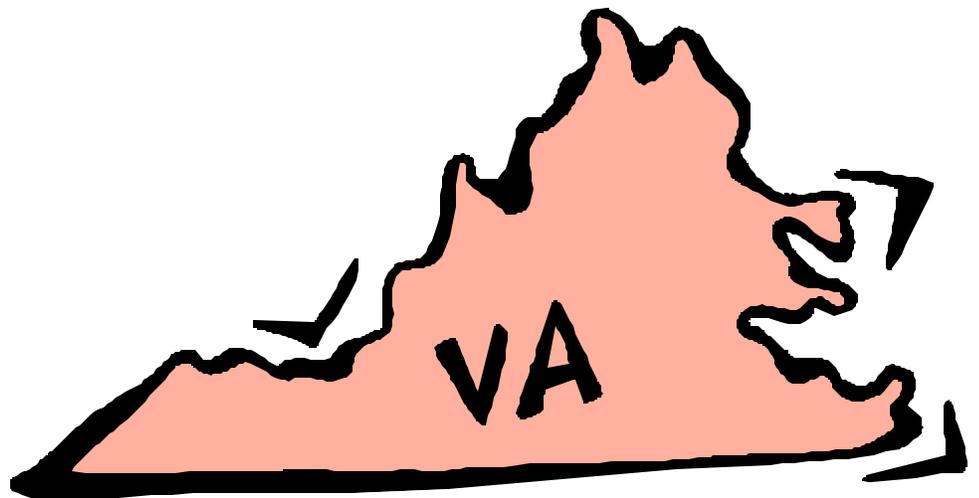

Things You Should Know

Virginia is a place of unparalleled beauty. From the white beaches of the Eastern shore to the green forests of the Blue Ridge Mountains, Virginia is a place for lovers.

But Virginia is *not* a welcoming place for people with disabilities and their families. The Commonwealth operates one of the most under-funded and regressive community support systems in the nation. What can be done about it?

Plenty.



David Pitonyak

Version June 3, 2002

An ordinary, everyday, interest group

People who experience disabilities and their families are not a special interest group. They are an ordinary, everyday interest group. Most parents want the chance to raise their young children at home. They want their kids to learn alongside typically developing children in neighborhood schools. When children with disabilities grow into adulthood, they want the chance to make a contribution to the larger community. They want real jobs for real wages in the real world. They want the chance to live in safe, affordable housing indistinguishable from the housing that everyone else enjoys. In short, they want to “boldly go where everyone else has already been.”

Who are we

The Commonwealth Coalition for Community is a grass roots advocacy organization that believes Virginia can be a better, more welcoming place for people with disabilities and their families. Since its inception in 1996, members of the Coalition have actively worked to support family- and consumer-driven services in Virginia

through legislation, training, and our publication, *The Community Journal*.

Our Vision (1)

Sadly, Virginia operates one of the most under-funded community support systems in the nation (2). The Commonwealth, which ranks 13th in the nation in per capita income, ranks 45th in the nation in its fiscal support of community MR/DD services (Braddock et al., 2000). For this reason, we believe that Virginia must increase funding for community-based supports. But increasing the amount of money spent in community is not enough. We believe that every tax dollar should be invested wisely, in ways that help people to assume personal responsibility and participate fully in community life. We do not want the taxpayer’s resources to be used for services and supports that foster dependence and isolation.

We believe in opportunity...

First and foremost, we believe in opportunity. Meaningful opportunity.

We believe that Virginians with disabilities and their families want the opportunity to live ordinary, everyday lives. They are not a *special* interest group, but an *ordinary, everyday* interest group.

We believe in self-determination...

Each individual with a disability should have the authority to plan for his or her own future. With the assistance of family members, others the individual invites to participate, and/or personal agents, individuals should be given an opportunity to develop plans, exercise control over funding, and oversee implementation of those plans.

We believe in a family for every child...

All children should live with their families (or with other families if a child's biological family cannot provide a safe and healthy environment). Needed and desired support can be made available at home, school, recreational settings, and other community gathering places to enhance the participation of the child and the family. Supports should be developed for the *entire* family and should take into account the gifts and resources of each family member. When it is not possible for a child to live with his or her biological parents, the Commonwealth should commit itself to finding a family for every child.

We believe in inclusive neighborhood schools...

