

**NEVADA GOVERNOR’S COUNCIL ON**

**DEVELOPMENTAL DISABILITIES**

[406 East Second Street, Carson City, NV 89701](https://www.google.com/maps/place/406+E+2nd+St,+Carson+City,+NV+89701,+USA/@39.163589,-119.7640124,17z/data=!3m1!4b1!4m6!3m5!1s0x80990a9fa13337bf:0x24bc7ed1beb52ac2!8m2!3d39.163589!4d-119.7640124!16s%2Fg%2F11c1kjfcqn?entry=ttu)

**Phone:** 775-684-8619

**Fax:** 775-684-8626

**Website:**[www.nevadaddcouncil.org](http://www.nevadaddcouncil.org/)

**Facebook:** [www.facebook.com/NVGCDD/](http://www.facebook.com/NVGCDD/)

**Twitter:**[www.x.com/NVGCDD](http://www.x.com/NVGCDD)

**COUNCIL MEMBER HANDBOOK**

**Message from the Executive Director**

We hope this handbook is helpful to you as you begin your journey as a Council member and as a tool to use throughout your time with the Council. Please don’t hesitate to reach out to staff or other members of the Council with questions and NEVER be afraid to speak up during meetings if you don’t understand something. We are all here to help you and make your time with the Council successful and remind you to “Speak Your Mind Even If Your Voice Shakes”!

Sincerely,

Catherine Nielsen, Executive Director

**Council Staff and Contact Information**

Catherine Nielsen, Executive Director, 7756848620, [cmnielsen@dhhs.nv.gov](mailto:cmnielsen@dhhs.nv.gov)

Rebecca Ortiz, Executive Assistant, 7756848619, [Rortiz@dhhs.nv.gov](mailto:Rortiz@dhhs.nv.gov)

Marisol Rivas, Project’s Manager, 7756848622, [mrivas@dhhs.nv.gov](mailto:mrivas@dhhs.nv.gov)

Ellen Marquez, Self-Advocacy Coordinator, 7756848621, [elmarquez@dhhs.nv.gov](mailto:elmarquez@dhhs.nv.gov)

Kimberly Palma-Ortega, Public Health Liaison, [kimberlyp.o@outlook.com](mailto:kimberlyp.o@outlook.com)

Alysa Marquez, Intern, [amarquez@dhhs.nv.gov](mailto:amarquez@dhhs.nv.gov)

February 2024 Version

**Table of Contents**

[1. WHAT IS THE DEVELOPMENTAL DISABILITIES ACT (DD ACT)? 1](#_Toc159613824)

[1.1. Purpose of a Developmental Disabilities (DD) Council 2](#_Toc159613825)

[1.1.1. Our History 3](#_Toc159613826)

[1.1.2. Our Mission 5](#_Toc159613827)

[1.1.3. Definition of Developmental Disability (DD) 5](#_Toc159613828)

[1.1.4. Definition of Intellectual Disability (ID) 6](#_Toc159613829)

[1.1.5. What Is the Difference Between a Developmental Disability and Intellectual Disability? 6](#_Toc159613830)

[1.2. Federal Agencies and DD Network Partners 7](#_Toc159613831)

[1.3. Responsibilities of a DD Council 9](#_Toc159613832)

[1.3.1. Advocacy 10](#_Toc159613833)

[1.3.2. Systems Change 11](#_Toc159613834)

[1.3.3. Capacity Building 11](#_Toc159613835)

[1.4. Who are the Council Members? 11](#_Toc159613836)

[1.5. The Partnership between Members and Staff 13](#_Toc159613837)

[1.5.1. Council Member/Staff Partnership 13](#_Toc159613838)

[1.5.2. Council/Committee Chair Responsibility 13](#_Toc159613839)

[1.6. Basic Responsibilities of a Council Member 13](#_Toc159613840)

[1.6.1. Display The Following in All Manner of Council Business: 13](#_Toc159613841)

[1.6.2. Prepare For, Attend, and Take Part in Council and Committee Meetings 14](#_Toc159613842)

[1.6.3. Select the Executive Director 14](#_Toc159613843)

[1.6.4. Support and Annually Evaluate the Executive Director 14](#_Toc159613844)

[1.6.5. Ensure Effective Planning 15](#_Toc159613845)

[1.6.6. Implement and Watch the DD Council 5-Year State Plan 15](#_Toc159613846)

[1.6.7. Approve and Implement the Budget 15](#_Toc159613847)

[1.6.8. Build A Competent DD Council 20](#_Toc159613848)

[1.6.9. Ensure Legal and Ethical Integrity (Conflict of Interest, Code of Conduct, Etc.) 20](#_Toc159613849)

[1.6.10. Enhance The DD Council’s Public Standing 21](#_Toc159613850)

[1.7. Designated State Agency (DSA) 21](#_Toc159613851)

[1.8. 5-Year State Plan 22](#_Toc159613852)

[1.8.1. Areas of Emphasis 22](#_Toc159613853)

[1.8.2. Tools (Strategies) A DD Council Can Use To Implement The State Plan 22](#_Toc159613854)

[1.8.3. Tools (Strategies) A Council Cannot Use: 23](#_Toc159613855)

[1.9. Lobbying Vs. Educating 23](#_Toc159613856)

[1.9.1. What Is Educating? 24](#_Toc159613857)

[1.9.2. What Is Lobbying? 25](#_Toc159613858)

[1.10. Why Is the Independence of The Council Important? 26](#_Toc159613859)

[1.11. What Else Do I Need to Know About My Council? 26](#_Toc159613860)

[1.12. What Can/Should I Do in a Meeting? 27](#_Toc159613861)

[1.12.1. Basic Meeting Rules 27](#_Toc159613862)

[1.12.2. Things to know… 27](#_Toc159613863)

[1.12.3. Making a Motion (Basics) 28](#_Toc159613864)

[1.13. Nevada Open Meeting Law (OML) 28](#_Toc159613865)

[1.13.1. Legislative Intent 28](#_Toc159613866)

[1.13.2. Basic Terms of OML 28](#_Toc159613867)

[2. COUNCIL POLICIES AND PROCEDURES 31](#_Toc159613868)

[2.1. Governance Policy 31](#_Toc159613869)

[2.1.1. Evaluations 32](#_Toc159613870)

[2.1.2. Monitoring and Evaluating of Grantees and Projects 32](#_Toc159613871)

[2.1.3. Conflict of Interest 32](#_Toc159613872)

[2.1.4. Fiduciary Responsibilities and Code of Conduct 36](#_Toc159613873)

[2.1.5. Evaluation of the Executive Director 38](#_Toc159613874)

[2.1.6. Response to Persons, Publication or Public Medium 38](#_Toc159613875)

[2.1.7. Budget Committee 39](#_Toc159613876)

[2.1.8. Discretionary Funds 39](#_Toc159613877)

[2.1.9. Reimbursable Expenses/Support for Members to Attend Council/Committee Meetings 39](#_Toc159613878)

[2.1.10. Policies and Procedures for Accommodation 40](#_Toc159613879)

[3. RULES OF ORGANIZATION AND PROCEDURE 43](#_Toc159613880)

[3.1. Council Bylaws 43](#_Toc159613881)

[3.1.1. Definitions 43](#_Toc159613882)

[3.1.2. Name 46](#_Toc159613883)

[3.1.3. Purpose 46](#_Toc159613884)

[3.1.4. Role and Function 47](#_Toc159613885)

[3.1.5. Philosophy 47](#_Toc159613886)

[3.1.6. Council Responsibilities 48](#_Toc159613887)

[3.1.7. Statewide Planning 53](#_Toc159613888)

[3.1.8. Plan Objectives - The Plan Shall Be 54](#_Toc159613889)

[3.1.9. Council Membership 55](#_Toc159613890)

[3.1.10. Meetings 57](#_Toc159613891)

[3.1.11. Officers 58](#_Toc159613892)

[3.1.12. Committees 58](#_Toc159613893)

[3.1.13. Procedure for Amendment 63](#_Toc159613894)

[3.1.14. Delegates to The National Association of Councils on Developmental Disabilities 63](#_Toc159613895)

[3.2. Council Position Statements 63](#_Toc159613896)

[3.2.1. Position on Accessibility 63](#_Toc159613897)

[3.2.2. Position on Community Support 65](#_Toc159613898)

[3.2.3. Position on Employment 66](#_Toc159613899)

[3.2.4. Position on Guardianship and Supported Decision Making 68](#_Toc159613900)

[3.2.5. Position on Health Care 69](#_Toc159613901)

[3.2.6. Position on Housing 71](#_Toc159613902)

[3.2.7. Position on Human and Civil Rights 72](#_Toc159613903)

[3.2.8. Position on Mental Health 74](#_Toc159613904)

[3.2.9. Position on Public Transportation Systems 76](#_Toc159613905)

[3.2.10. Position on Sexual Health 77](#_Toc159613906)

[3.2.11. Position on Transparency, Accountability, and Inclusion 80](#_Toc159613907)

[3.2.12. Position on Transportation 81](#_Toc159613908)

[3.2.13. Position on Voting 82](#_Toc159613909)

[4. MEMORANDUM OF UNDERSTANDING (MOU) 85](#_Toc159613910)

[4.1. Purpose 85](#_Toc159613911)

[4.2. Background 86](#_Toc159613912)

[4.3. Objectives 86](#_Toc159613913)

[4.4. Statement Of Agreement 87](#_Toc159613914)

[4.4.1. Identification/Designation of the Administering Agency 87](#_Toc159613915)

[4.4.2. Provisions of Operating and Administrative Support 88](#_Toc159613916)

[5. OUR 5-YEAR STATE PLAN 94](#_Toc159613917)

[5.1. Goals, Objectives & Activities 94](#_Toc159613918)

[5.1.1. GOAL 1 94](#_Toc159613919)

[5.1.2. GOAL 2 96](#_Toc159613920)

[5.1.3. GOAL 3 99](#_Toc159613921)

[6. COMMONLY USED ACRONYMS 101](#_Toc159613922)

[7. CONFLICT OF INTEREST POLICY 104](#_Toc159613923)

[7.1. Purpose 104](#_Toc159613924)

[7.2. Actions 104](#_Toc159613925)

[7.3. Disclosure 106](#_Toc159613926)

[8. MEMORANDUM OF UNDERSTANDING-VOLUNTEER IN STATE SERVICE 107](#_Toc159613927)

# 1. WHAT IS THE DEVELOPMENTAL DISABILITIES ACT (DD ACT)?

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 Public Law **106-402** (usually called the DD Act) is federally implemented by the Administration on Intellectual and Developmental Disabilities. In 1963, individuals with developmental disabilities faced exclusion from many areas of public and private life, including most schools and community spaces. Many of these people spent most of their lives in large, state-run institutions. These institutions were often grossly underfunded, and reports of systemic abuse and neglect were common. It is in this context that President John F. Kennedy signed the law now known as the [Developmental Disabilities Assistance and Bill of Rights Act (DD Act)](https://www.acl.gov/node/106). <https://www.acl.gov/node/106>.

Since the DD Act was enacted, it has come to represent a fundamentally different vision of what it means to live with a developmental disability. It is a vision rooted in the belief that,

*“Disability is a natural part of the human experience that does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.”*

Title I, Subtitle B in the DD Act explains the function of a Council. This title highlights that DD Councils must include and support people with developmental disabilities and their families, to take part in the design of, and have access to needed community services and individualized support. These include other forms of assistance that promote self-determination, independence, productivity, integration, and inclusion in all parts of community life.

Other disability laws that might be helpful to know about:

* The Americans with Disabilities Act of 1990
* The Fair Housing Act of 1989
* National Voter Registration Act 1993 + the Help American’s Vote Act
* Civil Rights of Institutionalized Persons Act 1980
* Individuals with Disabilities Education Act 1975 (IDEA)
* The Rehabilitation Act of 1973
* Olmstead Decision of 1999
* Achieving a Better Life Experience (ABLE) Act of 2014

## 1.1. Purpose of a Developmental Disabilities (DD) Council

DD Council’s purpose is to help people with developmental disabilities leverage self-determination, be independent, productive, and coordinated, and get integrated in all aspects of collective living. Councils on Developmental Disabilities are in every State and selected US territories. DD Council members serve as volunteers and are appointed by the state governor to represent and advocate for people with developmental disabilities and their families.

While some DD Act programs provide direct services to individuals, the 56 [State Councils on Developmental Disabilities (DD Councils)](https://www.acl.gov/node/467) are designed to take a holistic approach to create structural change with a long-term impact. We do not engage in direct service. We are designed to be run by and for the developmental disability community.

