

“Meaning well is only half our duty; thinking right is the other, and equally important, half.” ~ Samuel Gridley Howe *“When positive images are attached to a party, that party is more likely to be first viewed positively, and then to be accorded or afforded positive roles.”* *“A person needs not only to be in but also of the community.” ~ Wolf Wolfensberger* *“Injustice anywhere is a threat to justice everywhere.” ~ Martin Luther King, Jr.* *“Overprotection can keep people from becoming all they could become. Many of our best achievements came the hard way. We took risks, fell flat, suffered, picked ourselves up, and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try.” ~ Robert Perske* *“Even people who practice oppression will generally idealize liberty; even people who practice deception will idealize truth.” ~ Wolf Wolfensberger* *“In the past, we found clever ways to build avoidance of risk into the lives of persons living with disabilities. We have learned that there can be healthy development in risk taking... and there can be crippling indignity in safety!” ~ Robert Perske*



The 2010
West Virginia
Developmental Disabilities Council
Legislative Statements

*The mission of the West Virginia
Developmental Disabilities Council
is to assure that West Virginia citizens
with developmental disabilities receive
the services, supports and other forms of assistance
they need to exercise self-determination and achieve
independence, productivity, integration
and inclusion in the community.*

LETTER FROM THE CHAIR

Dear Friends and Colleagues,

I am very pleased to share with you The 2010 West Virginia Developmental Disabilities Council Legislative Statements. The Council has spent much of the last year working closely with other disability groups and listening to the struggles of individuals with developmental disabilities and their families. We feel that the issues addressed in The 2010 Statements reflect the issues of utmost importance to West Virginia's citizens with developmental disabilities.

The West Virginia Developmental Disabilities Council is a federally funded State agency established in 1972 by Executive Order of the Governor of West Virginia in accordance with the provisions of Section 124 of the Developmental Disabilities Assistance and Bill of Rights Act of 2000. Of the 32 Members of the Council, over 60% are Gubernatorial appointees with developmental disabilities and family members. The remainder of the Council is comprised of State agency representatives and interested stakeholders.

As you will see, WV citizens with developmental disabilities and their families are very concerned with the availability of community supports and services, accessible quality health care, inclusive educational settings, and the availability of supported employment opportunities.

We ask that you carefully consider the thoughts and concerns of our citizens with developmental disabilities and their families as you examine legislation which may affect the quality and availability of services and supports.

Sincerely,

Jeannie Elkins

Jeannie Elkins, Chairperson

Jeannie Elkins lives with her family in Ashford, WV in Boone County. She is a former President of the Autism Society of WV, ASWV conference chair, and founder/president of the South Central WV Chapter of the Autism Society in 1995. Jeannie graduated from Partners In Policymaking (PIP) in 1998 and has since provided several presentations to PIP participants. She also serves on the Olmstead Advisory Council, the Advisory Council of the Medley/Hartley Advocacy Program, is an active member of the Fair Shake Network, and is the current Chairperson for the Advisory Board of the WV Autism Training Center. She has actively served on the Council since 1999 and was elected as Chairperson of the Council in April 2007.

Jeannie and her husband have one son, Alan age 26, who was diagnosed with autism in 1987 at age 4. In 2004, Alan was recognized for "outstanding achievement" by the Autism Society of WV. He has been employed by Boone Memorial Hospital in Madison, WV for five years and was their "employee of the month" during his second year at BMH. Besides having a job he loves, Alan likes to swim and go to concerts and movies with family or friends.



*Jeannie Elkins with her son, Alan
Ashford, WV
Boone County*



*Health and Wellth Program
of the Arc of the Mid-Ohio Valley
Parkersburg, WV
Wood County*

The Health & Wellth Program provides education and support to people with developmental disabilities about the importance of healthy lifestyles, including exercise, nutrition, and obtaining regular medical check-ups and health screenings. The project also works to improve access to community fitness and health related activities in several counties.

The Arc of the Mid-Ohio Valley was funded by the West Virginia Developmental Disabilities Council to implement the Health and Wellth program.

HEALTH

Access to quality health care and related supports has long been an issue for WV's citizens with developmental disabilities.