An inclusive education means that young people with disabilities should

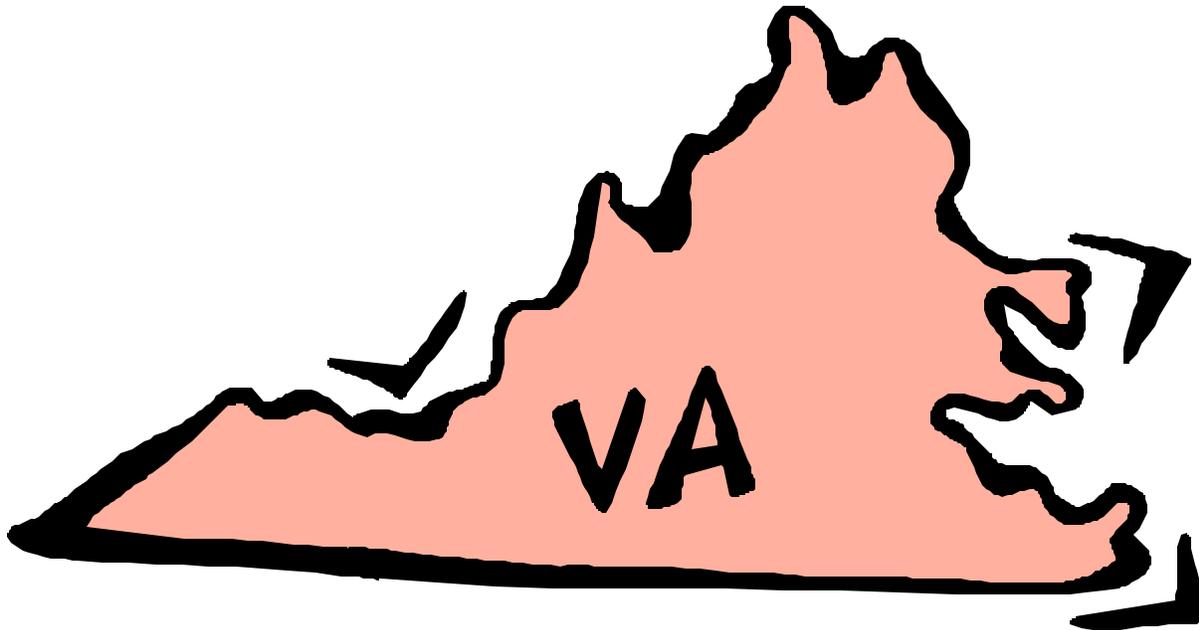
Vision is the fundamental force that drives everything else in our lives. It impassions us with a sense of unique contribution that's ours to make. It empowers us to put first things first, compasses ahead of clocks, people ahead of schedules and things.

- Covey, Merrill & Merrill, 1994

attend regular age appropriate classes with other young people from their neighborhoods. Inclusion is not mainstreaming. Inclusion is a complete system of support for the child, the child's peers, and the faculty and staff of the school.

We believe in safe and affordable housing...

Each individual with a disability should have the opportunity to live in homes (typical range of dwellings) in which



they have tenure and control over the environment. People have the right to the safety and security of tenure (ownership or lease). They should have the right to decide where they live and with whom.

We believe in real work for real wages in the real world...

Real work for real wages in the real world means that people with disabilities should have the opportunity to participate in the labor force to the same extent as any other person in the community. Given proper support, people with disabilities should be able to find and keep real work for real wages in the real community.

We believe in universal physical accessibility...

All people should have the right to move about freely in the community. A simple motto for our times, "To boldly go where everyone else has already been!"

We believe in health care that promotes well-being...

People with disabilities deserve access to the best possible health care and psychological services. People need to feel well and have access to professionals who can help them to achieve physiological and psychological well-being. Particular attention should be paid to positive behavioral supports that preclude the necessity of crisis intervention services.

If someone asks you if Virginia is a supportive place for people with disabilities and their families, what will you tell them?

Facts about Virginia's service system

Sadly, Virginia operates one of the most regressive and under-funded community support systems in the nation. According to a study commissioned by the Virginia legislature, "Virginia's fiscal effort for total mental retardation services has substantially lagged the nation during much of the last 20 years. In 1996, fiscal effort for community services was 46% below the national average effort level...fiscal effort for total mental retardation spending in the state during 1977-1996 advanced 16% while the national increase during that 20-year period was 60%" (CHPS Consulting, 1998, Appendix C, p.3).

Consider this: Virginia is literally surrounded by states that rank higher in their fiscal support of community programs. North Carolina (25), Tennessee (42), West Virginia (14), Maryland (34), and the District of Columbia (5) all devote a greater portion of their resources to community programs. Of Virginia's neighbors, only Kentucky (50) ranks lower than Virginia (45) (Braddock et al., 2000, p.187).