DD Councils look to create positive change through advocacy, systems change, and capacity building. They provide training and technical assistance to advocates, families, and service providers. They bring together businesses, service providers, agencies, policymakers, and community groups to find solutions to persistent problems. They develop and test innovative programs and service models. Most importantly, DD Councils facilitate the reach of concerns raised and faced by individuals with developmental disabilities to the policymakers whose decisions affect their lives.

We are authorized in accordance with Public Law **106-402** of the [Developmental Disabilities Assistance and Bill of Rights Act (DD Act)](https://www.acl.gov/about-acl/authorizing-statutes/developmental-disabilities-assistance-and-bill-rights-act-2000) and established under **NRS 232.320** within the State of Nevada. The NGCDD is funded annually by the Federal Department of Health and Human Services with matching funds of **25%** appropriated by the Nevada Legislature.

The Council has designated the [Nevada Department of Health and Human Services](http://dhhs.nv.gov/) as our Designated State Agency to provide support to the Council under the regulations of the DD Act Section **125(d)**.

### **1.1.1. Our History**

The Nevada Governor’s Council on Developmental Disabilities (NGCDD) began by executive order of the Governor on July 1, 1971. Prior to the advent of systems change and the development of programs like the Independent Living and Personal Attendant Care programs, the Council focused on providing services to Nevadans with developmental disabilities who “fell through the cracks.” The Council’s philosophy at the time was to use federal funding maximally to purchase services for people with DD while keeping the administrative costs minimal. Eventually, many of these services were included in other state programs and the Council began using its federal funds to focus on systems change in the State. In the late 1980s systems change became the mandate of the DD Act and the Administration on Developmental Disabilities, so the Council shifted its approach to comply with the DD Act and to address the more important issue of systems change on behalf of Nevadans with DD. Even though it was not thought of as a ‘systems change’ at the time, the Council did help establish some important permanent programs for people with DD in Nevada through Council funding early on. Many of these programs still exist today.

Since the late 1980s and early 1990s, the Council’s focus has shifted to systems change. The Council recognized, along with the Administration on Developmental Disabilities, that it could have a much greater impact and reach a lot more people with DD by helping change the system that is supposed to provide the services needed by people with disabilities. To this end, the Council began providing start-up funding for those programs that would be able to continue their services once the Council funding is depleted. The Council was able to leverage millions of dollars beyond its minimum allotment. The Council provided funding to bring experts in Olmstead and other national disability policymakers to Nevada to meet with and train legislators, policymakers, consumers, state agency directors, and others in disability issues and systems changes that are needed. The hiring of a Housing Development Specialist and collaboration with the Office of Disability Services, Department of Human Resources, and Centers for Independent Living to implement the “Money Follows the Person” project are additional examples of the Council’s focus on systems change.

Time has seen the Council evolve from a “little-known, do it alone” Planning Council serving only a few Nevadans with disabilities, into a dedicated institution of committed people appointed by the Governor who are impacting the lives of thousands of Nevadans with disabilities. It has evolved from an agency-driven Council to a consumer-driven Council that believes in and actively support training people with disabilities to become leaders in the community, leaders who will help change the system so that people with disabilities can make informed decisions about their own lives. The fact that at least 60% of the members of the Council are either people with developmental disabilities or parents of children with DD is a sign of the evolution toward a consumer-driven Council.

### **1.1.2. Our Mission**

The NGCDD engages in advocacy, systems change, and capacity building activities for people with developmental disabilities and their families in order to promote equal opportunity, self-determination, and community inclusion.

The NGCDD believes in, advocates for, and uses the best practices of:

* **Community Inclusion:** The opportunity to live and exist as a contributing member of society while being valued for your abilities and uniqueness regardless of disability.
* **Empowerment Through Self-Advocacy:** Empowering individuals through activities that teach self-advocacy skills and support self-determination.
* **Experience Based Informed Choice:** Respecting the rights of individuals with disabilities to fully experience all options and then make their decisions about choosing the most suitable path for them as per their experience.
* **Dignity of Risk:** The right to take risks in life, same as everyone else. “To deny the right to make choices in an effort to protect the person with disabilities from risk is to diminish their human dignity.”
* **Nothing about Us without Us:** No discussion or decision that affects people with disabilities should conclude without their input.
* **Person First Language:** Put the person before the disability. It describes what a person has, not who a person is.

### **1.1.3. Definition of Developmental Disability (DD)**

A severe, chronic disability of an individual that—is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; results in substantial functional limitations in 3 or more of the following areas of major life activity:

* Self-care
* Receptive and expressive language
* Learning
* Mobility
* Self-direction.
* Capacity for independent living
* Economic self-sufficiency

…and reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

### **1.1.4. Definition of Intellectual Disability (ID)**

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem-solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18.

### **1.1.5. What Is the Difference Between a Developmental Disability and Intellectual Disability?**

"Developmental Disabilities" (DD) is an umbrella term that includes intellectual disability but also includes other disabilities that are apparent during childhood. DD are severe chronic disabilities that can be cognitive, physical or both. The disabilities appear before the age of 22 and are likely to be lifelong. Some developmental disabilities are largely physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that includes a physical and intellectual disability simultaneously, for example, Down syndrome or fetal alcohol syndrome. Intellectual disability encompasses the “cognitive” part of this definition, that is, a disability that is broadly related to the thought process. Intellectual and other developmental disabilities often occur together. (Source, AIDD).

## 1.2. Federal Agencies and DD Network Partners

* **UCEDD** means University Centers for Excellence in Developmental Disabilities Education.
* **P & A** means Protection & Advocacy System.
* **DHHS** means The United States Department of Health and Human Services.
* **ACL** means Administration on Community Living.
* **AOD** means Administration on Disabilities.
* **OIDD** means the Office of Intellectual and Developmental Disabilities.

**The United States Department of Health and Human Services (DHHS)** is tasked with enhancing the health and well-being of all Americans, by providing effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health, and social services.

**The Administration for Community Living (ACL)** increases access to community support and resources for the unique needs of older Americans and people with disabilities. They are the Federal agency responsible for oversight of the DD Act and associated programs.

**The Administration on Disabilities (AOD)** works with states, communities, and partners in the disability networks to increase the independence, productivity, and community integration of individuals with disabilities.

**The Office of Intellectual and Developmental Disabilities (OIDD)** is dedicated to ensuring that people with disabilities have opportunities to make their own choices, contribute to society, have support to live independently and live free of abuse, neglect, and exploitation.

In each state and territory, OIDD grantees (agencies) form a developmental disabilities network, or DD Network, made up of State Councils on Developmental Disabilities, State Protection and Advocacy Systems, and University Centers for Excellence in Developmental Disabilities.

* DD Councils identify the most pressing needs of people with developmental disabilities in their state or territory. Councils are committed to advancing public policy and systems change that help these individuals gain more control over their lives.
* The P&A protects the legal and human rights of all people with developmental disabilities.
* UCEDDs perform interdisciplinary training, community service, technical help, research, and information dissemination activities.
* The Council operates in partnership with the [Nevada Disability and Advocacy Law Center](http://www.ndalc.org/) (NDALC) and the [Nevada Center for Excellence on Disabilities](http://nced.info/)(NCED) under the “Developmental Disabilities Network”.

Infographic showing the DD Network Partners (UCEDDs, DD Councils and P&A's) have seperate mandates but work together under the DD Act as equal partners. 




The picture above shows how DD Networks work together. For a [full breakdown](https://www.hhs.gov/about/agencies/hhs-agencies-and-offices/index.html) of the agencies listed above and all their programs visit: [www.hhs.gov](file:///\\dhhs-ad.state.nv.us\health\Shares\DO\SHARED\NGCDD\Council%20Member%20Handbook%20and%20Policies\Council%20Member%20Orientation%20Materials\www.hhs.gov).

## 1.3. Responsibilities of a DD Council

* Promote and support advocacy, systems change and capacity building for people and families with developmental disabilities.
* Develop and monitor the 5-year State plan.
* Develop and monitor grants and contracts.
* Review the designated state agency from time to time.
* Report on DD Council activities.
* Prepare, approve, and put a budget into action annually.
* Hire and evaluate the Executive Director

When the Council acts, it must do so as a group. Individual members have no power; authority comes from the Council as a whole.

### **1.3.1. Advocacy**

* The DD Act defines “advocacy” as an active support of policies and practices that promote self-determination and inclusion in the community and workforce for individuals with developmental disabilities and their families.
* Advocacy is mandated for all Councils by the DD Act to address 3 major requirements:

1) Establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities;

2) Support opportunities for ‘leadership-ready’ individuals with developmental disabilities to provide leadership training to people with the same issues and who possess the potential to lead from front in the future;

3) Support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions.

The DD Act **does not** mandate Councils to fund a statewide self-advocacy organization. Councils may choose to support advocacy in other ways in addition to following the DD Act mandate such as:

* + - * + Advocating for inclusive services and support by participating in boards and coalitions that address issues important to people with developmental disabilities and their families.
        + Advocating public policy and laws that support the rights of people and families with developmental disabilities.
        + Training parents of children with developmental disabilities about education rights (IDEA) and how to advocate for their child’s inclusive education.

### **1.3.2. Systems Change**

According to the DD Act, “systems change activities” means a sustainable, transferable, and replicable change in some aspect of service or support availability, design, or delivery that promotes positive or meaningful outcomes for individuals with developmental disabilities and their families.

Systems change can take collaboration among many different agencies or within one agency. It must involve the community and stakeholders. Systems change activities taken on by DD Councils should result in laws, regulations, policies, practices, or organizational changes that are person-centered or family-centered and directed, and increase access to required services and assistance.

### **1.3.3. Capacity Building**

According to the DD Act, “capacity building activities” means activities (e.g. training and technical assistance) that expand and/or improve the ability of individuals with developmental disabilities, families, support, services, and/or systems to promote, support, and enhance self-determination, independence, productivity and inclusion in community life.

Capacity building can be individual/familial, organizational, or both. Example: Sheltered Workshop to Community Employment service providers train them on how to support people with I/DD to obtain employment in the community. Employment services are now person-directed and community-based.

## 1.4. Who are the Council Members?

60 percent of all the Council members must be:

* People with developmental disabilities.
* Parents or guardians of children with developmental disabilities.
* Immediate relatives or guardians of adults with intellectual disabilities who cannot speak for themselves.
* In addition, these Council members cannot be managing employees of an agency that receives money from the Council.

Among the members of the Council described above:

* 1/3 must be individuals with developmental disabilities.
* 1/3 must be parents or guardians of children with developmental disabilities, or immediate relatives or guardians of adults with developmental disabilities.
* 1/3 must be a combination of individuals with developmental disabilities or family members of people with developmental disabilities.
* At least one DD Council member must be an individual; or immediate relative or guardian of an individual with a developmental disability who lives or used to live in an institution.
* The other members of the DD Council speak and act for agencies and organizations listed below:
  + Rehabilitation Act.
  + Individuals with Disabilities Education Act.
  + Older Americans Act.
  + Maternal and Child Health Programs of Title V of the Social Security Act.
  + Medicaid/Title XIX of the Social Security Act.
  + University Center(s) for Excellence in Developmental Disabilities.
  + Protection and Advocacy System.
  + Local and non-governmental agencies involved with services for individuals with developmental disabilities.
  + Non-profit groups involved with services for individuals with developmental disabilities.
  + Non-Governmental Agency from Disability Community.

## 1.5. The Partnership between Members and Staff

### **1.5.1. Council Member/Staff Partnership**

Council members and Council staff have responsibilities that are directly tied to their position; other responsibilities are joint – meaning, both Council members and Council staff partner to perform the responsibility. In general:

* Staff and Council members are partners working toward the same goal.
* Council members supply guidance for Council activities.
* Staff supply meaningful, relevant information and assistance to the Council.

### **1.5.2. Council/Committee Chair Responsibility**

The Chair helps run Council meetings. Committee Chairs help run committee meetings. Chairs encourage and foster Council engagement. The Chair needs to build strong partnerships with Council members and the Executive Director. The partnership between the Chair and the Executive Director serves as the face of the Council.

## 1.6. Basic Responsibilities of a Council Member

DD Council members serve as volunteers and are appointed by the state governor to represent and advocate for people and families with developmental disabilities.

### **1.6.1. Display The Following in All Manner of Council Business:**

* Honesty.
* Working knowledge of the Council’s mission, goals, and objectives.
* Respect of Council views.
* Respect for others and tolerance of differing views.
* Responsiveness.
* Concern for the Council’s development.
* Duty of Care. Members of the Council should exercise reasonable care in the decision-making process, using proper business judgment.

