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WV Developmental Disabilities Council

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# The 2012 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 individual sensory and learning styles.

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 be protected against restraints and seclusion, as well as segregation, expulsion, or other inappropriate punishment as a result of uniform discipline policies.

Educators will be provided more training and technical assistance on inclusive education and diverse learning styles.

Parents will receive appropriate training and supports so they can advocate effectively on behalf of their child.

Students with developmental disabilities and their parents will receive additional supports/training and planning at all stages of transition.

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 have access to appropriate training and higher education which helps them obtain competitive employment.

### **Education Funding**

The Council will monitor the FY 2012 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.





*Kouper Elliott  
Moundsville, WV  
Marshall County*

*Kouper, a kindergartener at McMinch Elementary School in Marshall Co, WV was diagnosed with Hypotonic Cerebral Palsy at eighteen months and with autism two years later. After receiving WV Birth to Three services for two and a half years, he transitioned to services that did not help him progress. His mother advocated for him to receive more specialized and inclusive services.*

*Although inclusive education has been difficult at times, Kouper is learning from his peers at the same time they are learning from and accepting him. During this process, his teachers are learning how to better teach Kouper, other students with disabilities, as well as students without disabilities.*

*Kouper is progressing daily and like many boy his age, he enjoys his iPod, computer, wrestling with his brother, and McDonalds' cheeseburgers.*

## 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 67% of students with disabilities and 30% 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.

Students with developmental disabilities have a right to positive behavior interventions that are planned and carried out by qualified staff. Additionally, the WV Department of Education must establish minimum, nationally validated, safety standards and procedures concerning the use of restraint and seclusion in the public schools. All forms of aversive consequences to challenging behavior must be prohibited.

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

Dear Friends and Associates,

I wish to present to you The 2012 West Virginia Developmental Disabilities Council Legislative Statements. The Members of our Council have worked diligently with other disability groups to learn the concerns of individuals with developmental disabilities and their families, and then to communicate those needs accurately to you. The issues that we target in The 2012 Statements are those of most significance to West Virginia's citizens with developmental disabilities.

The West Virginia Developmental Disabilities Council is a 32 Member Council where over 60% of the Members are gubernatorial appointees with developmental disabilities and family members. The remainder of the Council is comprised of representatives from State agencies and interested stakeholders. We are 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.

A great deal of time was spent traveling around the state to assure input was received from those who may not necessarily have a chance for their voices to be heard. After collecting data hearing from the citizens of West Virginia, the Council came together with essential areas of concern. As you will see, West Virginians with developmental disabilities and their families are very concerned with the availability of supports and services within their communities, accessible quality health care, inclusive education, and participation in meaningful supported employment.

As legislation is brought before you for action this year, please regard the ideas and feelings of West Virginia citizens with developmental disabilities and their families. We ask that you consider the impact of the quality and availability of services and supports for these individuals in your decision making process. Thank you for your time and consideration in these matters.

Sincerely,

Stacey Thomas, Chairperson

*Stacey Thomas lives with her family in Hedgesville, WV in Berkeley County. She is the coordinator of the Eastern Panhandle Autism Group and helps many families advocate for needed services for their family members and friends. Stacey graduated from Partners in Policymaking (PIP) in 2009 and has since become a gubernatorial appointee of the WV Developmental Disabilities Council. Since her appointment in 2010, she has actively served on the Council and was elected as Chairperson of the Council in April 2011. She also serves on the Executive Committee and has visited Washington D.C. to meet with our State's Representatives.*

*Stacey and her husband have three sons, Dylan, age 12, Aidan, age 9, who was diagnosed with autism at age 2, and Carsen, age 8. They enjoy helping others and spending time with family and friends*





*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

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.

# 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. Although recent development of the Traumatic Brain Injury Home and Community Based Waiver is a step in the right direction, the very limiting eligibility criteria will continue to result in many individuals who have a traumatic brain injury not having 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.

## 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/ID (formerly known as ICFs/MR) 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)      | ▪ Birth-to-Three program               |
| ▪ Independent Living Services                            | ▪ Aged and Disabled Waiver             |
| ▪ DRS Community-Based Services Development Initiative    | ▪ DRS Long-Term Attendant Care Program |
| ▪ Traumatic Brain Injury Home and Community Based Waiver |  |

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.

## 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.



Angela Ramsey  
Parkersburg, WV  
Wood County



*Angie values the opportunity to be included in activities in her community that everyone else gets to participate in throughout everyday life. When asked about her personal assistants and community supports, she replied, “Without them I would not be able to do the things that I love to do, like shopping for clothes and jewelry, going to the movies, and everything else I get to. “If I need help, they try everything they can to make it work and take me where I want to go.” Her ability to access I/DD Waiver services and other community supports enables Angie to live in a home that she shares with two roommates, attend church every Sunday, improve her reading skills by attending an Adult Learning class several times a week, be involved in volunteer and recreational activities of her choice, and participate in conferences and meetings that allow her to build on her skills as a self-advocate.*

*Angela Ramsey was awarded the 2011 Self-Advocate of the Year Award for People First of the Mid-Ohio Valley, and has held an office in her local chapter for the past three years. Angie is the oldest of 4 grandkids and helped raise her younger cousins. Angie is described by those who know her as “very determined,” as “one of the kindest people I know,” and as someone who “has a smile that will light up a room”.*

## 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.

## 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 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 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)

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

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.

## 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.



Elizabeth Field  
Morgantown, WV  
Monongalia County

*Elizabeth Field's varied educational and work experiences have helped her obtain a job she truly enjoys and is very good at!*

*Prior to graduating from University High School in 2010, Elizabeth earned a certificate in the General Foods Program at Monongalia County Technical Education Center (MTEC). She later expressed an interest in working with children and was then able to obtain work experience through the School Transition to Employment Project (STEP) at Pleasant Day Child Care and the Morgantown Early Learning Facility. After high school, Elizabeth returned to MTEC to attend the Care and Guidance of Children class and obtained a State-Level Apprenticeship Child Development Specialist Certification.*

*Elizabeth is now working as a teacher's assistant at the Morgantown Early Learning Facility. She teaches a lesson, supervises children, and prepares children for their naps. Though her educational and work experiences were made possible through the coordinated efforts of Vocational Services, Inc., Elizabeth was referred to and attended the MTEC, which is not always typical referral for students with developmental and other disabilities. With the much needed adoption of the Individual Work Readiness Certification (IWRC), where students can be recognized for mastery of particular competencies rather than required to learn and master all competencies and receive a standard certificate, more students with developmental disabilities will be able to obtain needed training and certification to obtain valued and fairly waged jobs.*

## 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.

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 valued, 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.