The Medicaid Waiver Program

The Federal Medicaid Waiver Program is one way in which states have

Virginia currently operates
one of the most under-funded and regressive
community support systems in the nation.
If our politicians don't act quickly,
it could get worse.

expanded their community support system. Although the Virginia Waiver program grew by 466% between 1992-1996, Virginia still ranks 41st in the nation overall. In 1996, the level of state spending per capita was 63% below the national average.

Consider what our closest neighbors spend (no data were provided for the District of Columbia) (Braddock et al., 2000, p. 17):

\$23.76 West Virginia
\$15.08 Maryland
\$11.19 Tennessee
\$10.92 North Carolina

And then consider what we spend per capita:

\$ 6.62 Virginia

The Waiting List

There are significant waiting lists for community services in Virginia. According to the State Comprehensive State Plan (2000), there are 5,169 people waiting for services. These individuals include:

1440 adults currently waiting for vocational or day supports.

2562 children and adults on the waiting

list for residential supports.

534 young adults who will soon graduate from their schools and will need something meaningful to do during the day.

220 additional children and adults who will join the waiting list for residential supports in the upcoming year.

It is also clear that the primary caregivers of people on the waiting list are aging. One day, they may no longer be able to care for their loved ones. According to the Department of Mental Health, Mental Retardation and Substance Abuse Services report, *Comprehensive State Plan 2000*, the age of the primary caregiver for the people on the waiting list breaks down this way:

- Under age 50: 33.8% (1739)
- Age 50-59: 22.6% (1163)
- Age 60-69: 15.4% (790)
- Age 70+: 10.4% (535)
- No caregiver: 17.9% (919)

Who will help people on Virginia's waiting list when a primary caregiver becomes to old or passes away? Will Virginia's community support system be able to help the person to live in his or her home community?

Virginia's commitment to institutions

Despite the clear demand for community-based services, Virginia continues to support large institutions and other models of congregate care.

The Commonwealth ranks 14th nationally in its support of institutions (Braddock et al., 2000). Nearly 43% of the State's limited funds go to support 1,870 people living in five public institutions (DMHMRSAS, 2000).

Persons with disabilities are also likely to end up in one of the state's psychiatric facilities or many nursing homes. Units for persons with mental retardation are maintained in two of the state's psychiatric facilities, although no data are available regarding the number of people served and the associated spending there. Almost 1,100 people with mental retardation or related developmental disabilities are living in nursing homes. Spending for these individuals totaled \$28 million in 1996 (CHPS Consulting, 1998, Appendix C, p.2).

Despite years of research that demonstrate a clear advantage to supporting people in community-based settings (e.g., Hayden, DePaepe, 1994; Nisbet, Clark, & Covert, 1991), and a growing number of states that are closing their facilities (Braddock et al., 2000), Virginia has made no announcement of plans to close its

facilities or end, once and for all, the institutionalization of people in nursing homes (CHPS Consulting, 1998, p. 4-3).

To summarize: The Commonwealth of Virginia operates one of the most under-funded community support systems in the nation. Despite years of research that demonstrates that people with disabilities benefit from living ordinary, everyday lives, the Commonwealth continues to invest its limited resources on services which lead to isolation and dependency.

Self-Determination

Each individual with a disability should have authority to plan for his or her own future. With the assistance of family members, others the individual invites to participate, and/or personal agents, individuals should be given an opportunity to develop plans, exercise control over funding, and oversee implementation of those plans.

In a study by the Center for Economic Policy Analysis, Arthur Lyons and Maryann Mason described the basic cornerstones of self-determination:

“People often do not think about the

For every \$1 that Virginia spends on services which are consumer-directed, we spend \$3,410 on services directed by professionals.



For every dollar the Commonwealth spends on direct payments to families, we spend \$180 on services and supports operated by professionals

most commonplace features of their lives, things they literally take for granted. For example, it is said that nomads who spend their entire lives in a desert rarely think about sand and can describe it only with difficulty. People who have breathed only clean air, without ever experiencing air pollution, do not reflect on air quality and cannot fully appreciate the importance of clean air compared to its alternatives. In the same way, people rarely consider the most common aspects of the freedom they experience in the communities where they live. “There are four prerequisites for community:

1. **Authority** to hire and fire service provider. Such authority allows people to decide who will provide the services they need and to establish the conditions under which those services will be provided.
2. **Responsibility** to take action without prior approval from a professional. People with this responsibility are empowered to prioritize their own service needs and obtain the benefits of the service without a pre-approved plan.
3. **Discretion** to allocate resources. People have discretion over resources used for their benefit when the resources come in the form of cash instead of direct

services, case management, and commodities.