### **1.6.2. Prepare For, Attend, and Take Part in Council and Committee Meetings**

Staff put significant effort into compiling the information you need, thus as a Council member will need to be fully informed and take part in meetings. As a Council member, you must respond to email inquiries from staff promptly, review materials before meetings, and be prepared to actively participate, ask questions, and give input during meetings.

### **1.6.3. Select the Executive Director**

The Council shall, consistent with State law, recruit and hire a Director of the Council, should the position of Director become vacant, while supervising and annually evaluating the Director.

### **1.6.4. Support and Annually Evaluate the Executive D**ir**ector**

DD Council members should ensure the Executive Director (ED) has the moral and professional qualities to further the goals of the organization, and annually evaluate them following applicable policies and procedures. It is important that the annual evaluation for a DD Council Executive Director be conducted by the DD Council (not the DSA or other entity of the state).

The Executive Director works for the Council but is responsible for the oversight and effective management of Council operations including compliance with all Federal and State rules and regulations. Other duties include oversight of:

* Fiscal preparation, planning, management, and reporting
* 5-year state plan preparation, planning, implementation, and reporting
* Community relations
* Support to Council
* Public policy

Staff members work under the direction of the Executive Director and are subordinate to and evaluated by the Executive Director. Council members may not assign tasks to Council staff.

### **1.6.5. Ensure Effective Planning**

DD Council members should actively take part in the planning process for the 5-year State Plan. This is a DD Act mandate. “The Council shall develop the State plan and submit…” Active participation means that a DD Council member will use the information gained from the Comprehensive Review and Analysis (the present status of services and support provided for people with DD and their families in the State) and information from the public to identify the unmet needs of people with DD and their families.

**Council members stand for all people with I/DD in the State**. The leadership and guidance provided by a Council member affects all people with I/DD and should not be focused on personal interests.

### **1.6.6. Implement and Watch the DD Council 5-Year State Plan**

Each year the Council must create and send a report based on the progress of our 5-year state plan. This report is called the Annual Program Performance Report – or PPR. We give a status report on all activities of the 5-year State plan during our Evaluation and full Council meetings.

Council members should **actively take part** in following the progress of the 5-year State plan and helping to complete tasks where possible.

### **1.6.7. Approve and Implement the Budget**

*Everyone’s favorite subject! But what is a Budget?*

* Formal statement of the goals of an organization in financial terms (numbers).
* Reflects the Council’s State Plan – the budget is the plan of how a Council will fund its State Plan goals and objectives.
* Is for a specific period – fiscal year, or calendar year.

#### Common Budget Terms

* **Allotment:** Money awarded.
* **Administrative Costs:** An expense that is incurred in directing or managing the Council; costs related to the Council as a whole (common examples: utilities, rent, accounting).
* **Expenditure:** Items bought and paid for within the same fiscal year.
* **Obligate**: A legal ‘promise’ to pay money that has been set aside for a specific activity or purpose.
* **Liquidate:** Spending money that has been obligated.
* **Match:** The non-Federal charge of costs that the Council’s partners must contribute to carry out the purposes of the grant.
* **Federal Fiscal Year (FFY):** October 1-September 30.
* **Calendar Fiscal Year:** January 1 - December 31.
* **State Fiscal Year (SFY):** July 1-June 30th.
* **Federal Award Year (FAY):** Federal Fiscal Year in which Congress supplies the Federal award. We run on the federal fiscal year however; we monitor funds on the state and federal fiscal year based on the current Federal Award Year.

#### Federal Allotment

* Each fiscal year a Council receives an allotment from the Department of Health and Human Services, Administration on Community Living. This is our Federal Award.
* Allotments are based on the population of the State; the extent of the need for services for individuals with developmental disabilities and; the financial need of the State.
* Councils are given a total of three years to spend one grant award (2 years to obligate, and another year to liquidate.

#### State Allotment

* 25% of our federal award.
* Can be in dollars or in-kind (fairly evaluated including space, equipment, or services).
* Can’t give fewer general dollars than the year before.
* Nevada Legislature gets to decide what our authority is each year (how much of our state and federal funds are spendable after their approval).

#### Federal Regulations

* All costs must be reasonable, necessary, traceable to specific activities of our state plan, consistent with past spending, and allowable per Federal regulations.
* At least 70% of a Council’s allotment must be used to implement the Council State Plan.
* No more than 30% of a Council’s allotment may be used for administrative costs – the 30% includes the Designated State Agency reimbursement percentage of 5% of the annual award.
* Each Council shall prepare, approve, and implement a budget using amounts paid to the State to fund and implement all programs, projects, and activities that include:
  1. Conducting hearings and forums as the Council believes necessary to carry out its duties.
  2. As determined by Council policy:
     + 1. Reimbursing members of the Council for reasonable and necessary expenses (including expenses for child-care and personal assistance services) for attending Council meetings and performing Council duties; Supporting Council members and staff traveling to authorized training and technical assistance activities, including In-house training and leadership development activities.
       2. Carrying out proper subcontracting activities
       3. Hiring and keeping qualified staff, consistent with State law.
       4. Paying a stipend to a member of the Council if such member is not employed, or is required to give up wages from other employment to attend Council meetings and perform other Council duties.
       5. Directing the expenditure of funds for grants, contracts, interagency agreements that are binding contracts, and other activities authorized by the approved State plan.
  + The State cannot apply hiring freezes, reductions in force, prohibitions on travel, or other policies to Council staff, to the extent that they impact the staff, functions funded with Federal funds, or prevent the Council from carrying out its duties.

#### Who Prepares the Budget?

The Executive Director and/or related staff work with their Designated State Agency to prepare the budget for Council approval. Once the Council approves the annual budget, the staff is tasked with implementing the budget.

#### Who Monitors the Budget?

The Executive Director and/or related staff regularly watch expenditures. Council members receive a financial report at Council meetings. The purpose of the Council budget report is so that members can watch the obligation and liquidation of the Council grant award(s). The purpose is not to review and approve each expenditure incurred by the Council. Staff and the Designated State Agency will ensure expenditures are in concert with the budget and meet State and Federal rules for allowable costs.

#### Questions To Consider When Reviewing A Council Financial Report:

* Are our expenses in line with our budget?
* Are we meeting the overall budget? If not, why?
* Is a grant’s spending according to schedule?
* Were all grantee expenses allowable? If not, how did the Council handle any unallowable expenses?
* Do we have unobligated funds for the current year?
* What is the Council planning for these funds?

#### Match

* Matching funds include non‐federal public or private funds
* Can be cash or in‐kind, fairly evaluated.
* If staff is doing something toward the state plan it doesn't need to be matched.
* The Council’s Self-Advocacy Coordinator’s salary is not matched.
* Can't use federal funds to match federal funds.
* Can't duplicate match (can't use funds already claimed for another Federal Match).

#### DD Council Members Should Help in Developing, Approving, and Implementing the Annual Budget

This is a DD Act mandate. Each Council shall prepare, approve, and implement an operating budget – this often includes tasks such as approving funds for grant projects/initiatives, approving funds for Council staff to conduct activities, and/or approving new and continuation grant awards. In addition, a DD Council should supply financial oversight by watching the Council’s financial status on a regular basis (most Councils do this as part of their regularly scheduled meetings).

For a DD Council member to fulfill their role, and perform the responsibilities of their role, the following is common information DD Council staff provide to DD Council members:

* Annual Operating budget
* Funds awarded for grants and/or contracts for Initiatives
* Summary of Federal Year of Funds
* Funds Available for Future Projects

Common responsibilities of DD Council staff related to budget activities include: establishing the operating budget for the DD Council, allocation of funds among strategies and initiatives; finalizing expenditures of funds within the budget approved by the DD Council; completing financial reports in a timely manner; and, recommending budgetary activities.

### **1.6.8. Build A Competent DD Council**

* Find potential members for appointment; orient and mentor new members; periodically evaluate individuals and overall DD Council membership effectiveness
* A DD Council will only be as effective as its individual members. The DD Act allows for DD Councils to recommend people to the Governor to serve as members. This is not a mandate but is allowed and should work in concert with the process the DD Council follows in the State/Territory.

### **1.6.9. Ensure Legal and Ethical Integrity (Conflict of Interest, Code of Conduct, Etc.)**

Be knowledgeable about legal and ethical requirements for public officials; follow all conflict of interest policies (and other policies, as applicable) to ensure the public trust. Words such as diligence, commitment, and vigilance are often attached to a DD Council’s member’s role as they oversee Council business – words such as compliance, transparency, and accountability are often attached to the DD Council’s reputation and public standing.

Here's a simplistic breakdown of these terms:

* **Compliance** means that the DD Council is adhering to the regulatory (DD Act mandates) and legal conditions required for the funding and operation of a DD Council.
* **Transparency** means being open with correct information about funding, the use of funding, major activities, and other areas such as organizational policies and procedures, requests for information, etc.
* **Accountability** refers to the ability to follow DD Council policies and procedures. Annually, a DD Council must share information with policymakers, the public, agencies, and other stakeholders about the DD Council’s activities, accomplishments, and challenges for specific reporting periods. In addition, the DD Act mandates all Councils to adopt and use a conflict of interest policy to ensure DD Council members are free from real or perceived conflict(s) of interest.

### **1.6.10. Enhance The DD Council’s Public Standing**

We should be able to talk about the DD Council’s mission, accomplishments, and goals to the public and gain support from the community.

Council members serve as a link between the Council and the people of the State. The ability to accurately communicate what we do is vital. Council members should be able to talk about the Council’s achievements (information in annual reports, press releases, and website announcements), our state plan, purpose, and mission.

## 1.7. Designated State Agency (DSA)

DD Councils must have a Designated State Agency (DSA). The DSA can be the DD Council or another agency or office of the State. The DSA receives federal funds and pays for all expenses of the DD Council. The Office on Intellectual and Developmental Disabilities has stated, “There does not have to be any program relationship between the Council and its Designated State Agency”, it is primarily a fiscal relationship.

The Act says that DD Councils cannot have a DSA that is an agency that pays for or provides services to people with developmental disabilities unless it was a DSA before 1994.

## 1.8. 5-Year State Plan

The State plan tells the public how services and programs for individuals with DD and their families should look five years from now. The plan gives guidance to the Council on how to spend its resources. Each year, Councils must review and update their plan, if necessary. (Please also refer to page 50 for more information on the 5-Year State Plan.)

The DD Act describes Areas of Emphasis that are important to people with developmental disabilities. DD Councils can spend money and perform activities in these areas.

### **1.8.1. Areas of Emphasis**

* Quality Assurance (Self-Advocacy)
* Child-care
* Education and early intervention
* Employment
* Health
* Housing
* Recreation
* Transportation
* Formal and Informal Community Supports

### **1.8.2. Tools (Strategies) A DD Council Can Use To Implement The State Plan**

* Research and data gathering.
* Educating (informing) the media and public.
* Educate the Governor, legislature, and agencies on policy that affects people with I/DD.
* Help self-advocates and families to learn about and connect with the political process.
* Grants/Demonstration of approaches to services and support.
* Input from the community.
* Members should only speak on behalf of the Council consistent with its policies.

### **1.8.3. Tools (Strategies) A Council Cannot Use:**

* Protest politics.
* Lawsuits.
* Lobbying.
* Representing individual interests.

## 1.9. Lobbying Vs. Educating

A key mission of Councils is to provide information to policymakers on the use of available and potential resources to meet the needs of individuals with developmental disabilities in their state.

DD Act Sections **125(a)(5)(J)**, **143(a)(2)(L)**, **153(a)(1)**, and **161(2)(D)(iii)** outline Council’s responsibility for educating policymakers:

Sections **125(a)(5)**, Councils are authorized under the provisions of the Developmental Disabilities Assistance and Bill of Rights Act, (the Act), to “educate,” “advise” or “inform” Federal, State, and local policymakers in order to assist policymakers to improve the services and opportunities available to individuals with developmental disabilities and their families. The “policymakers” referred to in the statute include members of Congress, officials of the Federal executive branch, Governors, members of State legislatures, and staff of State agencies.

Councils have been mandated to undertake such action to help policymakers improve the services and opportunities available to individuals with developmental disabilities and their families. In addition, State Councils and P&As have the responsibility under the Act to advocate on behalf of individuals with developmental disabilities [See Sections **121(1)**] and for enactment or amendment of legislation at the State level affecting individuals with developmental disabilities. Notwithstanding the Congressional authorization of activities to “educate,” “advise” or “inform” Federal, State, and local policymakers and to be “advocates,” certain prohibitions are applicable on activities that are considered to be lobbying which are applicable to all ADD grantees.

