

**The West Virginia
Developmental
Disabilities Council's mission
is to assure that
West Virginians 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 Legislators, Friends, and Associates:

I am happy to share with you the West Virginia Developmental Disabilities Council 2014 Legislative Statements.

The West Virginia Developmental Disabilities Council (DD Council) is comprised of 32 Members, 20 of whom are citizens with developmental disabilities and family members appointed by the Governor. Two at-large Members representing local and non-governmental agencies or private, non-profit groups concerned with services for people with developmental disabilities are also gubernatorial appointments. The remaining Members are representatives from State agencies charged with the provision of services to people with developmental disabilities.

The DD Council is a federally funded state agency which was established in 1972 by Executive Order of the Governor in accordance with the provisions of Section 124 of the *Developmental Disabilities Assistance and Bill of Rights Act*.

Issues that are important to most all citizens, such as education, employment, and health care, are also important to our citizens with developmental disabilities and their family members. In this document we have tried to provide background information on several

specific issues that particularly affect people with developmental disabilities, followed by a checklist of points to consider when analyzing legislation during this session.

As you review legislation for action this year, we ask that you consider the needs and concerns of West Virginia citizens with developmental disabilities and the impact of proposed legislation on the quality and availability of services and supports.

Our staff will be happy to discuss any questions or concerns you may have on any of these issues that arise.

Thank you for your time and consideration.

Sincerely,

A handwritten signature in black ink that reads "Stacey Thomas". The signature is written in a cursive, flowing style.

Stacey Thomas, Chairperson

HEALTH

Access to quality, individualized health care and related supports has long been an issue for WV's citizens with developmental disabilities. The 2011 DHHS *National Healthcare Quality Report* ranked WV 50 of 51 on the quality of the states' healthcare services.

People 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 dental cleanings and exams, mammograms, and gynecological examinations.

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

People who acquire a traumatic brain injury during their developmental years (0-21) may become eligible for services through the I/DD Waiver program. Often those services do not provide the supports necessary to adequately meet their needs. Although the Traumatic Brain Injury Home

and Community Based Waiver is underfunded it is a step in the right direction.

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 and effective services of the highest quality. The Council supports legislation that promotes a healthier environment, and ensures better access to quality, patient-centered health care statewide.

SAFEGUARDING VULNERABLE PEOPLE

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 medical care for people with developmental disabilities. We reject limitations of treatment policies directed at people with impairments. Further, the Council will safeguard against policies that seek to hasten death by medical professionals who have the authority to judge the value of a person's life by invoking "quality of life" concerns.

RESPIRATORY CARE

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

DENTAL CARE

The Council will support legislation that provides dental care for adults. Currently Medicaid covers dental care for enrolled children. Covered dental services for enrolled adults 21 years of age and older are limited to emergent procedures to treat fractures, reduce pain or eliminate infection. West Virginia leads the nation in loss of permanent teeth. The Council's concern is that poor oral health leads to other health issues. Poor oral health can also hinder the way a person is perceived, particularly individuals with developmental disabilities.

LEGISLATION CHECKLIST: HEALTH

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

Publicly funded health insurance programs will provide reasonable and adequate reimbursement for necessities such as tube feeding formulas and other supplies.

People with developmental disabilities will have patient-centered adequate and affordable health care in their own homes.

Home and vehicle adaptations will be included as a covered service through the Medicaid State 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, therapeutic, and social supports.

EMPLOYMENT

People with disabilities have been denied opportunities for real community work, especially people who have developmental disabilities. In the twenty-three years since the passage of the *Americans with Disabilities Act*, the employment rate for working age adults with developmental disabilities has not improved. It is estimated that

less than 15% of adults with developmental disabilities in WV are working in regular, inclusive employment settings with co-workers without disabilities. Responsible State agencies in West Virginia must improve and expand job preparation and supports for all people with developmental disabilities. West Virginia needs to adopt policies that support employment in the general workforce as the first option for working aged adults 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. The work we do is an important part of defining who we are.

Supported employment encourages people to become more independent and integrated in their communities. It provides on-going support services to people with developmental and other disabilities. These supports can include minimal on-the-job training, assistive/adaptive technology, personal care assistants, transportation, or other individualized supports that allow a person to obtain and maintain employment. Supported employment services are as individualized and unique as the employee. Often, co-workers provide natural supports

to the person as they begin to understand what kind of support is needed and as they develop a relationship based on familiarity and respect. Recent studies indicate that providing on-going support services for people with severe disabilities significantly increases their rates for employment retention. It is estimated that there are 20,000 West Virginia citizens with developmental disabilities who are 16-64 years of age. People with developmental disabilities are an untapped pool of workers for employers. Competitive, supported, customized, and self-employment approaches enable people with developmental disabilities to work, pay taxes, and contribute to society.

A recent study found that WV has a low enrollment of people with disabilities who participate in federal work incentive programs such as the Medicaid Buy-In program (M-WIN), Plan for Achieving Self-Support (PASS), and the Impairment-Related Work Expenses (IRWE) program. Those federal programs allow people with disabilities to earn a living wage and not lose benefits.