4. **Integration.** The service-delivery system supports integration when programs and services incorporate interactions that bring people with and without disabilities into contact with one another.

“The four prerequisites do not by themselves guarantee full community life for anyone who enjoys them but they are the minimum necessary for community to be possible. Furthermore, they all must be present simultaneously, much as a table cannot stand firmly unless all of its legs are present and functioning” (pp. 1-2).

What does the State of Virginia really believe when it comes to self-determination?

If you want to know what an organization or state really believes when it comes to disability services, look at how it spends its money. Don't bother to read the mission statement or listen to noble promises. Check out the budget. A budget is a statement of beliefs.

What does the state of Virginia really believe when it comes to self-determination?

Virginia currently operates a statewide

self-determination project funded for approximately \$100,000 per year. The total cost of our MR/DD system per year is \$341 million, which means that for every dollar the Commonwealth spends on services which are consumer-directed, we spend \$3,410 on services directed by professionals.

There is reason to be optimistic, however. Governor Gilmore recently convened a Task Force to re-write the Medicaid Waiver. Among other things, the Task Force has recommended, for the first time, the inclusion of consumer- and family-directed supports in Virginia's Waiver.

To summarize: While it is true that we have a scarcity of funds in the service system, it is also true that we depend almost exclusively on professionals to maintain that scarcity. It seems that Virginia has little faith in people who experience disabilities to manage their own budgets.

A family for every child

All children should live with their families (or with other families if a child's biological family cannot provide a safe and healthy environment). Need and desired support can be made available at home, school, recreational settings, and other community gathering places to enhance the participation of the child and the family. Supports should be developed for the *entire* family and should take into account the gifts and resources of each

family member. When it is not possible for a child to live with his or her biological parents, the Commonwealth should commit itself to finding a family for every child.

It is generally recognized that moms and dads know best what their young children need. But in Virginia, our politicians give millions of dollars to professionals to operate segregated services for children, while little is done to support families to raise their children at home.

A report commissioned by the General Assembly states that, in 1996, "six hundred families received family support, at an average cost of \$1000 per family. This per capita spending level is low in comparison to other states. In fact, **Virginia's per capita spending for family support was the second lowest in the nation** — 95% below the national level" (CHPS Consulting, 1998, Appendix C, p.2).

While the rest of the nation has been steadily increasing direct payments to families (by an average of 87% since 1991), Virginia's support for families has decreased in the same period by 4% (Ibid, 1998).

Let's look at how Virginia compares to its neighbors (data for the District of Columbia is not available) (Braddock, 2000, p. 27):

- In North Carolina, 3, 752 families are served with an average yearly expenditure of \$6,100 per family.
- In West Virginia, 2, 461 families are served, with an average yearly expenditure of \$1,879 per family.

- In Tennessee, 1,902 families are served with an average yearly expenditure of \$1,689 per family.
- In Maryland, 5,007 families are served with an average yearly expenditure of \$2,374 per family.
- **In Virginia, 1,928 families are served with an average yearly expenditure of \$970.**

While it is true that there is an overall scarcity in Virginia's system. It is also true that we depend upon professionals to manage that scarcity. For every dollar the Commonwealth spends on direct payments to families, we spend \$180 on services and supports operated by professionals.

It is also known that the Commonwealth has institutionalized many young children in the name of "treatment" and continues to do so, despite years of protests from advocates. Amazingly, the Department of Mental Health, Mental Retardation, and Substance Abuse Services (DMHMRSAS) does not maintain data on the number of children living in a public or private institution (in state or out of state)!

Does this sound like "family values" to you?

Inclusion

An inclusive education means that young people with disabilities should attend regular age appropriate classes with other young people from their neighborhoods. Inclusion is not mainstreaming. Inclusion is a complete system of support for the child, the child's peers, and the

While the rest of the nation has been steadily increasing direct payments to families (by an average of 87% since 1991), Virginia's support for families has decreased in the same period by 4%

faculty and staff of the school.

Colleen Tomko (2000) writes, "Inclusion is part of a much larger picture than just placement in the regular class within school. It is being included in life and participating using one's abilities in day to day activities as a member of the community. It is being a part of what everyone else is, and being welcomed and embraced as a member who belongs.

"[Inclusion] must be created with proper planning, preparation, and supports. The goal of inclusion is achieved only when the child is participating in the activities of the class, as a member who belongs, with the supports and services they need...Instead of getting the child 'ready' for the regular class, the regular class gets ready for the child."