Any grants the Council awards are extensions of the Council and must comply with Council mandates.

### **1.9.1. What Is Educating?**

Using a nonpartisan approach, advocate a position or viewpoint in a balanced way - discussing the advantages and disadvantages with enough explanation of the facts to allow the policymaker to form an independent opinion or conclusion. A nonpartisan approach does not require neutrality about outcomes for individuals with developmental disabilities but needs to show an unbiased attitude when considering alternatives for meeting the needs of individuals with developmental disabilities.

*Examples of Educating/Advocating (CAN DO):*

* Provide information to policymakers on how a policy/issue/bill/law affects or has the potential to affect individuals with disabilities.
* Use social media to get the word out about a policy/issue/bill/law.
* Members can speak on behalf of the Council if their message matches our Policy Statements.

### **1.9.2. What Is Lobbying?**

Any attempt to directly influence a politician or public official to vote one way or another. Councils cannot present unsupported opinions, distorted facts, judgmental terms, or conclusions based more on strong emotions rather than on objective factual conclusions. Councils cannot influence the outcome of Federal, state, or local elections, contribute to political parties, use funds to influence or attempt to influence policymakers or agency officials, influence the enactment of legislation and related activities that are applicable to Administration on Intellectual and Developmental Disability grantees (Councils are considered grantees).

*Examples of Lobbying (CANNOT DO):*

* Ask a policymaker to specifically vote yes or no on a specific policy/issue/bill/law.
* Use social media to ask people to contact policymakers to specifically vote yes or no on a policy/issue/bill/law.
* As an individual you may give your opinion and/or testify as you wish. We encourage you to let Legislators know you are a member of the NGCDD so they can be informed of all the work we do, however, if you are not specifically authorized by the Council ED to testify on behalf of the Council, you MUST state for the record that you are there as an individual and not representing the Council.
* Remember an appointment to a Council position is a volunteer position. Being a Council member DOES NOT make you a Federal, State, or Council employee and it is against the law to represent yourself that way.

**Legal and Related References:**

*Public Law 106-402, Developmental Disabilities Assistance and Bill of Rights Act of 2000 (42 U.S.C. 15001 et seq).*

## 1.10. Why Is the Independence of The Council Important?

State Councils on Developmental Disabilities are unique in the state government framework. DD Councils are afforded protection under the DD Act and yet are often placed in unbending state structures. There are several clauses in the DD Act that DD Councils should know about for their interactions within state structures. Here’s a list of a few:

1. The first is the “noninterference clause”. The clause says that the DSA, or any other agency or office of the State, cannot get in the way of the DD Council and the implementation of the DD Council’s 5-year State plan, employees, budgets, or specific activities.
2. The second is the statements about budgets. A state or territory cannot apply hiring freezes, make the DD Council reduce its staff, impose travel restrictions on DD Councils, or tell a DD Council they cannot use federal funds to carry out activities under the DD Act.
3. A third area of independence concerns DD Council staff hiring and supervision. A DD Council must hire a Director of the Council should the position become vacant, and supervise and annually evaluate the Director. The Council Director hires, supervises, and annually evaluates the staff of the DD Council. The staff of the DD Council, while working for the Council, shall work solely for the DD Council – staff cannot be assigned duties by the Designated State Agency or any other agency or entity of the State. The DD Council must remain consistent with State laws and policies that govern hiring and personnel issues.

## 1.11. What Else Do I Need to Know About My Council?

Some questions you might find helpful to ask the DD Council Chairperson, Executive Director, or DD Council member might be:

* How is the DD Council set up in our State (for example: Executive Order, State Statute)?
* What is the DD Council’s vision and/or mission statement?
* Who is the DD Council’s Designated State Agency (DSA)?
* Who are the representatives of our DD Network programs?
* Who are the DD Council Staff and what is their job(s)?
* What is the DD Council attendance policy?
* Where are the DD Council meetings held?
* Where can I find DD Council meeting dates?
* Who do I contact for questions and support?

## 1.12. What Can/Should I Do in a Meeting?

All members have equal rights, privileges, and obligations. Rules must be administered impartially. In voting, members have the right to know what motion is before the assembly and what yes and no votes mean.

### **1.12.1. Basic Meeting Rules**

* Respect the role of the Chair during meetings.
* The agenda tells what can be discussed and voted on during the meeting.
* Items not on the agenda can only be brought up during the public comment periods.
* Items brought up during public comment cannot be voted on but can be added to the next meeting agenda with Council agreement.
* Nevada Open Meeting Law will be followed.

More about Open Meeting Law in the next section.

**1.12.2. Things to know…**

* Addressing the Chair: Chair or Chairperson
* Quorum: Applies to full DD Council and committee meetings.
* Point of Order: Can be called when there is a breach in basic meeting conduct.
* Member Rights: The minority has rights that must be protected. Members must not attack and/or question the motives of other members.

### **1.12.3. Making a Motion (Basics)**

1. Anytime during discussion, a Council member announces they would like to make a motion and says the motion clearly and concisely.
2. If someone else agrees with the motion, they will second it.
3. If no one seconds the motion, the motion dies.
4. A motion can be amended before the vote.
5. The Chairperson will call for a discussion/vote.
6. All remarks must be courteous, on-point, unbiased, and non-judgmental.
7. Council staff will tally the votes and announce if the motion is carried or not.

## 1.13. Nevada Open Meeting Law (OML)

### **1.13.1. Legislative Intent**

* The Nevada Open Meeting Law (OML) was enacted in 1960 to ensure that the actions and deliberations of public bodies are conducted openly.
* Their actions should be taken openly and their deliberations should be conducted openly.

### **1.13.2. Basic Terms of OML**

1. **Notice:** The right of the public to know about the meeting in a timely manner including the time, place, and location of the meeting. Notice is usually provided on the Agenda.
2. **Agenda:** **NRS** **241.020(2)** Except in an emergency, written notice of all meetings must be given at least 3 working days before the meeting. The notice must include:
3. The time, place, and location of the meeting.
4. A list of the locations where the notice has been posted.
5. The name and contact information for the person designated by the public body from whom a member of the public may request the supporting material for the meeting and a list of the locations where the supporting material is available to the public.
6. An agenda consisting of:
7. A clear and complete statement of the topics scheduled to be considered during the meeting.
8. A list describing the items on which action may be taken, and clearly denoting that action may be taken on those items by placing the term “for possible action” next to the appropriate item.
9. Periods devoted to comments by the general public. The Board may not act based on public comment except if it relates to an action agenda item. The Board may not discriminate public comment based on viewpoint. Comment may be limited to areas relevant to Board authority. Repetition and caustic personal attacks may be limited. Any time limit or other permissible restriction on public comment should be spelled out on the agenda.
10. **Public Body:** Any administrative, advisory, executive, or legislative body of the State or local government (NRS does not include the Nevada State Legislature) that advises or makes recommendations to any entity that expends, disperses, or is supported by tax revenue. Also includes bodies that are publicly funded, Governor appointed, or created by law.
11. **Meeting:** The gathering of members of a public body at which a quorum is present to deliberate toward a decision or to take action on any matter over which the public body has supervision, control, jurisdiction, or advisory power.
    1. **Quorum:** A simple majority of the membership of a public body or another proportion established by law.
    2. **Deliberate/Discuss:** Collectively examine, weigh, and reflect upon the reasons for or against the action. Discussion must not exceed the scope of a clearly and completely stated agenda topic.
    3. **Action:** Decision made by a majority of the members present during a meeting of a public body. Or, a commitment or promise made by a majority of the members present during a meeting of a public body. The public body cannot act on an item not designated as an action item.
    4. The public must be able to hear or observe
12. **Minutes:** Notes from the meeting; draft must be available within 30 working days after the meeting. Minutes do not need to be a word-for-word account of the meeting.
    1. NGCDD meetings are recorded and subject to public inspection.

For more information:

Office of the Attorney General

**Phone** (775) 684-1100 or (702) 486-3420

**Fax** (775) 684-1108 or (702) 486-3768

<http://ag.nv.gov/About/Governmental_Affairs/OML/>

# 2. COUNCIL POLICIES AND PROCEDURES

## 2.1. Governance Policy

The Council is responsible for forming the basic policies within which the Council office operates. Policies are created by the Council during regular meetings and upon a majority vote. Policies are developed to address specific issues or subjects that require additional direction from Council members, Standing Committee members, or staff. Policies remain in force until terminated, revised, or suspended by the Council. The officers of the Council, a chairperson and vice–chairperson, are elected by the Council.

The role of the **Chairperson** is to:

* Hire, supervise, and evaluate the Executive Director.
* Serve as liaison between the Council and the Executive Director.
* Prepare agendas for the quarterly Council meeting with support from the Executive Director.
* Represent the Council at state and national conferences.

The **Vice-chairperson** assumes the responsibilities of the Chairperson in their absence.

The **Executive Director** is hired by the Council to implement policy, assure compliance with state and federal law, and direct the day-to-day operations; which include:

* Hiring and supervising staff positions in accordance with state personnel policies and regulations.
* Serving as liaison between the Council and DSA.
* Assisting in carrying out the requirements of Part B of the Developmental Disabilities Assistance and Bill of Rights Act of 2000.
* Developing and authorizing contracts and sub-grants to carry out projects.
* Authorizing expenditures from the approved Council budget.

### **2.1.1. Evaluations**

The Council shall evaluate its progress towards the achievement of goals and objectives on an annual basis at the end of the federal fiscal year. This is accomplished by an annual review of the state plan, completion of an annual program performance report, and an annual self-evaluation process.

### **2.1.2. Monitoring and Evaluating of Grantees and Projects**

Grantees and internal projects shall be monitored on a quarterly basis through the submission of quarterly reports. Grant project status reports shall be included in Council information packets distributed at or prior to each Council meeting.

### **2.1.3. Conflict of Interest**

#### Section I. Statement of Purpose and Principles

All Developmental Disabilities Council members and employees enter into participation with the Council intending to serve the public and to further the independence, productivity, and integration within the community of people with developmental disabilities. Through these policies, the Council intends to ensure with reasonable prudence that no member or employee realizes or creates an appearance of realizing financial gain of any character, nature, or amount from Council actions. Members and employees shall not engage in any conduct or activity that might reasonably be interpreted by the general public as tending to adversely affect the performance of their official duties. Each member and employee shall, at all times, follow the procedures defined in these policies.

#### Section II. Authority

Nevada Statutes are applicable to members, sub-committee members, and employees of the Council. All Council members, sub-committee members, and employees are required to comply with all appropriate state statutes, including the following rules set forth by the Commission on Ethics, Chapter 281 – Public Officers and Employees:

* **NRS 281.481:** General requirements; exceptions.
* **NRS 281.501:** Additional Standards - Voting by public officers; disclosures required of public officers and employees; effect of abstention from voting on quorum; Legislators authorized to file written disclosure.
* NRS 281.505: Contracts in which a public officer or employee has an interest are prohibited; exceptions.

#### Section III. Definitions

1. **Direct Financial Interest** – Any situation that will result in a pecuniary benefit in the form of cash, salary, or property to a person or his/her immediate family.
2. **Immediate Family** – Any spouse, child, stepchild, parent, or stepparent of a person.
3. **Indirect financial interest** – Any situation that will result in a financial advantage to another person or organization with which a person has a relationship or association.
4. **Pecuniary Benefit**- Benefit in the form of property, but does not include:

* Property with a value of less than twenty dollars ($20.00).
* Food, drink, or entertainment authorized as a proper deductible expense for income tax purposes under the U.S. Internal Revenue Code up to an amount of one hundred dollars ($100.000) per year.
* Contributions to a political campaign of a public servant as provided in NRS 294A.100.

#### Section IV. Individuals and Organizations Covered

Personal financial gain and private benefit to members, sub-committee members, and employees through their participation in the Council shall be considered a conflict of interest. This policy shall apply to:

1. The member or employee of the Council himself or herself;
2. Any person, not an employee or member of the Council, serving as a member of a sub-committee of the Council.