EMPLOYMENT FIRST INITIATIVE

The Council will support legislation that promotes valued, integrated employment with competitive wages as the first and preferred out-

come for people with developmental disabilities. The Council asserts that employment is an outcome, not a program.

LEGISLATION CHECKLIST: EMPLOYMENT

People with developmental disabilities will have health care services available to them when they become 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 interests, 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 the person's abilities, and provides job coaching and other supports the person needs to be successful on a long-term basis.

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

COMMUNITY SUPPORTS

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

Often people with developmental disabilities are unnecessarily deprived of their rights because a guardian is appointed for them. With some exceptions, people with developmental disabilities can be supported to make decisions without being stripped of their civil rights. In WV, the legal counsel appointed to represent the best interest of the alleged protected person is required to, among other things, take all steps to limit the scope of guardianship to the individual's actual needs and make all arguments to limit the amount of the intervention. Courts are required to take into consideration the availability of less restrictive alternatives (medical powers of attorney, advance directives, surrogate decision-makers, etc.). In reality, if someone applies for guardian- ship of

a person with developmental disabilities, more likely than not a guardian will be appointed. And furthermore, courts in many areas of the state do not allow for limitations to guardianship as required by law.

West Virginia’s long-term care and behavioral health care service systems are biased 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 more money on out-of-date, institutional models. One of West Virginia’s better programs for supporting people to live in the community is the I/DD Waiver. People who are denied I/DD Waiver services receive little in the way of alternative supports. Those who do qualify are put on a managed enrollment list which currently has over 700 people waiting. People who are eligible but waiting receive very few supports or services. This can result in people having no options other than unnecessary and expensive institutional care. West Virginia 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, congregated

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 the rebalancing of Medicaid and other public funding.

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 comply with 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/IID (formerly known as ICFs/MR), other group homes, and psychiatric hospitals, and to be supported to live integrated lives in communities around the state.

HOUSING

The Council will advocate for decent, safe, and accessible housing for people with develop-

mental disabilities in neighborhoods of their choice by accessing programs such as the Section 8 Federal Housing Voucher program.

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 fully participate in the community. The Council will support legislation that allows for the re-direction of Medicaid and other funding from segregated facilities and programs to integrated community services and supports.

UNSERVED/UNDERSERVED

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

GUARDIANSHIP

The Council will advocate for the use of alternatives to guardianship for people with developmental disabilities. The Council also advocates for the training of appointed counsel, mental hygiene commissioners, and judges on the necessity to explore limitations to guardianship so that the appointment of full guardianship would be used only as a means of last resort, and rarely.

BEHAVIORAL HEALTH LICENSURE REGULATIONS

The Council would oppose any changes to licensure and other rules that would cause persons' private homes to be designated or treated like facilities.

LEGISLATION CHECKLIST: COMMUNITY SUPPORTS

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

People with developmental disabilities will be able to choose who provides service coordination to them.

People with developmental disabilities 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, exploitation, sexual assault, and preventable death.

People with developmental disabilities will be able to access providers that assure personnel are expertly trained and qualified.

EDUCATION

The Individuals with Disabilities Education Act (IDEA) requires states to provide a free and appropriate public education in the least restrictive environment. In West Virginia, 71% of students with developmental disabilities are not enrolled in full-time regular classes (at least 80% of the school day). Often, the only interaction they have with their non-disabled peers is in the lunch

room. The graduation rate for students with disabilities is about 10% less than the rate for all students.

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 physical restraints in the public schools. Students must be protected from all forms of aversive treatment due to challenging behavior (as provided in law).

Children with developmental disabilities should attend 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 opportunities 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, 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 West Virginia varies considerably across counties, schools, and classrooms. It is largely dependent on the leadership of local administrators, the attitudes and training of all educators, and the involvement of informed parents. All children need challenge to grow. Children who have delayed development need to be educated with children who are more skilled and can serve as positive peer role models.

A recent project of the WV DD Council has shown that students with developmental disabilities can learn a trade in a Career Technical Education program. This project was a collaborative initiative with the WV Department of Education that has created a

new certificate, the Individualized Work Readiness Certificate (IWRC).

EDUCATION

The Council will support any legislation that strengthens the flexibility of Career Technical Education programs to modify courses so that more students with developmental disabilities become eligible to earn certificates.

LEGISLATION CHECKLIST: EDUCATION

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)*, *Elementary Secondary Education Act (ESEA)*, formerly known as *No Child Left Behind Act (NCLB)*, 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 restraint, segregation, expulsion, or other inappropriate punishment due to their disability.

Students with developmental disabilities will be free from bullying and harassment while receiving a public education.

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

Parents will receive appropriate training and support in order to advocate effectively on behalf of their children.

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

Students with severe developmental disabilities will have the opportunity to participate in transitional school to work activities, and have access to career technical education.

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

Students with developmental disabilities will be

educated by appropriately trained teachers who have high expectations of them and who will use effective teaching methods to provide a strong and challenging educational curriculum.

Graduation from high school with a regular diploma (rather than a modified diploma) will be the first and most desired outcome for students with developmental disabilities.

Students with developmental disabilities will have appropriately trained aides when aides are needed.