Consider these guidelines from *The Prompter*, a newsletter of Parents Reaching Out:

Inclusion Is:

1. All children learning in the same school with the necessary services and supports so that they can be successful.
2. Each child having his/her unique needs met in integrated environments.
3. All children participating equally in all facets of school life.
4. Encouraging friendships and social relationships between students with and without disabilities.
5. Arranging for students with disabilities to receive their education and job training in regular community environments.
6. A new service delivery model for special education which emphasizes collaboration between special education and regular education.
7. Providing support to regular education teachers who have children with disabilities in their classrooms.
8. Children learning side by side even though they may have different learning goals.
9. Teaching all children to understand and accept human differences.
10. Providing an appropriate individualized educational program for all children.
11. Taking parents' concerns seriously and making parents meaningful participants in the planning process.

Inclusion is not:

1. Dumping children with challenging

needs into regular classes without proper supports and services they need to be successful.

2. Trading the quality of a child's education or the intensive support service the child needs for integration.
3. Ignoring each child's unique needs.
4. Sacrificing the education of typical children so that children with challenging needs can be integrated.
5. All children having to learn the same thing, at the same time, in the same way.
6. Doing away with special education services or cutting back on special education services.
7. Expecting regular education teachers to teach children with challenging needs without the support they need to teach all children effectively.
8. Locating special education classes in separate wings at regular school.
9. Ignoring parents' concerns.
10. Maintaining separate schedules for students in special education and regular education.
11. Students with disabilities receiving their education and job training in facilities outside of their community.

Inclusion is considered best educational practice. In a recent study by Dr. Jill England (1997), 80% of the students were shown to have higher levels of achievement than in the pull-out or special education class. Nationally the research indicates achievement at or above previous years. It has also been demonstrated that academic performance for non-disabled children increases in schools which offer inclusive practices.

Is inclusion happening in Virginia?

When it comes to inclusive educational practices, Virginia receives failing grades. Despite a national trend towards educating children with disabilities in inclusive settings, the vast majority (97.7%) of Virginia's children are educated in segregated classrooms (OSERS, 1999). That means that for every child included in a typical classroom in Virginia, 49 children are segregated in separate classrooms, or separate schools.

The Arc (formerly known as the Association for Retarded Citizens) gives the Commonwealth an "F" for its efforts to include children with disabilities in their neighborhood schools (Davis, 1995).

Safe and affordable housing

Each individual with a disability should have the opportunity to live in homes (typical range of dwellings) in which they have tenure and control over the environment. People have the right to the safety and security of tenure (ownership or lease). They should have the right to decide where they live and with whom.

Bonnie Shoultz from the Center on Human Policy writes, "For many people with mental retardation, home has meant one of two options: living with family members or living with groups of other people with disabilities. Either

way, it has often meant living in a home not of one's own, and having other people make most of the decisions about mealtimes, recreation, roommates, and almost all other aspects of life.

"Increasingly, parents and adults with mental retardation are pursuing help with setting up, for the individual, a "real" home, a home like other people create for themselves in our society. People with disabilities are beginning to be heard when they ask that agencies and service systems rethink their practices and regulations, especially those that interfere with adults' dreams about homes of their own."

As stated earlier, Virginia's waiting list for community-based services is among the longest and most neglected in the nation. Today, over 5,000 Virginians with disabilities are waiting for community-based services (and another 220 are being added each year).

If you think that receiving community-based residential support in Virginia leads to an ordinary, everyday life, think again.

According to the U.S. Census Bureau, the average size of a Virginia household is 2.6 people. But 53% of all Virginians supported by our residential service delivery system live with seven or more people (Braddock et al., 2000).

47% (3291) are served in settings with 1-6 residents/

6% (452) are served in settings of 7-15 residents.

47% (3272) are served in settings of 16 or more residents.

The Commonwealth ranks 14th nationally in its support of institutions. Nearly 43% of the State's limited funds go to support 1,870 people living in five public institutions (DMHMRSAS, 2000).

According to the *Comprehensive State Plan 2000-2006*, the number of people residing in the MR Training Centers in Virginia was as follows in October, 1999:

- Central Virginia Training Center: **729 people.**
- Northern Virginia Training Center: **200 people.**
- Southwestern Virginia Training Center: **200 people.**
- Southside Virginia Training Center: **518 people.**
- Southwestern Virginia Training Center: **223 people.**
- Total: **1,870 people.**

Persons with disabilities are also likely to end up in one of the state's psychiatric facilities or many nursing homes. Units for persons with mental retardation are maintained in two of the state's psychiatric facilities, although no data are available regarding the number of people served and the associated spending there. Approximately 1,200 Virginians with mental retardation or related developmental disabilities are living in nursing homes. Spending for these individuals totaled \$34 million in 1996, at an average cost of \$27,296 per person (CHPS Consulting, 1998, Appendix C, p.2)(4).

