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WV Developmental Disabilities Council

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The 2011 West Virginia Developmental Disabilities Council

# Legislative Statements



The mission of the West Virginia Developmental Disabilities Council is to assure that West Virginians with developmental disabilities receive the services, supports, and opportunities they need to achieve independence, productivity, integration, and inclusion into the community.

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, responsive to their sensory and learning style needs.

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), the Carl Lee Perkins Act, State Regulations, and other related disability laws and parents will receive appropriate training in these so they can advocate effectively on behalf of their child.

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.

Students with developmental disabilities will have access to appropriate training and higher education which helps them obtain competitive employment.

#### **Education Funding**

The Council will monitor the FY 2011 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.



Justin Daniels Delbarton, WV Mingo County

Justin, a senior at Burch High School, is in a program that allows him to develop the skill set he <u>NEEDS</u> to obtain a job he WANTS.

Through the Career and Technical Education (CTE) Pilot Project, he is able to attend the Auto Service Technology Program at Mingo Career and Technical Center and obtain an Individual Work Readiness Certificate. The Certificate requires competencies needed to meet industry standards while allowing person-centered and focused skills acquisition.

Vocational Services, Inc. (VSI), in cooperation with the WV Department of Education, developed the project to ensure students with developmental disabilities, who are not typically enrolled in or referred to CTE programs, are able to do so with their peers. In the first year of this DD Council funded project, 12 students have participated or enrolled.

With a variety of work skills and the opportunity to engage in work exploration, Justin will be equipped to acquire full-time employment he enjoys and succeed in.

# **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.

# LETTER FROM THE CHAIR Jeannie Elkins lives with her family in Ashford, WV in Boone County.

Dear Friends and Colleagues,

I am very pleased to share with you The 2011 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 2011 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 Elkino

Jeannie Elkins, Chairperson

Jeannie Elkins lives with her family 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. since becoming Chair she has served as committee member and Chair of the Information and Assistance Technical Centers (ITAC) Technical Assistance Institute in Washington DC and has also worked with the Administration on Developmental Disabilities on the MTARS for the Indiana DDC and the Alaska DDC.

Jeannie and her husband have one son, Alan age 27, 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 six 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.



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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 ID/DD Waiver (formerly known as 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 ID/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.

#### **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/DD (formerly known as ICFs/MR) and other group homes, and 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:

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

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 ID/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 licensures rules that would cause persons' private homes to be designated or treated like facilities.

## Guardianship

The Council will advocate for clarification of Guardianship laws to permit the pursuit of limited guardianship in all areas of the State, and to allow for family members who are guardians to be providers of service under the ID/DD Waiver program.

#### LEGISLATION CHECKLIST

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.



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."

Bob, like everyone, values his independence and inclusion in everyday life in his community. Through the use of his earnings, the ID/DD Waiver (formerly known as 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 eight years. 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**

The Council will advocate against the further development of segregated, congregate service settings. The Council will support legislation that invests 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 must have 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.

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# **COMMUNITY SUPPORTS**

People who have developmental disabilities, like everyone else, want to lead typical, healthy, productive, and full lives in communities of their choice. People with developmental disabilities want <u>control</u> over their own lives, <u>freedom</u> from abuse and neglect, and <u>choices</u> in who provides services and supports. They want to be given <u>responsibility</u> 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 ID/DD Waiver (formerly known as 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.

## 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 buyin to SCHIP.

#### **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.

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Jimmy Manno Grafton, WV Taylor County

Do you love your job and enjoy going to work every day? Jimmy Manno does! Jimmo has been employed at the Grafton Farm & Home Supply for over a year. He enjoys his job and socializing with his co-workers, customers, and store owners, Bob and Robin Sharp. Bob reported that **the job is "a good fit for Jimmy, his personality and job skills have been an asset."** Jimmy is a hard worker and enjoys staying busy. When asked if he would like to do anything different he responded, "No, this is my job."

With funding from the West Virginia Developmental Disabilities Council, Job Squad, Inc. in Bridgeport, WV assisted Jimmy in obtaining paid employment using creative employment finance strategies. Jimmy used money from a life insurance policy to negotiate paid employment by purchasing a fork lift, which saved the owners thousands of dollars in operating costs. This enabled the owners to be able to afford to hire another worker – Jimmy!

# **EMPLOYMENT**

People with disabilities have been denied opportunities to work, especially people who have developmental disabilities. Twenty 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.

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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 34,000 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.

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