#### Section V. Actions Prohibited

1. No person included in Section IV shall seek to influence the vote regarding the awarding of a contract or grant by the Council when that person knows that he or she has a direct or indirect financial interest in the award.
2. Except as reimbursement for approved out-of-pocket expenses, no person included in Section IV may directly receive funds, including any portion of his/her salary, from any grant or contract funded by the Council without first disclosing his/her relationship to the project. That person must refrain from participating in any discussion, decisions, or review by the Council on that grant or contract. Following disclosure, the person may answer technical questions and provide factual information if requested by the Council.
3. Council members and sub-committee members who are paid employees of organizations that have affiliated regional or local chapters shall not participate in the discussion, selection, or award of grants or contracts when an affiliated chapter is an applicant or recipient. After disclosing that affiliation, the Council member or sub-committee member may, at the request of the Council, answer technical questions and provide factual information.

#### Section VI. Exceptions

1. Nothing herein shall be construed to prohibit any firm, agency, or organization that any member, sub-committee member, or employee of the Council is associated with appearing, rendering services in relation to any matter before, or transacting business with the Council.
2. Any individual who has a developmental disability or who has a relationship, by blood or marriage, with a person with a developmental disability shall not be construed as having a conflict of interest based solely on that disability or relationship.
3. Any individual who is also a consumer of services shall not be construed to have a conflict of interest in a specific project or organization if his/her participation is only as a consumer and if he or she exercises no administrative or decision-making authority in the project or organization.

#### Section VII. Disclosure

1. Each person included in Section IV shall disclose all conflicts of interest, including those who are uncertain about their status or are potentially going to fall into the category as soon as the conflict becomes apparent.
2. Disclosure of conflict or potential conflict of interest shall be made to the full Council prior to any discussion of the issue of conflict.

#### Section VIII. Determination of Conflicts

1. A declaration of conflict by any person included in Section IV shall be accepted when that person indicates that a definite conflict exists.
2. When a person indicates that they are uncertain whether a conflict exists in a specific situation or when there may be a potential future conflict of interest, the Council shall determine whether a conflict exists.

#### Section IX. Procedures

1. All persons included in Section IV shall sign a confirmation document when they are appointed which acknowledges that they have received the Conflict of Interest Policy.
2. Disclosure of conflict of interest shall be recorded in the minutes of the meeting.
3. Any person who has disclosed or been found to have a conflict of interest must not, in relation to the matter in conflict unduly influence or vote in those areas where the conflict arises.

#### Section X. Violations and Penalties

1. Any Council member, sub-committee member, employee, or another person may bring suspected violations of this policy to the attention of the Chairperson who shall in turn report to the Council. The Council shall;
2. notify the person alleged to be in violation of the allegation;
3. gather pertinent documentation to support the allegation and to counter the allegation;
4. review all pertinent documentation in relation to established policy;
5. substantiate or dismiss the allegation.
6. If the Council finds an intentional violation of these policies by a Council member, the Council shall forward a recommendation, with appropriate documentation to the Governor for his review and action.
7. If the Council finds an intentional violation of these policies by a sub-committee member who is not a member of the Council, the Chairperson shall remove that person from the sub-committee.
8. If the Council finds an intentional violation of these policies by the Executive Director, the Council shall initiate appropriate personnel action. In the case of the other employees, the Council shall forward findings to the Executive Director who shall initiate appropriate personnel action.
9. If the Council finds that an unintentional violation of these policies occurred, the Committee shall define the area of conflict of interest and instruct the person to refrain from participation or discussion when that area is the subject of Council actions.

### **2.1.4. Fiduciary Responsibilities and Code of Conduct**

Members have a public duty to implement the spirit and intent of the Developmental Disabilities Assistance and Bill of Rights Act and the Council’s State Plan Goals and Objectives and shall fulfill the fiduciary responsibility as a member of “Governance”.

* **Fiduciary** means to protect the public trust.
* **Governance** is the role you have assumed accepting the position of Council member. The Council members ‘govern’ the activities of the Council.

#### Code of Conduct:

Outlined below is the code of conduct members should follow:

1. Members shall respect the unique needs, values, and choices of persons with developmental and intellectual disabilities and their families.
2. Members shall be fully alert to and fully disclose situations that may cause a conflicting interest or have the appearance of a conflict. When a conflict of interest arises, the member shall act in accordance with the Council By-laws and Governance Policy.
3. Members shall abstain from disruptive, disrespectful, and abusive behavior towards others; will at all times act with courtesy, dignity, and decorum; and shall respect the differing opinions of other members.
4. Members shall fulfill their duties in a manner that reflects awareness of cultural differences and shall not discriminate against individuals based on disability, race, ethnicity, creed, religion, color, gender, age, sexual orientation, or national origin.
5. Members shall, in all circumstances when representing the Council, conduct themselves in a manner that preserves the credibility and reputation of the Council.
6. Members shall not speak for the full Council or act for the Council unless specifically authorized to do so.
7. Members shall “recognize” and “respect” the roles and duties of the Council Chair, Executive Director, and his/her authority over staff.
8. Members shall actively participate in Council meetings.

#### Removal/Sanction of Council Members:

The Council, as a result of an affirmative vote of (60%) of its members, may petition the Governor to remove a Council member or may sanction a Council member for any of the following reasons:

1. Negligence of duty, which includes, but is not limited to, missing two or more consecutive meetings without a valid excuse.
2. Conduct activities that are harmful to or opposed to the best interests of the Council.
3. Abuse of Council members, Council staff, or Grantees.
4. Violations of Council By-laws or Governance Policy.
5. A Council member becomes ineligible to continue to serve as a member.

Prior to a vote for removal or sanction, “that” Council member shall be presented with a notice in writing which states the grounds of the intended removal or sanction and “that” Council member shall have the opportunity to present a case to the full Council. The Council member being recommended for removal or sanction shall not be entitled to vote on the action.

### **2.1.5. Evaluation of the Executive Director**

The Chair of the Council shall cause at least an annual evaluation of the Executive Director by the Executive Committee to be submitted to the Bureau Chief of the Designated State Agency. Such evaluation process is to begin two months prior to the Executive Director’s annual date of hire and culminate in a timely fashion to coincide with the annual date of hire.

### **2.1.6. Response to Persons, Publication or Public Medium**

Whenever there is an individual comment or an article that comes from a publication or public medium, wherein statements or comments are made for which a response on behalf of the Council may be in order or be desirable, the Executive Director and the Chair of the Council shall discuss the matter in a timely fashion, and determine:

1. If there will be a response, and
2. What the response will be?

If a decision is made to respond to such comment(s) or statement(s), then those two persons will present the response by a phone call, personal meeting, or letter. If time permits, a draft of such response shall be sent to the Council for review and comment, prior to distribution. If not, then the remainder of the Council or appropriate persons will be notified of what has occurred. This process provides for a timely response and notice to the Council.

### **2.1.7. Budget Committee**

The budget committee shall consist of the Chair and Vice-chair of the DD Council, a fiscal representative of the Designated State Agency, and other members as appointed by the DD Chairperson. This committee will report at each DD Council meeting.

### **2.1.8. Discretionary Funds**

A discretionary fund of up to $15,000 will be established annually to assist in the achievement of the goals and objectives of the Council’s 5-year State Plan. Funds will be utilized in compliance with State and Federal regulations. The NGCDD Executive Director shall have the authority to use discretionary funds for Council members and staff travel to conduct in/out of state business and/or training, membership fees for professional organizations, software for creating and maintaining accessibility compliance, website hosting and maintenance, data collection and analysis, subscriptions to professional publications and overflow of Consumer Leadership Applications. The NGCDD Executive Director shall obtain prior approval from the Executive Committee for the use of any funds not mentioned above. All funds utilized will be reported to the Council at the following Council meeting.

### **2.1.9. Reimbursable Expenses/Support for Members to Attend Council/Committee Meetings**

#### Travel Reimbursement

Reimbursement of travel expenses for Council members, Committee members, and staff doing business for the Council, including mileage and per diem, shall be in accordance with the State Administrative Manual (SAM) Chapter 0200. Travel expenses shall be pre-approved by the Executive Director.

#### Childcare Reimbursement

Reimbursement of costs for childcare can be provided to those members that require this service in order to attend Council-related activities as funds are available with prior approval of the Executive Director.

#### Stipends (Federal Law 42 U.S.C. sec. 15025(c)(8)

A stipend of $40 per day with a maximum of $200 per event can be provided to a member if such member is not employed or must forfeit wages from other employment to attend Council meetings and perform other Council duties. Stipends must be pre-approved by the Executive Director. Reimbursements may be deemed taxable and the Council is not responsible for the tax liability

#### Letters to Employers

Upon member request, letters can be written to employers on behalf of the Council beseeching employer support for the member to attend and continue receiving wages while attending Council/Committee meetings.

### **2.1.10. Policies and Procedures for Accommodation**

#### Section I. Support of Council/Committee Members

All Council and Committee members will be provided with the support services they need in order to fully participate in Council and Committee meetings. Support services include, but are not limited to:

a. **Transportation:** If a member is unable to travel by themselves, the Council will pay all necessary costs for an attendant or driver to transport them. It is the responsibility of the member to notify Council staff to arrange for the hiring of the attendant or driver.

b. **Attendant Care:** If a member needs a personal attendant to assist them while attending meetings, the Council will pay for the cost of this service. It is the responsibility of the member to notify Council staff to arrange for the hiring of the personal care attendant.

c. **Communication Assistance:** If a member needs assistance to communicate or interpret/understand the proceedings of the meetings, the Council will provide this assistance. Such assistance may include an interpreter (sign language), a facilitator, or a communication device (communication board). It is the responsibility of the member to notify Council staff to arrange the appropriate communication assistance.

d. **Accessible Materials**: All materials to be used during Council meetings will be made accessible to members with vision impairments at their request. Accessible means that the materials may be printed in Braille, printed in large type, or read onto audio tape.

e. **Facility Accessibility:** All meetings of the Council and committees will be held in facilities that are fully accessible to any member using a mobility device.

#### Section II. Accommodations for Public Participation

All meetings will be held in accordance with the Nevada Open Meeting Law (Nevada Revised Statutes Chapter 241 – Meetings of State and Local Agencies).

#### Section III. Overnight Accommodations

It is the policy of the Council to encourage all Council members to exercise personal rights, responsibilities, and choices. Therefore, the selection of overnight accommodation while traveling on Council business is the responsibility of each individual Council member. Council staff will inquire as to the accessibility of accommodations and will report the responses to these inquiries in writing to Council members. The staff is not responsible for verifying the verbal claims of any business establishment.

If a Council member has difficulty with the accessibility of overnight accommodations, she/he should bring the matter to the Council’s attention. After consideration of the facts, the Council may write to the owner/manager of the facility informing them of the problems encountered.

#### Section IV. Contracts

All contracts for grant funds shall include regulations from **Title 45** of the Code of Federal Regulations (CFR).

#### Section V. Publications

All publications prepared and distributed by the Council shall be made available in alternative formats if requested.

#### Section VI. Grievance Procedures

Individuals have the right to grieve compliance with ADA, sexual harassment, and discrimination in accordance with the Nevada Administrative Code (NAC).

# 3. RULES OF ORGANIZATION AND PROCEDURE

## 3.1. Council Bylaws

### **3.1.1. Definitions**

The term **“Council”** refers to the NGCDD.

The term **“Year”** refers to the Federal fiscal year from October 1 through September 30.

The term **“DD”** refers to Developmental Disabilities, which is further defined below.

The term **“ID”** refers to Intellectual Disabilities.

The term **“citizen member”** refers to a person with an intellectual and/or developmental disability, a family member of a child with an intellectual and/or developmental disability, or an adult who has an intellectual and/or developmental disability and is unable to advocate for themselves.

The term “**agency member”** refers to a person who represents a relevant state agency, as identified by the DD Act. These include representatives of:

* (I) State entities that administer funds provided under Federal laws related to individuals with disabilities, including the Rehabilitation Act of 1973 (**29 U.S.C. 701 et seq.**), the Individuals with Disabilities Education Act (**20 U.S.C. 1400 et seq.**), the Older Americans Act of 1965 (**42 U.S.C. 3001 et seq.**), and titles V and XIX of the Social Security Act (**42 U.S.C. 701 et seq. and 1396 et seq.**);
* (II) Centers in the State; and
* (III) the State protection and advocacy system; and
* (IV) representatives, at all times, of local and nongovernmental agencies, and private nonprofit groups concerned with services for individuals with developmental disabilities in the State in which such agencies and groups are located.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 defines a developmental disability as a severe chronic disability of an individual that:

* is attributable to a mental or physical impairment or a combination of mental and physical impairments.
* is manifested before the individual attains age 22.
* is likely to continue indefinitely.
* results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency.
* reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, support, or other assistance that are lifelong or of extended duration and are individually planned and coordinated.
* includes infants and young children from birth to age nine who have substantial delay in growth or specific congenital or acquired conditions, and may be considered to have a developmental disability without limitations in meeting three or more of the areas of major life activity. A child can still be treated under the Act if they showcase a high probability of experiencing DD later in life if adequate services are not provided.