Eight states, including West Virginia,

and the District of Columbia, have closed all of their MR/DD facilities. It is estimated that in the period between 1985 and 1999, there were 118 closures or planned closures of institutions in 36 states. To date, Virginia's policy makers have made no announcement of a plan to close one of the five state-operated MR/DD facilities (Braddock et al., 2000, pp. 8-9).

Community services are more economical

Community services are, as a whole, far more effective (and less costly) than institutions. Even the most intimate living arrangements, such as supported living (which provides people with support in their own home or apartment *regardless of their disability, medical condition, or behavior*) are more cost effective than institutions or congregate living arrangements (Smith, 1990).

In 1998, Virginia ranked 46 among states in placement of individuals with disabilities in community placements for 15 or fewer individuals (Braddock et al., 2000, p. 4).

Institutions are costly. In the past three decades, thousands of Americans with disabilities left institutions and are now living successfully in their communities. Despite the significant reductions in the overall census of facilities nationwide, however, the costs of operation have risen steadily. By the end of 2001, David Braddock and other researchers (1991) estimate that the average cost of institutionalization will reach \$113,000 nationwide.

The annual cost of institutionalizing a

person in Virginia in 1998: \$84,315 (5).

In its *Position on Residential Living Arrangements*, the national Arc (formerly known as The Association for Persons With Mental Retardation), states, "It is commonly acknowledged that small community-based living arrangements are effective for all people with mental retardation, behavioral or physical disabilities. Conversely, it is well documented that institutional environments have many and serious adverse effects. They have demonstrated a lack of success in providing essential opportunities for growth and development needed by persons with mental retardation" (Davis, 1994)

Virginia's failing grades

In its *Report Card to the Nation On Inclusion of People with Mental Retardation in Community Housing*, the Arc (formerly the Association for Retarded Citizens) gives Virginia failing grades in two important areas — a "D" for our efforts to help people leave institutions and an "F" for our efforts to help people find small, intimate housing arrangements (Davis, 1994).

Real work, for real wages, in the real world

Real work for real wages in the real world means that people with disabilities should have the opportunity to participate in the labor force to the same extent as any other person in the community. Given proper support, people with

"The cost of placing an individual into competitive employment with support is \$3,219 compared to the \$8,005 annual cost of keeping an individual in a day program or sheltered workshop, and \$10,567 for group supported employment."

- Paul Wehman
Director
Rehabilitation Research and
Training Center

disabilities should be able to find and keep real work for real wages in the real community.

Paul Wehman is the Director of Virginia's Rehabilitation Research and Training Center in Richmond. In an *Richmond Times Dispatch* OpEd piece (originally published in 1996; but updated for this publication in 2000), Wehman describes supported employment and why it is so important.

"Supported employment is paid, competitive employment at a minimum wage or better in retail, food services,

The mean hourly wage for people in supported employment is \$5.42.

The mean hourly wage for people in sheltered employment is \$2.42.

Nearly two-thirds of the individuals served in sheltered workshops and day activity centers could benefit from supported employment services.

manufacturing, printing, libraries, and a variety of other settings with ongoing help or support at the job. It's dramatically different from subsidized work -- if you don't do the job, someone else has to.

"In 1995, more than 140,000 people with severe disabling conditions...were employed in the nation's competitive workforce with the help of job coaches and supportive co-workers and employers. While that's an increase from fewer than 10,000 in 1986, hundreds of thousands remain in non-productive situations waiting for their

chance to work.

"Since 1984, the number of working-age adults on Supplemental Security Insurance has increased from 4.2 million to 6.2 million, with the government's cash outlay increasing to \$48.3 billion in 1994. This cost is projected to increase to \$129 billion by the year 2005. We can't afford to continue this way.

"Supported employment can change the complexion of the disability rolls. After placement through supported employment, 52 percent of participants' *primary* income is their paycheck, rather than public assistance or disability benefits. These individuals, most of whom have never before worked in the competitive labor force, increased their annual earnings by an average of 490 percent. It's estimated that participants earn nearly \$600 million annually and pay more than \$100 million each year in federal, state, and local taxes. That's tax money paid into the budget rather than paid out in the form of disability checks and subsidized.

