakers need to hear from

the people who are living with the challenges and barriers associated with having a disability in Virginia. Iowa's DD Council website, ID Action, says it well: **"Opportunities to improve your life won't happen unless you're equipped and prepared to advocate for change...Advocacy has a great influence on how laws and policies turn out."**

Issues that may inspire your advocacy include better access to community services, better health care, increased job opportunities, reduced waiting lists, enhanced transportation, affordable housing, and improved educational services. It can be overwhelming to think about addressing all of these challenges. The key may be to focus on the one or two issues most important to you.

The Virginia Board, consistent with its federal mandate and its 2007-11 State Plan, continues to focus on the supports and services people with disabilities need to live successfully in the community, regardless of how significant their disability. We strongly believe that Virginia must infuse sufficient resources

into community based services and that our General Assembly members need to hear from their constituents not just during legislative session but throughout the year. The message must be clear, concise, factually based, and consistently voiced.

For example, we must continue to impress upon decision-makers that, while all new funds and waiver slots are truly appreciated, the allotment of a few hundred new slots per year is not nearly sufficient--not with an "urgent" MR waiver waiting list of 1,639, a nearly equivalent non-urgent list, and a growing DD waiver list, now at 649 (as of 10/4/06). Numerous additional persons needing services are not even eligible to be placed on a waiting list, including those currently in community based ICFs/MR and nursing homes. The current pace of resource commitment will only result in continued expansion of the waiting lists and a continued institutional bias toward services, not withstanding new federal grant dollars. We must advocate for an increased financial commitment to community service development and infrastructure, beyond just waiver slots, and ensure that the Commonwealth's oversight and quality assurance mechanisms keep pace with the expansion of community living opportunities.

Virginia was recently ranked #1 for its Business Friendly environment. It continues to receive well deserved awards related to the use of technology and management of state government. It is well past time for Virginia to also become a leader in providing quality home and community based services to its citizens with disabilities. Until true community living options exist, choice is an erroneous and misapplied concept. Many consumers, family members, advocates, Administration officials, and legislators are working hard to effect change--but we need to move beyond incremental progress. It is only through your Voice, your Vision, and your Involvement that community inclusion will become a priority and a reality. ♡

Citizens can track legislation on their own during the up-coming session using the free **"Lobbyist-in-a-Box"** feature on the General Assembly's webpage. For more information, visit <http://leg1.state.va.us/h015.htm>.

DD Network News

Heidi Lawyer

Georgia's Children's Freedom Initiative: An Example for Virginia

In the August 2006 *Voices and Visions*, the DD Network expressed concern that approximately 237 children in Virginia are being served in facilities, including 88 children in nursing homes (60 percent increase since 1996). In this issue, we look to Georgia, a state working successfully to bring children home through its Children's Freedom Initiative. Georgia's DD Network spearheaded this initiative, and Virginia's DD Network appreciates their providing the information for this article.

In 2005, over 140 children under age 21 resided in Georgia's state and private institutions, nursing homes, and hospitals. Georgia also served children in the Division of Family and Children Services group homes, hospital Intensive Care Units, and Department of Juvenile Justice Youth Detention Centers. Additional children were sent out-of-state because no in-state supports were available. This placed Georgia among the top ten states for children residing in institutions. Some of these children had lived their entire lives in institutions, without connections to families, interacting only with paid staff. As in Virginia, some families had to give up custody of their children to the State in order to receive services. Georgia realized that these children needed permanent homes with families or others who would care for them and that these caregivers needed supports necessary to provide that care, including mentors and allies with similar experiences.

The Governor's Council on Developmental Disabilities, Georgia Advocacy Office, Institute on Human Development and Disability, People First of Georgia, and Statewide Independent Living Council created the Children's Freedom Initiative to bring light to this issue, identify ways to support children, and make sure that no child in Georgia has to live in an institution just because he or she has a disability. This initiative's goal was "**A Georgia where children are prevented from going into institutions/facilities or are brought safely home from institutions/facilities into homes and families.**"

Among the activities undertaken to implement this initiative was a compilation of portraits of children



living in institutions, a related media campaign, and a summit. Most importantly, Georgia passed House Resolution 633 that urged the Departments of Human Resources, Community Health, Education, Labor, and Juvenile Justice to develop a course of action to identify, assess, and plan appropriate community supports for children under the age of 22 living in nursing homes, state hospitals, private ICFs, and public and private hospital ICUs. HR 633 required those agencies to submit an annual progress report to the Speaker of the House and to develop a budget proposal for the 2008 fiscal year. It also established an oversight committee comprised of members of the three federal partners (IHDD, GAO and GCDD) and other interested stakeholders, including legislators, to monitor the progress of the agencies.