A health access survey conducted on behalf of the WV DD Council indicated that women with developmental disabilities often do not have access to many of the preventive health measures that the medical community and health insurance programs promote as vital, including mammograms, gynecological examinations, and dental and vision services.

Home and vehicle modifications are not covered services under the State Medicaid Plan. For those who receive services through the MR/DD Waiver, a small amount of funding is available on a yearly basis. However, the cost of such modifications often places them out of reach for many families.

Some individuals who acquire a traumatic brain injury during their developmental years may become eligible for services through the MR/DD Waiver program. Often those services do not provide the supports necessary to adequately meet their needs. Many individuals who have a traumatic brain injury do not have access to any supports at all.

Over the last several years, there has been a dangerous trend developing in our state where health related services and supports for our citizens with developmental disabilities have been severely reduced or eliminated.

HEALTH

The Council will continue to advocate for people with developmental disabilities and their families/guardians to have access to a comprehensive health care system that provides the most appropriate, effective, quality services. The Council supports legislation that promotes a healthier environment, and ensures better access to quality health care.

LEGISLATION CHECKLIST

Publicly funded health insurance programs will include adequate coverage of essential assistive technology, augmentative equipment, preventive and maintenance dental, and hearing and vision services.

People with developmental disabilities will have adequate and affordable home health care.

Home and vehicle adaptations will be included as a covered service through the State Medicaid Plan.

LEGISLATION CHECKLIST (continued)

Medical students and other health care professionals will receive information and training specific to developmental disabilities.

People who acquire brain and spinal cord injuries during their developmental years will receive appropriate medical, psychiatric, training, and therapeutic, and social supports.

The environment will be made safer by the removal or elimination of toxins (such as heavy metals and other chemicals) that are linked to poorer health and the onset of disabilities.

Protection of Life

The Council is concerned about the very lives of people who are generally perceived to have a lower social status, particularly those who have developmental disabilities. Therefore, we uphold the principle of applying excellent standards of care for such people. We reject limitations of treatment policies directed at people with impairments. Further, the Council does not support any legislation that seeks to hasten death by medical professionals who would be given the authority to judge the value of a person's life by invoking "quality of life" concerns.

Children's Health Insurance Program (SCHIP)

The Council will support efforts to allow families/guardians (including families/guardians of children with developmental disabilities) to gain access to health insurance coverage through a buy-in to SCHIP.

Study on Ceiling on Benefits for Currently Enrolled SCHIP Recipients

The Council supports an interim study on ceiling benefits for those currently enrolled in the SCHIP. There is concern that some children who have disabilities or serious illnesses are reaching the maximum amount of benefits and are no longer eligible for SCHIP or any other health care benefits.

Uniform Health Care Screening Tool for Children

The Council supports the expanded legislation of the uniform health care screening tool to all children beyond kindergarten age, including children with developmental disabilities, to ensure comprehensive and quality health information storage and access by designated health care providers.

Ventilator Care

The Council would support legislation intended to allow people with developmental disabilities who need ventilator assisted breathing to be able to receive such services in their homes and communities.

WV Medication Administration by Unlicensed Personnel Act

The Council supports improvements to the *WV Medication Administration by Unlicensed Personnel Act* and the associated Rules so that people with developmental disabilities can receive the supports they need to keep them safe and healthy while increasing flexibility in the self-administration/direction of medications.

Patient Centered Medical Home

The Council supports the implementation of a patient centered medical home concept; especially to drive improvement in quality and continuity of care through the integration of Health Information Technology (HIT).



*AJ Moss
St. Albans, WV
Kanawha County*

AJ is a 2009 graduate of St. Albans High School in Kanawha County. One of his favorite classes in high school was the “Work Exploration Program.” By participating in this program, he was able to try a variety of different jobs in his community. As graduation approached, AJ was eager to obtain paid and meaningful employment.

Community Access, Inc. is funded by the WV Developmental Disabilities Council to implement the Student Transition to Employment (STEP) program. This unique initiative trains high school level personnel to become vendors with the WV Division of Rehabilitation Services and work with transitioning high school students after graduation. Many of the participating students would not otherwise receive these supportive adult services.