**NRS 435.007 (5) – Developmental Disability defined in Nevada Statue.**

**“Developmental disability”** means autism, cerebral palsy, epilepsy, or any other neurological condition diagnosed by a qualified professional that:

* + - * 1. is manifested before the person affected attains the age of 22 years;
        2. is likely to continue indefinitely;
        3. results in substantial functional limitations, as measured by a qualified professional, in three or more of the following areas of major life activity:

(1) Taking care of oneself;

(2) Understanding and use of language;

(3) Learning;

(4) Mobility;

(5) Self-direction; and

(6) Capacity for independent living; and

(d) results in the person affected requiring a combination of individually planned and coordinated services, support, or other assistance that is lifelong or has an extended duration.

**NRS 433.099 – Intellectual Disability defined in Nevada Statue.**

**“Intellectual disability”** means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

**(Added to NRS by 1975, 1591; A 2013, 662) — (Substituted in revision for NRS 433.174)**

You’ll notice some differences between the federal definition of “Developmental Disability” and the state’s definitions of “Intellectual Disability” and “Person with Related Condition”. Most notably, there is no reference to “physical” or “mental” impairment. The current policy and state Eligibility Determination Standards for Developmental Services provide further description of Intellectual Disability and Related Conditions. Person with Related Condition in **NRS 433.211** matches closely with **CFR 435.1010** definitions relating to institutional status: “*Institution for Individuals with Intellectual Disabilities or persons with related conditions”* means an institution (or distinct part of an institution) that—

(a) Is primarily for the diagnosis, treatment, or rehabilitation of Individuals with Intellectual Disabilities or persons with related conditions; *persons with related conditions means* individuals who have a severe, chronic disability that meets all of the following conditions;

(b) It is attributable to—

(1) Cerebral palsy or epilepsy; or

(2) Any other condition, other than mental illness, found to be closely related to Intellectual Disability because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of a person with an intellectual disability, and requires treatment or services similar to those required for these persons.

(c) It is manifested before the person reaches age 22.

(d) It is likely to continue indefinitely.

(e) It results in substantial functional limitations in three or more of the following areas of major life activity:

(1) Self-care.

(2) Understanding and use of language.

(3) Learning.

(4) Mobility.

(5) Self-direction.

(6) Capacity for independent living.

### **3.1.2. Name**

The name of this Council shall be the NGCDD, established in accordance with the provisions of the “Developmental Disabilities Assistance and Bill of Rights Act of 2000,” P.L. 106.402.

### **3.1.3. Purpose**

The purposes of this council are as follows:

1. To exercise those duties of the Council as set forth in the Developmental Disabilities Act and the Federal Regulations, guidelines, and directives pertaining to the Act.
2. To undertake, in the areas of emphasis, projects, and activities that will contribute to long-range comprehensive statewide planning for programs and services for people with developmental disabilities in the State of Nevada.
3. To act as Statewide representatives of the agencies and citizens of the State of Nevada in advising the various officers and agencies of the State concerning matters of relevance to people with developmental disabilities.
4. To act as a systems advocate for ensuring that a comprehensive service network is provided for citizens with developmental disabilities in the State of Nevada.

### **3.1.4. Role and Function**

The NGCDD is appointed by the Governor of the State to conduct systemic change, capacity building, and advocacy activities on behalf of all people with developmental disabilities.

### **3.1.5. Philosophy**

The NGCDD plans and implements all consumer inclusion, systems change and individual support from the philosophical base that independence is the key to human rights and enfranchisement for Nevadans with developmental disabilities. In so doing, the Council and its administering agency subscribe to and are guided by the following principles:

* We support the uniqueness, wholeness, and dignity of each person. We shall strive to respond to the individual needs and preferences of each person we support and serve.
* We enthusiastically advocate for the rights of people with disabilities so they may fully participate in and contribute to community life. This includes enjoying a secure home, family, friends, education, services, and work they find meaningful.
* We view all human life as having equal and unconditional value. Each life should be nurtured, respected, celebrated and fulfilled.
* We celebrate and embrace diversity and will consistently strive for true, and meaningful inclusion of all people.
* We support the life-long process of personal growth and development of all people.
* We will leverage every opportunity to educate others and to advocate for the basic civil rights of people with disabilities:

The right to self-determination.

The right to proper and timely medical care.

The right to a barrier-free environment and accessible transportation.

The right to an appropriate inclusive public education including postsecondary education.

The right to necessary assistance is given in a way that promotes independence.

The right to a choice of lifestyles and residential alternatives.

The right to an income for a lifestyle comparable to that of typical peers.

The right to training, and employment that is competitive and fulfilling.

The right to petition social institutions for equal treatment.

### **3.1.6. Council Responsibilities**

The Council, through Council members, staff, consultants, contractors, or sub-grantees, shall have the responsibilities described below:

1. **Systemic Change, Capacity Building, And Advocacy** - The Council shall serve as an advocate for people with developmental disabilities and conduct programs, projects, and activities that carry out the purpose of the DD Act.
2. **Examination of Areas of Emphasis** - Not less than once every 5 years, the Council shall examine the provision of and need for the Federal areas of emphasis to address on a statewide and comprehensive basis, which include, urgent needs for services, support, and other assistance for people with developmental disabilities and their families, pursuant to the DD Act.
3. **State Plan Development** - The Council shall develop and submit to the Secretary, the State Plan after consultation with the Designated State Agency. Such consultation shall be solely for the purposes of obtaining State assurances and ensuring the plan’s compliance with State law.
4. **State Plan Implementation** - The Council shall implement the State Plan by conducting and supporting the Federal areas of emphasis through systemic change, capacity building, and advocacy activities such as those described in (A) through (K).

(A) *Demonstration Of New Approaches*- the Council may conduct, on a time-limited basis, the demonstration of new approaches to enhance the independence, productivity, integration, and inclusion of individuals with developmental disabilities into the community through sources of funding other than DD funding. This may include assisting those conducting such successful demonstration activities to develop strategies for securing funding from other sources.

(B)*Outreach* - the Council may conduct activities to reach out to assist and enable people with developmental disabilities and their families who otherwise might not come to the attention of the Council to obtain services, support, and other assistance, including access to special adaptation of generic services or specialized services.

(C) *Training* - The Council may conduct training for individuals with developmental disabilities, their families, and personnel (including professionals, paraprofessionals, students, volunteers, and other community members) to enable such individuals to attain access to, or to provide services, support and other assistance, including special adaptation of generic services or specialized services for individuals and families with developmental disabilities. Such activities shall be designed to promote the empowerment of individuals with developmental disabilities and their families.

(D) *Supporting and Educating Communities* - The Council may assist neighborhoods and communities to respond positively to people with developmental disabilities and their families by encouraging local networks to provide informal and formal support and enabling communities to offer such individuals and their families access, resources, and opportunities.

(E) *Interagency Collaboration and Coordination* - The Council may promote interagency collaboration and coordination to better service, support, assist, or advocate for people with developmental disabilities and their families.

(F) *Coordination with Related Councils, Committees, And Programs* - The Council may conduct activities to enhance coordination with:

(i) Other councils or committees, authorized by Federal or State statute, concerning such people with disabilities (such as the State Interagency Coordinating Council under part H of the Individuals with Disabilities Education Act, the State Rehabilitation Advisory Council, and the Statewide Independent Living Council under the Rehabilitation Act of 1973, the State Mental Health Planning Council under part B of title XIX of the Public Health Services Act and other similar councils or committees);

(ii) Parent training and information centers under part D of the Individuals with Disabilities Education Act and other federally funded projects that assist parents of children with disabilities; and

(iii) Other groups interested in systemic change, capacity building, and advocacy for individuals with disabilities.

(G) *Barrier Elimination, Systems Design, and Citizen Participation* - The Council may conduct activities to eliminate barriers, enhance systems design and redesign, and enhance citizen participation to address issues identified in the State Plan.

(H) *Public Education and Coalition Development* - The Council may conduct activities to educate the public about the capabilities, preferences, and needs of people and families with developmental disabilities and to develop and support coalitions that facilitate the policy agenda of the Council, including training in self-advocacy, educating policymakers, and developing citizen leadership skills.

(I) *Informing Policymakers* - The Council may provide information to Federal, State, and local policymakers, including the Congress, the Federal executive branch, the Governor, the State Legislature, and State agencies. This is essential for increasing the ability of such policymakers to offer opportunities and to enhance or adapt generic services or provide specialized services to people and families with developmental disabilities. This can be done by conducting studies and analyses, gathering information, and developing and disseminating model policies and procedures, information, approaches, strategies, findings, conclusions, and recommendations.

(J) *Prevention* - The Council may conduct prevention activities as defined in the DD Act.

(K) *Other Activities* - The Council may conduct other systemic change, capacity building, and advocacy activities to expand and enhance the independence, productivity, integration, and inclusion of people with developmental disabilities into the community throughout the State on a comprehensive basis.

1. **State Plan Monitoring** - Not less than once each year, the Council shall monitor, review, and evaluate the implementation and effectiveness of the State Plan in meeting such plan’s objectives.

1. **Review of Designated State Agency** - The Council shall periodically review the appropriateness of the Designated State Agency and make any recommendations for change to the Governor.

1. **Reports** - The Council shall submit to the Secretary, through the governor, periodic reports on its activities as the Secretary may reasonably request and keep such records and afford such access thereto as the Secretary finds necessary to verify such reports.

1. **Budget** - The Council shall prepare, approve, and implement a budget using amounts paid to the State under this part to fund and implement all programs, projects, and activities under this part including:

(A) Conducting such hearings and forums as the Council may determine to be necessary to carry out the duties of the Council, reimbursing members of the Council for reasonable and necessary expenses for attending Council meetings and performing Council duties (including child care and personal assistance services), paying compensation to a member of the Council, if such member is not employed or must forfeit wages from other employment, for each day such member is engaged in performing the duties of the Council, supporting Council member and staff travel to authorized training and technical assistance activities including in-service training and leadership development, and appropriate subcontracting activities;

(B) Hiring and maintaining sufficient numbers and types of staff (qualified by training and expertise) and obtaining the services of such professional, consulting, technical, and clerical personnel (qualified by training and experience), consistent with State Law, as the Council determines to be necessary to carry out its functions; except that such State shall not (in accordance with Federal Law) apply hiring freezes, reductions in force, prohibitions on staff travel, or other policies that negatively affect the provision of staff support of the Council; and

(C) Directing the expenditure of funds for grants, contracts, interagency agreements that are binding contracts, and other activities authorized by the approved State Plan.

1. **Staff Hiring and Supervision** - The Council shall, consistent with State law, recruit, supervise, and annually evaluate (in accordance with State procedures) the Director. The Director shall hire, supervise, and annually evaluate other staff and be consistent with Federal and State non-discrimination laws. Dismissal of personnel shall be for cause only, based on documented performance evaluations, and consistent with State law and personnel policies. Council directors and staff who are exempt from State personnel policies may be dismissed based only on documented performance criteria.

1. **Staff Duties** - The staff of the Council shall be responsible solely for assisting the Council in carrying out its duties under this part and shall not be assigned duties by the Designated State Agency.

1. **Construction** - Nothing in this part shall be construed to preclude a Council from engaging in systemic change, capacity building, and advocacy activities for people with developmental disabilities and other relevant issues where appropriate.

### **3.1.7. Statewide Planning**

The Council shall develop a State plan every five years which is reviewed annually and includes:

1. A description of the services, support and other assistance being provided to, or to be provided to, people with developmental disabilities and their families under other federally assisted State programs, plans, and policies that the State conducts and in which people with developmental disabilities are or may be eligible to participate. These include programs relating to education, job training, vocational rehabilitation, public assistance, medical assistance, social services, child welfare, maternal and child health, aging, programs for children with special health care needs, children’s mental health, housing, transportation, technology, comprehensive health and mental health, and such other programs as the Secretary may specify;

(B) A description of the extent to which agencies operating such other Federally assisted State programs pursue interagency initiatives to improve and enhance services, support, and other assistance for people with developmental disabilities; and

(C) An examination of the provision, and the need for the provision, in the State of the four Federal priority areas and an optional State priority area, including -

1. An analysis of such Federal and State priority areas in relation to the degree of support for people with developmental disabilities attributable to either physical impairment, mental impairment, or a combination of physical and mental impairments;
2. An analysis of criteria for eligibility for services, including specialized services and special adaptation of generic services provided by agencies within the State, that may exclude people with developmental disabilities from receiving such services;
3. Consideration of the report conducted pursuant to the DD Act;
4. Consideration of the data collected by the State educational agency under the Individuals with Disabilities Education Act;
5. An analysis of services, assistive technology, or knowledge that may be unavailable to assist people with developmental disabilities;
6. An analysis of existing and projected fiscal resources;
7. An analysis of any other issues identified by the State Developmental Disabilities Council.