A summit was held to discuss how to successfully move the children to permanent homes and families. Issues addressed included lack of necessary supports in the community—including adequate, flexible family supports—and present payer methodology. It was determined that Georgia needed a multi-year plan to bring children home, which included preventing additional children from entering nursing homes or other institutions.

During its most recent session, the Georgia legislature approved funds so that all of the children in its state administered institutions can go home! Next year, the Georgia DD Network will work with the legislature to tackle the issue of children in private facilities and nursing homes. Congratulations to our sibling DD Network for its accomplishments and to the state of Georgia for setting an example of what can be done if the will exists. ♡♡

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

Next Board Meeting

December 8, 2006
Wyndham Richmond
Airport Hotel
4700 S. Laburnum Ave.
Richmond, VA

Upcoming Meetings:
March 16, 2007
June 7, 2007
September 21, 2007
December 14, 2007

Partners in Policymaking Update

Teri Barker-Morgan



September's opening session for the Partners in Policymaking (PIP) Class of 2007 featured in-depth training and discussion on the history of the disability rights movement and the human services system, highlighting the various paradigm shifts

that have occurred. The hard cold reality of how people with disabilities have been treated, their very existence marginalized in society as recently as the 1960's, was eye-opening and emotional for many class participants.

While confronting the historical experiences of people with disabilities head-on can be disturbing, these lessons of the past are nonetheless necessary. Through their persistence and advocacy, people with disabilities and their families have brought about the many changes offering opportunities for a real life, a life of full inclusion in all aspects of community.

After learning from the past, PIP participants turned their attention forward to dreaming about theirs or

their child's future. Methods for visualizing and planning that future highlighted in their training included person-centered planning, PATHs (Planning Alternative Tomorrows with Hope), and Maps.

October's session highlighted Virginia's Developmental Disabilities (DD) Network—the Partnership for People with Disabilities, the Virginia Office for Protection and Advocacy (VOPA), and the Virginia Board for People with Disabilities (VBPD). Under the federal DD Act, these agencies collaborate to improve services, knowledge, and policy in the disability arena. The work of their "DD Partners" is always of great interest to each new PIP class of "Partners".

At November's session, the Partners will receive a comprehensive overview of Medicaid and Virginia's system of Home and Community Based Waivers. "The Medicaid Maze" will be presented by Maureen Hollowell of the Endependence Center, Norfolk's Center for Independent Living (CIL). ♡♡

A Look at Yesterday and Tomorrow

YLF Update

Teri Barker-Morgan



Wanted! Young Leaders

Recruitment of Student Delegates for next summer's Virginia Youth Leadership Forum (YLF) has begun. Now in its eighth year, the 2007 YLF will take place from July 9-13 at Christopher Newport University in Newport News.

Please spread the news about this exciting and prestigious leadership development opportunity for young Virginians with disabilities.

Application packets have been mailed to high schools, service providers, and appropriate organizations throughout Virginia. If you have not received a YLF recruitment package, contact the Board immediately. Applications can also be downloaded and printed from the Board's website at www.vaboard.org/ylf.htm or obtained by contacting Teri Barker-Morgan at

**1-800-846-4464 (voice or TTY) or
teri.barker@vbpd.virginia.gov.**

The deadline for the receipt of applications is 5:00 pm, Friday, March 23, 2007.

At the Board's September meeting, Andrew Wawrzniak from Springfield, Virginia, shared his experiences as a Delegate to the 2006 Youth Leadership Forum. His poise and self-confidence were notable, as were his comments about the important lessons learned about leadership, perseverance, and setting a good example for others. Andrew spoke of YLF experiences that helped him shape his vision for his future, including new friendships, the technology fair, and an opportunity to meet the Governor. He left the 2006 Forum feeling more empowered and in control of his future.

Together, let's ensure that all Virginia high school students with disabilities and a desire to develop their leadership skills—and take control of their futures—have the opportunity to apply to become a YLF Delegate. ♡♡

Pass the word!

YLF 2007 is just around the corner!

Emergency Planning for People with Disabilities

Rebecca Currin, Virginia Office for Protection & Advocacy and Julie Stanley, Virginia Office of Community Integration

We will remember the summer and fall of 2005 as one of the worst hurricane seasons in U.S. history. The Gulf Coast was devastated by three hurricanes, and the New Orleans levees were breached, leading to widespread recognition that, despite fancy technology and advanced communications, we were not prepared to respond to major disasters. We also learned that emergency planning and response were woefully inadequate, particularly for seniors and persons with disabilities.



Photo courtesy of National Organization on Disability

In recognition of these hard-learned lessons, on June 28-30, 2006, the U.S. Departments of Health & Human Services and Homeland Security sponsored a Working Conference on Emergency Management and Individuals with Disabilities and the Elderly (www.add-em-conf.com for more information). The conference brought together state experts on disabilities, aging, and emergency management to discuss promising practices, formulate state teams, take a critical look at state emergency planning processes, and identify how they might strengthen with regard to individuals with disabilities and the elderly.