In AJ’s case, the STEP program enabled his job coach to assist him with job searches, prepare him for job interviews, and provide on the job training after he was hired. AJ is employed at Charleston General Hospital as a Dietary Technician. He is an enthusiastic worker who loves working in a hospital setting.

While AJ is happy with his current position, his dream job is a hospital security guard. As openings become available, and with the help of his job coach and co-workers, he will be given the assistance and support that he requires to become not only a successful worker, but an individual who pursues his dreams.

EMPLOYMENT

People with disabilities have been denied opportunities to work, especially people who have developmental disabilities. Nineteen years after the passage of the Americans with Disabilities Act, the employment rate for people with developmental disabilities has only minimally improved. People with disabilities still remain an untapped source for employers seeking new employees. It is estimated that less than 22% of working age WV citizens with developmental disabilities are employed. The national average is close to 40%. We need to close the gap and work toward becoming a leader in employing people with developmental disabilities.

Real work for real pay is important to everyone. It means having choices and making decisions, getting paid, living independently, contributing to our communities, and connecting with other people. Working is an important part of defining who we are.

One way that many individuals with developmental and other disabilities find and maintain a job is through supported employment. Supported employment allows individuals to obtain jobs that interest them in the competitive job market and work in integrated work settings at competitive wages. Supported employment allows individuals to become more independent, and it encourages community integration.

Supported employment provides on-going support services to the individual with developmental and other disabilities. These supports can include intensive on-the-job training, assistive/adaptive technology, personal care attendants, transportation, or other individualized supports that allow the individual to obtain and maintain employment. Supported employment services are as individualized and unique as the employee. Often, co-workers provide natural supports to the individual as they begin to understand what kind of support is needed and as they develop a relationship based on friendship and respect.

Recent studies indicate that providing on-going support services for people with severe disabilities significantly increases their rates for employment retention. Approximately 58% of those in supported employment retained competitive employment compared to 21% in traditional programs.

EMPLOYMENT

It is estimated that 32,703 West Virginia citizens have a developmental disability. People with developmental disabilities are an untapped pool for those seeking employees; less than 22% of working age people with developmental disabilities are employed; less than 7% of working age people with significant developmental disabilities are employed. Competitive, Supported, Customized, and Self Employment enable people with developmental disabilities to work, pay taxes, and contribute to society.

The Council will support legislation that ensures integrated employment for people with developmental disabilities with competitive wages, and emphasizes full time and part time employment.

LEGISLATION CHECKLIST

People with developmental disabilities must have health care services available to them when gainfully employed.

People with developmental disabilities will have the opportunity to receive job services from the provider of their choice.

People with developmental disabilities will have the opportunity to participate in customized employment that is based on individualized interest, strengths, and needs and may include job carving, self employment or entrepreneurial initiatives.

People with developmental disabilities will have the opportunity to participate in supported employment that focuses on a person's abilities and provides job coaching and other supports the individual needs to be successful on a long-term basis.

People with developmental disabilities will have the opportunity to access transportation and other employment supports.

People with developmental disabilities and their families/guardians will have timely access to appeals, grievance mechanisms, and safeguards.

Supported Employment

Within the Department of Health and Human Resources, Bureau for Behavioral Health and Health Facilities: The Council supports the maintenance of the current funding level of \$600,000 for Supported Employment.



*Bob Cain
Paden City, WV
Wetzel County*

Bob Cain lives in Paden City, WV in Wetzel County. He graduated from Partners in Policymaking in 2006. Bob was appointed by the Governor to the WV Developmental Disabilities Council in 2005 and currently serves as Vice-Chair of the Council. Bob works at REM West Virginia and is described as “very professional and respectful” and an “asset to [the] company.”

Through the use of his earnings, the MR/DD Waiver services and other community supports, he was able to rent a home and has been living there, with a friend, for the last seven years. Bob, like everyone, values his independence and inclusion in everyday life in his community. When asked about his personal assistants and community supports, he stated, “They are there for me. If I need assistance, they help me. [They have] allowed me to get where I am today.”

COMMUNITY SUPPORTS

People who have developmental disabilities, just like everyone else, want to lead typical, healthy, productive, and full lives in communities of their choice. People with developmental disabilities want control over their own lives, freedom from abuse and neglect, and choices in who provides services and supports. They want to be given responsibility to wisely use resources for their own support.