Legislators must change the flow of financial resources and reallocate funds from segregated day programs to integrated supported-employment programs. There is a practical reason for them to do so. The cost of placing an individual into competitive employment with support is \$3,219 compared to the \$8,005 annual cost of keeping an individual in a day program or sheltered workshop, and \$10,567 for group supported employment.

"In Virginia, nearly \$16 million was spent in 1998 for "work activity," while only \$5.5 million was spent to help

people enter real work. Yet the weekly earnings for people in supported employment were \$130 compared with \$61 for those in sheltered workshops. If the state converted only 25 percent of its spending from day programs to competitive employment opportunities, an additional 863 persons with severe disabilities could work -- at a savings to the state of \$2.5 million annually.

“Supported employment is a proven success. We can move people off disability rolls and into the competitive workforce — saving the government hundreds of thousands of dollars in the process. To expand the system in the next decade, we need legislators, employers, and private citizens to recognize and support an untapped resource — legions of people who want to work.”

Virginia’s emphasis on facility-based sheltered workshops

Virginia’s policies and rate structures favor sheltered workshops and group settings. Consider these “vital” statistics from the Office of Mental Retardation’s 1998 *Utilization Review*

- \$20.3 million was spent in Rehabilitation/Day Support Services for 2,163 persons. Average cost per person: \$9,405.
- \$16 million was spent in Sheltered Employment/Work Activity Centers for 2,093 persons. Average cost per person: \$7,683.
- \$6.6 million was spent in Group Employment services for 617 people. Average cost per person: \$10,499.

- \$5.5 million was spent on Supported employment services for 1,650 people. Average cost per person: \$3,312.

You might think that Virginia’s emphasis on congregate work and day support services is due to the level of disability of the people served. But think again. Previous studies have found that nearly two-thirds of the individuals served in sheltered workshops and day activity centers could benefit from supported employment services (Kregel, 1995).

And, if they were receiving supported employment services, they would almost surely be making better money. According to a report commissioned by the Virginia Board for People with Disabilities (2000), the mean hourly wage for supported employment is \$5.47 per hour, while the mean hourly wage for sheltered employment is \$2.42 per hour.

Universal physical accessibility

All people should have the right to move about freely in the community. A simple motto for our times, “To boldly go where everyone else has already been!”

Since its passage in 1990, the Americans With Disabilities Act (3) has given people with disabilities “a legal right to reasonable accomodation in many public facilities and private workplaces. Accommodations often include providing assistive technology devices (e.g., closed captioning or

telephonic devices for the deaf in hotel rooms) or modifying the existing built environment (e.g., providing wheelchair ramps at the entrances to public buildings) to make services accessible to users of assistive technology devices” (Russell et al., 1997).

Virginia operates an assistive technology service, but at this time no data are available on the current need for such services statewide.

Health care that promotes well being

People with disabilities deserve access to the best possible health care and psychological services. People need to feel well and have access to professionals who can help them to achieve physiological and psychological well-being. Particular attention should be paid to positive behavioral supports that preclude the necessity of crisis intervention services.

Good health is about more than a lack of disease. It is about a sense of “wellness.” One step in helping people who experience disabilities to achieve wellness is to ensure the provision of quality health care.

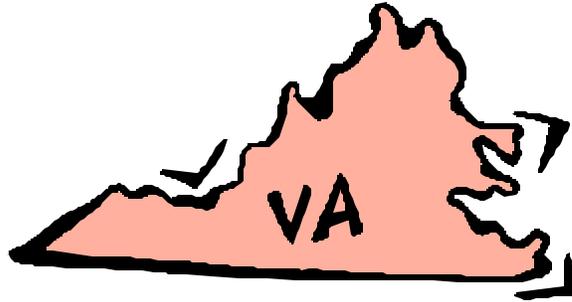
What constitutes quality health care for persons with disabilities is not well understood (Walsh and Kastner, 1999). We do know that people need access to qualified professionals in settings well equipped to address their health concerns. They need caregivers who understand the unique role that disability may play in their overall sense

of well-being. And they need professionals who understand that each person has a right to control his or her destiny, beginning with his or her own body.

Virginia has no comprehensive plan to monitor the health and well-being of citizens with disabilities. Needed is a periodic health risk assessment for people residing in our residential programs, and regional support services that help people to find good health care providers and monitor provider performance.

People who experience disabilities also need good mental health care and behavioral support services. Work is now underway in the Office of Mental Retardation to improve both mental health and behavioral support services. The Department has initiated a statewide training program to help caregivers identify the functions of an individual’s problem behaviors as the first step in developing meaningful behavior support plans.