### **3.1.8. Plan Objectives - The Plan Shall Be**

(A) Specify which of the Federal areas of emphasis selected by the Council for Council’s major systems change, capacity building, and advocacy activities are to be addressed during the plan period and describe the extent and scope of the Federal and State priority areas that will be addressed under the plan in the fiscal year;

(B) Describe the specific 1-year and 5-year objectives to be achieved, include a listing of the programs, activities, and resources by which the Council will implement its systemic change, capacity building, and advocacy agenda in selected areas of emphasis, and set forth the non-Federal share required to carry out each objective; and

(C) Establish a method for the periodic evaluation of the plan’s effectiveness in meeting the objectives.

### **3.1.9. Council Membership**

In General - The Developmental Disabilities Council shall conduct systemic change, capacity building, and advocacy activities on behalf of all people with developmental disabilities.

1. **Council Appointments** - The members of the Council shall be appointed by the Governor from among residents of the State. The Governor shall select members of the Council, at his/her discretion, after soliciting recommendations from organizations representing a broad range of people with developmental disabilities and individuals interested in people with developmental disabilities, including the non-State agency members of the Council. The Council shall coordinate Council and public input to the Governor regarding all recommendations. To the extent feasible, the membership of the Council shall be geographically representative of the State and reflect the diversity of the State with respect to race and ethnicity.
2. **Membership Rotation** - The Governor shall make appropriate provisions to rotate the membership of the Council. Such provisions shall allow members to continue to serve on the Council until each member’s successor is appointed. The Council through the Executive Director shall contact the Governor regarding membership requirements when vacancies remain unfilled for a significant period of time. A recommendation for dismissal from the Council will be made by a full Council vote for any member who misses two or more consecutive meetings without a valid excuse.
3. **Term Limitations** – Council-recommended members are appointed for three-year terms, for a maximum of three consecutive terms.

1. **Council Chairperson** - The Council Chairperson shall always be either a person with a disability or the parent/family member of a person with a disability. The Council Chairperson shall not be a representative of the mandatory agencies and organizations delineated in V(5).

1. **Representation Of Agencies And Organizations** - The Council shall at all times include representatives of the principal State agencies (including the State agencies that administer funds provided under the Rehabilitation Act of 1973, the Individuals with Disabilities Act, and title XIX of the Social Security Act), institutions of higher education, each University Center for Excellence in Developmental Disabilities Education, Research and Education institutions, the Protection and Advocacy Agency, local agencies, non-governmental agencies, and private non-profit groups concerned with services for people with developmental disabilities in the State. Such representatives shall:
2. Have sufficient authority to engage in policy planning and implementation on behalf of the department, agency, or program they represent; and
3. Recuse themselves from any discussion of grants or contracts for which such representatives’ departments, agencies, or programs are grantees or applicants while complying with the conflict of interest policies.
4. **Representation Of Individuals with Developmental Disabilities** - Not less than 60 percent of the membership of the Council shall consist of people who are;
5. All of the following:
6. individuals with developmental disabilities;
7. parents or guardians of children with developmental disabilities; or
8. Immediate relatives or guardians of adults with mentally impairing, developmental disabilities who cannot advocate themselves; and
9. Not employees of a state agency that receives funds or provides services under this part, and who are not managing employees of any other entity that receives funds or provides services under this part.
10. **Composition Of Membership with Developmental Disabilities** - Of the members of the Council described in paragraph (4):
11. One-third shall be individuals with developmental disabilities as described in paragraph (6) (A) (i);
12. One-third shall be parents of children with developmental disabilities as described in paragraph (6) (A) (ii), or immediate relatives or guardians of adults with mentally impairing developmental disabilities as described in paragraph (6) (A) (iii); and
13. One-third shall be a combination of individuals described in paragraph (6) (A).
14. **Institutionalized Individuals** - Of the members of the Council described in paragraph (7), at least one shall be an immediate relative or guardian of an institutionalized or previously institutionalized individual with a developmental disability or an individual with a developmental disability who resides or previously resided in an institution. This clause shall not apply if such an individual does not reside in the State.
15. **Non-Governmental/Nonprofit** - At all times a representative of a non-governmental, non-profit agency that provides services and support to people with developmental disabilities shall be a member of the Council.

### **3.1.10. Meetings**

The Council shall conduct a meeting at least quarterly as determined by the Chairperson. Notice of Council meetings plus agendas will be provided to the administering agency in accordance with Nevada Open Meeting Law. The agenda will be developed by the Executive Director and Council Chair. Each member of the Council shall have one vote. Proxies are not permitted.

The quorum at any meeting of the Council or any of its Committees shall consist of one-half of the members with the addition of the Chair or Vice-Chair of that Committee who has been appointed by that Committee’s Chair. A quorum of the Council shall be required for the affirmative transaction of any business of the Council. A majority of the votes will carry. All meetings shall be in compliance with Nevada Open Meeting Law.

### **3.1.11. Officers**

The Chairperson and Vice-Chairperson will be nominated by the members of the Council. Elections will be held biennially at the September meeting and will coincide with the Federal Fiscal year. The officers will be limited to two consecutive terms.

The Vice-Chairperson shall assume the responsibilities of the Chairperson in his/her absence and shall be prepared to assume the duties of the Chairperson at the end of the tenure.

### **3.1.12. Committees**

1. *The Council Shall Have The Following Standing Committees:*
   1. Executive Committee
   2. Policy Committee
   3. Planning/Evaluation Committee
   4. Budget Committee
   5. Other Committees
      * 1. Ad-Hoc Interview Committee
        2. Ad-Hoc Transportation Committee
2. *Committee Membership*
3. The Executive Committee shall consist of the Council Chairperson, Vice-Chairperson, and Chairpersons of the standing committees. Immediate Council past Chairs and Council past Vice-chairs may remain at their own discretion for a period of one year. After the one-year period, they may be reappointed by the sitting chair. It shall be chaired by the Council Chairperson.
4. The Chairperson of any committee shall be an appointed citizen member of the Council.
5. The Vice-Chairperson of the committee shall be an appointed citizen or agency member.
6. Members of standing and other committees and their chairs and/or facilitators shall be appointed by the Council Chairperson. The Chairperson of each committee shall be a Council member.
7. Membership on standing committees, other than the Executive Committee, shall include Council members and other individuals deemed by the Council Chairperson to have expertise and knowledge that will enhance the function of the committee.
8. All Council Members will be required to serve on at least one Council Committee.
9. Not more than 1/2 of any one committee shall be individuals who are not Council members.
10. The majority of any committee shall be citizen members.
11. Individuals appointed to committees shall have voting privileges within the committee but are not voting members of the Council.

(3) *Committee Duties*

**Executive Committee:**

* The Committee shall act on behalf of the Council when the Committee determines that a situation requires immediate attention and when it is not practical to convene a special Council meeting.
* The Committee shall recommend all Council by-laws and internal policies. This Committee shall act on behalf of the Council to approve by-laws and policies when the Committee determines that a situation requires immediate attention and when it is not practical to convene a special council meeting.
* Other duties deemed necessary by the Chairperson for the effective functioning of the Council are also included.
* The Council chair and vice-chair shall sit on this committee.
* The Chairs and Vice Chairs of all committees shall sit on this committee.

**Policy Committee:**

* The Committee shall highlight federal and state legislative issues of concern to the Council and make recommendations for informing congressional and state legislators about the impact of potential legislation.
* The Committee shall identify and recommend public information, council position statements, and advocacy activities about developmental disabilities that are appropriate for the Council to consider.
* Other activities as assigned by the Council Chairperson.
* This committee shall develop public policy statements.

* 1. **Evaluation Committee:**
* The Committee shall participate in the development of the proposed 5-Year Plan and its annual review and update.
* The Committee shall identify goals and objectives that can be met through the Notice of Funds Available (NOFA) process and assist in developing the NOFA.
* The Committee shall evaluate proposals for grants and make recommendations for funding to the full Council.
* The Committee shall design and administer a self-assessment of the Council’s compliance with federal requirements and the perception of the Council by other state and local entities.
* Other activities as assigned by the Council Chairperson.
  1. **Budget Committee:**
* The Budget Committee Chair shall be appointed by the DD Council Chairperson.
* The Budget Committee shall consist of the Chair and Vice-chair of the DD Council, a fiscal representative of the Designated State Agency, and other members as appointed by the DD Chairperson.
* The Committee shall review biennial budget requests and monitor the fiscal activity of the Council on a quarterly basis.
* The Committee shall establish the amount of funds available for sub-grants on an annual basis.
* This committee will report at each DD Council meeting.
* Other activities as assigned by the Council Chairperson.

**Other Committees:**

Other committees and task forces may be appointed by the Council Chairperson for specific periods of time to address particular identified issues when deemed necessary by a majority vote of the Council. Members of the standing committee and these committees and their chairs and/or facilitators shall be appointed by the Council Chairperson. The Chairperson of each committee shall be a Council member.

1. AD-HOC INTERVIEW COMMITTEE:

* The Committee Chair shall be the DD Council Chairperson.
* Additional required Committee Members shall include DD Council Network partners identified in the DD Act as the Protection and Advocacy Systems (P&A) and the University Centers for Excellence in Developmental Disabilities (UCEDD). No other agency members shall be members of this committee.
* Other Committee Members shall be appointed by the DD Council Chairperson, and a majority must be citizen members, including at least one person with a DD and at least one family member of such individuals.
* The Committee shall be an odd number and no more than 9 members as detailed above.
* This Committee shall be required to select an Interim Executive Director.
* The Committee shall be responsible for identifying the current needs for Council Executive Leadership, writing the job description and interview questions, reviewing potential candidates, interviewing candidates, and making the final selection of the Executive Director.
* This Committee shall disband after the hiring process of the Executive Director is complete.

1. AD-HOC TRANSPORTATION COMMITTEE:

* The Committee Chair shall be a DD Council Citizen Member.
* Additional required Committee Members shall include the DD Council Executive Director, DD Council Chair, Neighbor Network of Northern Nevada (N4) Executive Director, Nevada Department of Transportation Representative, Regional Transportation Commission North and Regional Transportation Commission South Representatives, Statewide Centers for Independent Living Representative, and at least 5 members of the public.
* Other Committee Members shall be appointed by the Chairperson.
* The Committee shall be an odd number and no more than 25 members as detailed above.
* The Committee shall use the NGCDD Transportation Ad-Hoc Committee White Paper and other best practice findings to educate transportation providers and policymakers on the barriers faced by people with I/DD while providing recommendations on best practices for systems change.
* This Committee shall be responsible for identifying the needs of the Transportation Summit for 2023.
* This Committee shall work with transportation providers and policymakers to implement best practice recommendations through the creation of a statewide transportation board(s), ensuring individuals with I/DD have prominent roles on those boards.
* This Committee shall be disbanded by the Executive Committee.

Other committees and task forces may be appointed by the Council Chairperson for specific periods of time to address specific identified issues when deemed necessary by a majority vote of the Council. Members of the standing committee and these committees and their chairs and/or facilitators shall be appointed by the Council Chairperson. The Chairperson of each committee shall be a Council member.

### **3.1.13. Procedure for Amendment**

The Rules of Organization and Procedures may be amended by recommendations of the Executive Committee and two-thirds votes of the members present and voting at any meeting; provided that the meeting notice and the wording of the proposed change are delivered to every member at least two weeks before the date of the meeting.

### **3.1.14. Delegates to The National Association of Councils on Developmental Disabilities**

The Chairperson and the Executive Director will be voting delegates at the National Association of Councils on Developmental Disabilities meetings. The Council may also elect an additional member to serve as a delegate. The Chairperson and Executive Director may attend the Annual Administration on Developmental Disabilities meeting. The Chairperson and Executive Director may designate his/her substitute to attend these National meetings.

## 3.2. Council Position Statements

### **3.2.1. Position on Accessibility**

Accessibility involves much more than providing ramps, it is the key element of inclusion and the baseline of equal service. Accessibility refers to the design of environments, products, and services that facilitate access for people with Intellectual and Developmental Disabilities (I/DD) to the same level of independence and privacy as anyone else. Ensuring effective access to information and services isn’t only about meeting legal requirements or satisfying a policy checklist - it is about constantly striving to expand meaningful participation for all.