WV’s service systems have strong biases toward segregated, institutional care such as nursing homes and group living settings rather than toward supporting people in their own homes and communities. The State spends much more money per person on out-of-date, institutional models. One of WV’s better programs for supporting people to live in the community is the MR/DD Waiver. However, most people with developmental disabilities receive little, if any, support or program services. This can result in people being forced into unnecessary and expensive institutional care. WV needs to “rebalance” its resources to better serve its citizens while being more economical.

COMMUNITY SUPPORTS

The Council will advocate against the further development of segregated, congregate service settings. The Council will support legislation that ensures adequate funding for services that support people with developmental disabilities to live in their own homes and neighborhoods, eliminates the institutional bias, and ensures rebalancing of Medicaid and other public funding.

LEGISLATION CHECKLIST

People with developmental disabilities will have the supports and services in their home communities where they live, learn, work and play. Those supports and services will be provided by a stable and well trained workforce.

People with developmental disabilities and their families/guardians will be able to choose who provides service coordination to them.

People with developmental disabilities and their families/guardians will control and direct the resources available to them.

Olmstead Implementation

The Council will advocate for full implementation of the WV Olmstead Plan as approved by the Governor in October 2005. This is WV's plan to carry out the *Olmstead* decision rendered by the US Supreme Court in June 1999. The decision mandates that people with disabilities have the right to receive state administered services, programs, and activities "in the most integrated settings." People with disabilities are to be given the opportunity to leave nursing homes, long term care facilities, ICFs/MR and other group homes, and state psychiatric hospitals, and to be supported to live integrated lives in communities around the State.

Public Funding

The Council will continue to advocate for the restoration of and increases in State and Federal funding necessary to maintain or enhance critical support services that allow people with developmental disabilities to live, learn, work, and play in the community. Of particular concern are the following programs and initiatives:

- MR/DD Waiver
- Ron Yost Personal Assistance Services Act (RYPAS)
- Independent Living Services
- Enhanced funding for autism services
- DRS Community-Based Services Development Initiative
- DD Family Support Program
- Aged and Disabled Waiver
- DRS Long-Term Attendant Care Program
- TBI/SCI Initiative
- Birth-to-Three Program

The Council will advocate for a Resolution to study concerns about the MR/DD Home and Community Based Waiver Program's policies/implementations. The Council will further advocate that individuals and families/guardians who rely on these funding sources gain greater control over the design and delivery of the related services. The Council supports the re-direction of Medicaid and other funding sources that give individuals with developmental disabilities authority over dollars to be used for their support. The Council will advocate for customized and individualized supports for those who continue to wait for services. The Council will advocate for implementation of a Money Follows the Person initiative and any legislation that supports that initiative.

Unserved/Underserved

The Council supports legislation that strengthens safeguards for people with developmental disabilities who do not qualify for or are being denied Medicaid MR/DD Waiver, Aged and Disabled Waiver, and other relevant publicly funded community supports. People with developmental disabilities must be protected from abuse, neglect, and preventable death, and have access to essential services and supports.

Behavioral Health Licensure Regulations

The Council would oppose any changes to the behavioral health licensure rules that would cause persons' private homes to be designated or treated like facilities. Furthermore, the Council would oppose any changes or interpretations that would cause family members/guardians who provide services to their relative who is a participant of publicly funded support services to be considered employees of service agencies for this purpose.

LEGISLATION CHECKLIST

People with developmental disabilities and their families will control and direct the resources available to them.

People with developmental disabilities will not be forced to live or work in segregated facilities.

People with developmental disabilities will live free from abuse, neglect, injuries, and preventable death.

People with developmental disabilities and their families/guardians will be able to access providers that assure personnel are adequately trained and qualified.