Virginia's delegation included the Offices of Community Integration for People with Disabilities, Commonwealth Preparedness, and Protection & Advocacy, as well as the Departments of Emergency Management, Health, and Aging. Each morning, recognized experts in the field presented the lessons learned since 2005. Afternoon discussions addressed specific topics and recommendations, giving particular emphasis to defining "special needs populations" and the usefulness—and pitfalls—of providing "special needs shelters" and maintaining "registries" of persons with special needs.

Conferees quickly reached two decisions: everyone needs to develop a personal emergency plan and persons with disabilities and seniors must be involved at every stage and level of emergency planning and response. Involvement in state level planning can be expedited by existing entities such as the Community Integration Implementation Team and Advisory Commission and the Virginia Board. At the local level, involvement of Centers for Independent Living, Disability Services Boards, Community Services Boards, Area Agencies on Aging, and numerous consumer groups is also essential.

On August 22, the delegation presented recommendations for inclusive, accessible sheltering and involvement of persons with disabilities and seniors at every level of emergency planning and response to the Community Integration Implementation Team. The Team agreed with the delegation's recommendations, and on September 19, they were presented to the Community Integration Advisory Commission. The Commission adopted the Team's recommendations and made several helpful suggestions of its own.

Get involved! Working with Citizen Corps, the Departments of Emergency Management and Health are funding a series of regional outreach and training sessions focused on emergency preparedness for people with disabilities, seniors, and other "vulnerable" populations. Virginia delegation members will be involved in planning these daylong events and hope to gain active participation from the disability and senior communities. The first forum, being developed with the disAbility Resource Center in Fredericksburg, is scheduled for March 2007. Once finalized, forum details will be posted at ww.vaemergency.com/train/calendar.cfm. ♡

Board Welcomes New & Returning Members

On August 1, 2006, Governor Tim Kaine commissioned three new members to begin serving four year terms on the Board. These members come at a very exciting time as the Board moves to increase its visibility and effectiveness as a policy maker and disability advocate within the executive branch and in the community at large. Representing a cross section of the Commonwealth, these new members are: Leon Alder, Director of Four County Transit operated by the Appalachian Agency for Senior Citizens, from Abingdon; Cecily Rodriguez, Deputy State Director for the Telamon Corporation, of Richmond; and Shirley Hicks, a paraprofessional for the Crossroads Community Services Board, from Rice. The Board is also privileged to congratulate four members reappointed by the Governor for a second four year term: Eric Clark from Richmond, Sandy Hermann from Virginia Beach, Mark Russell from Lynchburg, and Monica Schlessinger- Smyth from Glen Allen. ♡



(left to right) Secretary of the Commonwealth, Katherine K. Hanley, Board Members: Cecily Rodriguez, Leon Alder, and Shirley Hicks

Enabling Self-Determination & Independence

Katherine Lawson and Tom Driscoll

In 2002, with the help of the Endependence Center in Norfolk, a remarkable young woman named Tina Lewis transitioned from a nursing home to an apartment of her own. A bit of her story, drawn from her own words, appears nearby. Tina and others like her inspired the Board's current grant project with the Virginia Association of Centers for Independent Living (VACIL): **Consumer Choice in Community Living: Nursing Home Outreach and Transition Planning.**

One of those others, Felicia Goffigan, had just been appointed to the Board when it began developing requests for proposals for grants to be awarded in 2005. Representing an individual living in an institution, Felicia has also lived in a nursing home since experiencing a severe injury early in life. As a member of the Community Integration Committee, Felicia was a powerful voice for ensuring opportunities for persons with even the most severe disabilities to live in communities of their own choice rather than institutions and for providing the supports for them to do so.

Speaking from her specially equipped wheelchair and using a portable ventilator, Felicia shared with other committee members her dreams of leaving the nursing home, completing school, and attending college. The resulting Consumer Choice grant, which began in July 2005 and continues through June 2007, seeks to build on the experiences of pioneers like Tina and to enable the dreams of Felicia and others.

In announcing its receipt of the Consumer Choice grant, VACIL reported that more than 260 nursing homes in Virginia provide Medicaid funded services for more than 29,000 individuals. Of these, 763 are under age 44, and 2,997 are between the ages of 45 and 64. How many of these individuals would choose to leave if they knew of other options for their support is unknown. The Consumer Choice grant will identify individuals wanting to make that transition and the resources needed to make it possible.



A Voice of Experience

Hi, my name is Tina Lewis, and I'm 26 years old. I transferred from a nursing home in 2002 to my own apartment in Norfolk, where I still live today. It was not good living in a nursing home. A nursing home is like a hospital and sometimes makes you sick, sad, and depressed. That's why I feel that no other young adult should have to go through the things that I went through. No older adult either.