11



Recommendations for Reform of Virginia's System

Virginia can be a better, more welcoming place for people with disabilities and their families. But we must act.

#1:

Include *all* people who experience developmental disabilities.

Believe it or not, policy makers in Virginia only count people with mental retardation. People experiencing autism and other developmental disabilities are not included in projections about future need. Ask our policy makers to be honest about the true number of people requiring support.

#2:

Increase funding for community-based services.

We believe that Virginians with disabilities and their families want the opportunity to live ordinary, every day lives. For this reason, we believe that the state of Virginia must increase funding for community-based supports. It is no longer viable for the General Assembly and Governor to ignore the needs of people with disabilities and their families, especially those on the waiting list, through incremental increases in funding in what is already one of the nation's most under-funded community support systems.

#3:
Work with the federal government to increase Virginia's rightful share of Medicaid funding.

The Medicaid Waiver program is one way in which states have increased funding for community-based program. Virginia currently ranks 41st in the nation in the use of the Medicaid Waiver funds and must develop a plan with the federal government to increase these funds.

#4:
Close Virginia's MR/DD facilities and divert resources — financial and personnel — to a regional community system.

Institutions are costly and ineffective. Virginia must make a commitment to helping all 1,870 people living in the state's 5 MR/DD facilities to return home to their home communities. The effort must assure that the resources — both financial and personnel — now supporting the operation of the facilities be diverted to community settings.

#6:

Guarantee a family for every child.

Families are the best places for children to grow up. Virginia must stop the practice of institutionalizing children and adopt pro-family policies that support families to raise their children at home. When it is not possible for a child to be raised at home, the state should work to find well-trained and well-compensated families to raise the child.

#7:

Assure a truly independent DRVD.

At present, Virginia's watchdog group to assure that the rights of Virginians with disabilities are protected is housed inside of the very government it is charged to oversee. The Department for the Rights of Virginians with disabilities should be conflict-free (as is the case in 40 other states)

#8:

Increase the number of children attending school in their neighborhoods in typical classrooms.

It is unacceptable that nearly 98% of Virginia's children should attend separate classrooms and schools from other children in their neighborhood. The Commonwealth should pilot inclusion in several school systems each year, identify critical systems barriers that stand in the way, develop strategies for full inclusion, and disseminate the information statewide.

#9:

Increase home ownership for people with disabilities.

The Commonwealth should join forces with the National Home of Your Own Alliance and funding sources such as the Fannie Mae Foundation to increase home ownership for people with disabilities. The state should develop a comprehensive plan to address the current need, strategies for overcoming system-level and personal financial obstacles, and benchmarks for achieving specified goals.

**#10:
Divert 25% of the resources used to fund sheltered employment and day activity centers to supported employment.**

As Paul Wehman, Director of the Rehabilitation Research and Training Center points out, diverting 25% of the resources currently spent in Virginia's day support programs and sheltered workshops would result in an additional 863 people working each year — at a savings to the state of \$2.5 million annually. Additionally, the Commonwealth should identify system and rate obstacles that encourage congregate day and work services and even the playing field so that providers who wish to offer supported employment and individualized day supports are not punished for doing so.

**#11:
Assess the level of need for assistive technology and health care supports in Virginia.**

At present, there is no data available regarding the assistive technology needs or health care issues of people who experience disabilities in the Commonwealth. The General Assembly should commission studies to ascertain need, develop a working plan for improving the availability of assistive technology and good health care and benchmarks for assessing success in achieving prescribed goals.

Footnotes

1. The Commonwealth Coalition's vision is adapted directly from Thomas Nerney et al.'s essay, "An affirmation of community: A revolution of vision and goals" (July, 1995). *Newsletter of the Association for Persons with Severe Handicaps* (July, 1995). Many thanks to the New Hampshire Self-Determination Project.
2. According to Braddock, Hemp, Parish, & Rizzolo (2000), "Community services fiscal effort is defined in terms of the annual volume of community MR/DD expenditures in a given state, from federal, state, and local sources, per \$1000 in aggregate statewide personal income. This metric reflects the proportion of a state's aggregate wealth committed to the financing of community MR/DD services and controls for state-to-state differences in state wealth (Bahl, 1982)."
3. Public Law 101-336. The Americans with Disabilities Act of 1990.
4. According to Braddock et al (2000), nursing home placements for people with mental retardation and developmental disabilities actually increased in Virginia while declining by 14% nationally.
5. According to the Comprehensive State Plan (p.8) and Braddock et al. (2000), the cost per person per day in a Virginia institution is \$231. Over a year (x 365 days), this amounts to \$84, 315 per person.

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