Anna Smith
Belleville, WV
Wood County

“I love reading, typing on the computer, and my teacher, Mrs. Evans,” says Anna Smith, a first-grader at Lubeck Elementary in Wood County. Thanks to her school’s practice of inclusion, Anna has plenty of friends to choose from, including two classmates without disabilities who attended her birthday sleepover. She is well-known by everyone – receiving continual “Hi Anna” greetings, with multiple hugs and pats on the back, as she walks through the hallways everyday. “We don’t want them to be sent to another school or taught in a different classroom...that just isn’t fair,” says Olivia, 10, Anna’s older sister. “My friends think kids with disabilities should be treated the same as everyone else,” she adds. It’s this mindset of acceptance that enables Anna to be included with her typically-developing peers outside of school-in community activities-like taking dance classes, being in 4-H, showing sheep at the fair, and actively participating in children’s church.

EDUCATION

Inclusion is a right. The Individuals with Disabilities Education Act (IDEA) requires states to provide a free and appropriate public education in the least restrictive environment. In WV, only about 50% of students with developmental disabilities are enrolled in full-time regular education classrooms. Children with severe developmental disabilities are the least likely to be included in regular classes. Most frequently they are placed in self-contained classrooms. Often, the only interaction these children have with their non-disabled peers is in the lunchroom.

Children with developmental disabilities should be attending neighborhood schools along with their brothers, sisters, and peers. Including students with developmental disabilities in regular classrooms in their neighborhood schools and providing them with the necessary supports enhances their opportunity for success.

Inclusion has been receiving attention not only from national and local education systems, but also in popular media. Opposition to inclusive educational settings is frequently based on the erroneous assumption that inclusion is not beneficial to children without disabilities. Research has shown quite the opposite. All children benefit from inclusive classrooms. Children educated in inclusive settings form more meaningful and long-lasting friendships, they are more aware of the needs of others and have an increased understanding and acceptance of diversity. They have a higher sense of self esteem and have more strongly developed moral and ethical principles. Additionally, skill acquisition is enhanced for all students through increased opportunities to master concepts by practicing and teaching others, thus creating improved academic outcomes. Schools such as A.I. Boreman in Tyler County have shown that students without disabilities can actually perform higher academically in an inclusive environment.

The quality of educational services and commitment to inclusion in WV varies considerably across counties, schools, and classrooms. It is largely dependent on the leadership of local administrators, the attitudes and training of regular and “special” educators, and the involvement of informed parents. All children have the right to be educated by highly qualified teachers who invest their time and skills to provide the highest quality education possible.

EDUCATION

The Council will advocate against the further development of segregated educational settings. The Council will support legislation that ensures equal opportunities for students with developmental disabilities to be educated in regular education classrooms, in their home school, and in other inclusive educational settings.

LEGISLATION CHECKLIST

All students with developmental disabilities will get a free and appropriate public education.

Students with developmental disabilities will not be excluded from regular classes with their non-disabled peers.

There will be a full implementation of the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, the Americans with Disabilities Act (ADA), and other related disability laws.

Students with developmental disabilities will have the opportunity to participate in transitional school to work activities, and have access to community adult education and training.

Students with developmental disabilities will be protected against restraints and seclusion, as well as segregation, expulsion, or other punishment as a result of uniform discipline policies.

Education Funding

The Council will monitor the FY 2010 school aid funding formula for public schools and other funding for higher education services for students with developmental disabilities.

No Child Left Behind

The Council will monitor the West Virginia Department of Education's implementation of the federal *No Child Left Behind Act* and any State legislation pertaining to the Act for any possible adverse effects on WV's children who have developmental disabilities.

Gracie, a kindergartener at Milton Elementary in Cabell County, was born with a developmental disability. After receiving Birth to Three services, her mother advocated for her to be completely included in preschool and general education. She receives all services and supports in her general education classroom. Although the curriculum is modified, it is age appropriate and she is taught with her peers. Because Gracie has learned, eaten, and played with her peers, she attends birthday parties and other activities outside of school with her classmates. It has allowed Gracie the opportunity to be accepted by her peers for the person she is and not the disability she has. The faculty was hesitant at first, but because they have thought outside of the box and worked as a team this has been a positive experience for all, and has given Gracie and those around her the opportunity to learn.



*Gracie Black
Milton, WV
Cabell County*



110 Stockton Street, Charleston, WV 25312

304-558-0416 (phone), 304-558-0941 (fax), 304-558-2376 (TDD)

www.wvddc.org