I moved into an accessible apartment. I have doors that work by remote control. I have a PERS unit, a button that you carry around with you in case you "fall and can't get up" so you can call for help. I have a roll-in shower which is kind of cool. I hire my own personal assistants because I like to set my own schedule and I like to hang out and have fun with my friends. I'm working on getting employment, and I also want to go to college. I participate with a young adult advocacy group. We talk about different issues and how to make the world more accessible for us.

People can't believe that I live on my own. They seem amazed by the things that I do, like going grocery shopping and paying bills by myself. Most of all, my friends and family are very proud of me.

I would just like you to know that it feels good to be out of a nursing home, in your own place, where you can do whatever you want, whenever you want. It's going to be kind of shaky at first, but you will be fine. Every part of life has challenges. Your life is what you make it. And the harder you try, the more you will succeed. ♪♪

(Tina is a graduate of Partners in Policymaking)

During the grant's first year, working statewide through its affiliated Centers for Independent Living, VACIL began that identification process. Over the next year, VACIL and the Board hope to successfully transition twelve or more individuals from nursing homes to appropriately supported community settings. Levels of support, including financial assistance where appropriate, will vary based on individual needs but may include Medicaid waivers, housing alternatives, community-living skills training, peer support and counseling, and advocacy assistance to help plan

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Virginia Receives Funds for "Real Choice"

On September 15, U.S. Secretary for Health & Human Services Mike Leavitt announced the award of nearly \$20 million in federal funding to help states "rebalance" their long-term support programs for people with disabilities or chronic illnesses. Virginia, one of the eight states chosen this year to receive a **"Real Choice Systems Change Grant for Community Living"**, will receive \$2,245,258 to be spent between now and September 30, 2011.



The Department of Medical Assistance Services and the Department of Mental Health, Mental Retardation and Substance Abuse Services will serve as lead agencies on this initiative. The Board and its DD Network partner, the Partnership for People with Disabilities, played a significant role in developing Virginia's Real Choice grant proposal, and the Department of Aging and its information and resource network collaborator, SeniorNavigator, will be key partners in its implementation.

Goals for the Real Choice Systems Change initiative are to improve access to information on the full range of community-based services, develop a more self-directed service delivery system for consumers, and imple-

ment a comprehensive quality management system for service providers. Key elements will include development of appropriate information technology, creation of flexible financing arrangements that promote community living options, and coordination of long-term supports with affordable, accessible housing. Related pilot projects are underway involving several local Area Agencies on Aging, and the project will provide a template for wider applications that will transform Virginia's entire health and human resources system in the future.

On November 1, Virginia applied for a related **"Money Follows the Person Rebalancing Demonstration Project"** grant from the Centers for Medicare and Medicaid Services. The Board also participated in development of this proposal which, if approved, could provide in excess of \$33 million in additional funds to reduce Virginia's reliance on institutional care while expanding and improving consumer-directed, community-based services. More information on both the Real Choice and Money Follows the Person initiatives may be found at www.cms.hhs.gov/RealChoice. ♡♡

Board Approves Grant Opportunities for 2007



At its September 13 meeting, the Board approved preparation of Requests for Proposals (RFPs) for 2007 **Competitive Grant opportunities**. Solicited projects will further the Board's 2007-2011 State Plan goals and focus on community integration, housing, transportation, and self-advocacy. Following their approval by the Board at its December 2006 meeting, specifics of the RFPs and application instructions will be publicly announced and posted to the Board's website at www.vaboard.org/grants.htm. Applications will be due in March 2007, and projects awarded funds will begin in July 2007.

In September, the Board also approved resumption of its **Innovative Grant Program**, a discretionary funding opportunity that encourages and supports creative, original, and pioneering strategies that may address any areas of emphasis and goals in the Board's 2007-2011 State Plan. Typically, the Board has allocated up to \$50,000 per year for Innovative Grants, but it can approve higher amounts at its discretion. A copy of the State Plan can be found on the Board's website. Specific guidelines and procedures for submitting an Innovative Grant concept paper will also be available on the Board's website beginning January 1, 2007. ♡♡

Enabling Self-Determination & Independence

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transition and life afterwards. Securing affordable, accessible housing (see cover story) will be a major obstacle for many.

By the conclusion of the grant, its participants' collective experiences will help to establish a person-centered process that will guide others in making the transition from a nursing home to a home of their own. The project will also distribute related information to individuals living in nursing homes and their families, identify additional persons wanting to make the move to more integrated community settings, provide them with transition coaching, and collect data to inform policy makers of transition barriers.

Over the next year, many more success stories will emerge. Like Tina's story--and Felicia's dreams--they will inspire and enable others make the transition from an institution to independence. ♡♡