Providing equal access to all individuals with disabilities is the key element of the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1992 (ADA). The ADA provides a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities, requiring State and local governments to communicate effectively with people who have I/DD just the same as they would do with someone without these disabilities.

The NGCDD support and promotes the right of individuals with I/DD to meaningful participation and equal access to information, products, and services through universal, accessible design.

**The NGCDD’s current 5-year state plan addresses accessibility under Goal 1, Objective 1.3:**

Reduce identified barriers to accessing technology and digital information for individuals with I/DD experiencing racial and/or ethnic disparities, Deaf/Hard of Hearing, Blind/Visual Impairment, and/or those living in rural communities.

*Policy Recommendations:*

* Promote the inclusion of accessible technologies, and the need for universal, accessible design through education and practices that dispel the myths and misguided understanding of what accessibility is and is not.
* Promote equal access to services and environments by encouraging the adoption of universal design principles and implementing accessible, inclusive practices into all aspects of public engagement.
* Work with the Nevada Legislature and the State of Nevada to mandate training for all State of Nevada employees on the need for accessibility as well as how to create and maintain accessible content.
* Work with the Nevada Legislature and the State of Nevada to mandate the development of inclusive public meeting protocols across all state entities and the requirement of training for state employees on accessible approaches.
* Work with the Nevada Legislature and the State of Nevada to mandate a review of procedures and policies to ensure they are consistent with inclusive and accessible goals.

### **3.2.2. Position on Community Support**

Over 5.4 million children and adults have developmental disabilities, and most of them live at home with families. However, they often receive too few, if any, services and face long waiting lists for needed support.

The NGCDD believes that people with developmental disabilities should receive community support to allow them to live in the setting of their choice for enabling them to participate fully in their community life. Children with developmental disabilities should remain with their family or an alternative family model and receive the necessary support to enhance their community living.

*Policy Recommendations:*

* Change state services and programs to reflect the preference for community-based services versus institutional living.
* Address inequities in access to and funding for direct support caregiver services for all disability populations; including increasing wages for direct support professionals to create a more stable and qualified workforce.
* Ensure the availability of respite care for families with members of all ages and disabilities.
* Promote the use of special needs trusts to financially assist families with disability related-expenses to empower people with developmental disabilities to become more self-sufficient. Promotion of the use of asset development is also critical.
* Remove waiting lists for community living options by increasing financial and other supportive resources.
* Ensure the rapid movement of individuals with developmental disabilities from institutions to community options with necessary support and the transfer of the individuals’ funds to the community programs.

### **3.2.3. Position on Employment**

Working-age people with developmental and other disabilities are among the most unemployed and underemployed segments of our society. Too often, unemployment is accepted as an inevitable result of living with a significant developmental disability. Employment is the avenue to independence and increased socialization for individuals with developmental disabilities.

The NGCDD believes that individuals with developmental disabilities who can and want to work should have access to the resources and support necessary to gain and maintain meaningful community-based employment.

*Policy Recommendations:*

* Remove barriers that create disincentives for people with developmental disabilities to find and maintain competitive employment (employment includes supported employment, job training, and job coaching) with competitive wages in the community. These barriers may include transportation, flexible options for on-the-job support, and continued or potential health care benefits.
* Implement “Employment First” policies that transform the expectations of state agencies, service providers, and people with developmental disabilities. Under “Employment First’, the expectation is that a person with a developmental or other disability can and wants to work, and a successful outcome is finding these individuals meaningful and gainful employment that meets their needs and interests by tailoring services to help them succeed in the workforce.
* Fully fund the state vocational rehabilitation (VR) programs that are significantly underfunded to meet the employment needs of individuals with severe disabilities who need VR services to obtain employment.
* Engage the private sector to raise awareness about and support for inclusion of people with developmental disabilities in the workforce and provide training, incentives, and other support to the business community to increase the hiring of people with developmental disabilities.
* Increase, maintain, or reallocate funding for transition-to-work programs that successfully assist young people with developmental disabilities as they age out of education settings and prepare to seek, gain, and maintain meaningful employment. Increase accountability at the local level to ensure that students have jobs when they graduate.
* Strengthen funding for self-employmentinitiatives that enable people with developmental disabilities to start their own businesses and/or be self-employed.
* Adopt proactive policies by federal, state, and local government agenciesto recruit, hire, train and, mentor people with developmental disabilities.
* Provide incentives to employers to support integrated, community employment at minimum wage or above.

### **3.2.4. Position on Guardianship and Supported Decision Making**

Guardianship is a legal proceeding that can remove certain civil rights and privileges of an individual by assigning control of his/her life, or aspects of their life to someone else.

Many options, other than guardianship, are available to provide counsel, guidance, and assistance with making decisions. The principles of Informed Choice, Person-Centered Planning, and Self-Determination dictate that adults with intellectual/developmental disabilities (I/DD) are respected and supported in making their own life decisions. Individuals who can make life decisions with support from others around them should be enabled to do so.

Supported decision-making is recognized as a less restrictive alternative to guardianship; whereby, trusted supporters are afforded the legal status to be with the adult, participate in discussions, help gather and evaluate information, consider, and communicate decisions so individuals with I/DD understand the situations and choices they face and can make their own decisions without the need for a guardian.

The NGCDD supports the rights of individuals with I/DD to direct their own lives to the maximum of their abilities through changes to the guardianship system in Nevada – A system that promotes the best practices of Person-Centered Planning, Informed Choice and Self Determination through Supported Decision Making.

*Policy Recommendations:*

* Empower individuals by applying the principles of Self-Determination, Informed Choice, and Person-Centered practices in all aspects of their lives.
* Educational and training material about alternatives to guardianship should be provided to people with I/DD, trusted supporters, and educational, medical, financial, legal, and other professionals in order to ensure consistency and opportunity across the state.
* Support legislation that promotes Supported Decision-Making options to be considered as alternatives to guardianship.

### **3.2.5. Position on Health Care**

Individuals with intellectual and developmental disabilities (I/DD) are more likely to experience early death, chronic conditions, and preventable health, dental, and vision problems, compared to persons without disabilities. Even with limited access to affordable care, people with I/DD often face difficulty in recognizing and communicating their own health care needs. Moreover, there is a significant shortage of qualified, trained health care professionals who are prepared and willing to treat individuals with I/DD.

The NGCDD believes that comprehensive health care programs must provide affordable health, dental, and vision care coverage, improved quality, and better cost control while addressing the significant health and health care disparities faced by individuals with developmental disabilities. In addition to improving access to quality medical care for persons with I/DD, the health care system must improve the way our State provides long-term services and support related to all systems of health care such as referrals to affordable and qualified medical professionals, education on preventative health measures, assistance, and supervision with activities of daily living, taking medication, and preparing meals.

*Policy Recommendations:*

Comprehensive health care must adequately address the following:

* Access to affordable health, dental, and vision care coverage for Nevadans with developmental disabilities, removing any bias based on pre-existing conditions, congenital impairments, or whether the intervention is habilitative or rehabilitative in nature. People with I/DD must not experience disability-related discrimination in decisions to provide, delay, deny, or limit health care interventions or treatments.
* People with I/DD must not experience disability-related discrimination when making end-of-life decisions.
* Ensure medications are appropriate to the needs of the patient and do not cause undue harm.
* Assure greater access to quality care by health care providers trained to meet the medical needs of individuals with developmental disabilities.
* Provide appropriate, accessible health, dental, and vision care for individuals with developmental disabilities.
* Ensure all policies and programs result in the creation of equal treatment in health-related services to all individuals.
* Beginning in youth, encourage the inclusion of individuals with I/DD in education, prevention, and wellness programs for overall health, dental, and vision care.
* Develop and strengthen the “medical home” model to meet the health, dental, and vision care needs of individuals with I/DD.
* Support the development and continuation of programs that provide education to optometrists and dental professionals on the needs of individuals with I/DD.
* Support the understanding that wellness, prevention, health promotion, and a robust public health infrastructure are essential components of health care.
* Ensure data and assessments of health outcomes are collected and must include disability status. Public health initiatives must support the goal of reducing health care disparities for people with disabilities and improving health and function.
* Ensure sufficient information is available to understand the risks, demands, potential for significant pain, and benefits of any procedure for which consent is sought provided in ways that accommodate reading, language, learning, and other limitations that are common among persons with I/DD.
* Ensure medical facilities are ADA accessible and have accessible examination and diagnostic equipment that address complex health care needs.
* Ensure medical facilities and providers respect and follow supported decision-making (SDM) agreements. This includes understanding and supporting that many individuals with disabilities are their own guardians and do not have a guardianship.
* Encourage coordinated health care between providers and facilities, with an intentional focus on patients who may be un/underinsured.
* Adopt policies that increase access to telehealth services.
* Encourage health care providers and facilities to work with Medicaid to ensure access to patients who may lack regular access to care.
* Encourage the adoption of policies that promote a spectrum of services to fully recognize that health care is unique to the individual.

### **3.2.6. Position on Housing**

Across the nation, people with developmental disabilities face a severe crisis in the availability of decent, safe, affordable, and accessible housing. Nevada continues to promote inclusion for people with developmental disabilities to live in their communities and guard against return to congregate facilities or other institutions.

The NGCDD believes that citizens with developmental disabilities should live in inclusive, safe, and affordable communities of their choice and be provided with the needed individualized support and accommodations.

*Policy Recommendations:*

* Increase the supply of affordable and accessible housing options that are integrated into the community, including temporary housing, rental housing, and/or home ownership to meet the growing unmet needs of people with disabilities and their families.
* Significantly increase funding for and protect the integrity of HUD programs, U.S. Department of Agriculture housing programs, as well as all other federal/state housing programs providing funding for people with disabilities.
* Provide funding to address the need for safe, affordable, and accessible emergency housing for individuals with disabilities.
* Remove barriers that prevent people from temporary housing, rental housing, or buying their own homes.
* Require that projects developed with public funds apply design standards identical to those in Section 504 of the Rehabilitation Act.
* Eliminate discrimination based on disabilities in all sales, rental, and other non-assisted living accommodations.
* Encourage adoption of universal design as new units are built or remodeled to include key financing stakeholders.

### **3.2.7. Position on Human and Civil Rights**

All individuals regardless of their abilities are entitled to human rights as well as the protection and benefits of the civil rights laws of their country. Individuals with intellectual and/or developmental disabilities are humans and thus are afforded all of the same rights and protections as everyone else. Disability rights are human rights. Everyone deserves to be included and live a full life in their community—accessing the same public spaces, housing opportunities, education, and work as anyone else.

People with I/DD can be found in people of any age, gender identity, race and ethnicity, sexual orientation and sexuality, faith or religion, culture, language, economic status, immigration and legal residency status, familial status, support need, and among people who have other disabilities. Freedom from discrimination is a basic human right and yet many individuals with I/DD have been unjustifiably denied or limited in their lifetime. People with I/DD have the right to share the benefits and riches of society and the world as well as the right to make their own contributions to their communities and society. They have often been denied these rights and opportunities.

The NGCDD believes that all are entitled to human and civil rights regardless of age; gender; race/ethnicity; sexual orientation; cultural, linguistic, geographic, and spiritual diversity; economic status; severity of disability; intensity of needed support; and other factors that expose them to increased risk of rights violations.

*Policy Recommendations:*

* Make all policies and services aligned with disability rights.
* Ensure the inclusion and full participation of persons with disabilities in all facets of community living.
* Increase knowledge of disability rights among all State and public program personnel and ensure the inclusion of people with disabilities into all aspects of their work.
* Ensure the right to medical, psychological, and functional treatment, including prosthetic and orthotic appliances, medical and social rehabilitation, education, vocational training and rehabilitation, aid, counseling, placement services, and other services. All of these will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.
* People with disabilities shall be protected against all exploitation, regulations, and treatment of a discriminatory, abusive, or degrading nature.
* People with disabilities have the right to access care without the fear of denial of treatment.
* People with disabilities have the right to utilize Supported Decision Making.
* People with disabilities have the right to respect and dignity.
* Support the concept of “dignity of risk” which is the right of a person to make an informed choice to engage in experiences meaningful to him/her and which are necessary for personal growth and development.

### **3.2.8. Position on Mental Health**

Individuals with Intellectual and/or Developmental Disabilities are at an increased risk of co-occurring disabilities with mental health conditions. These mental health conditions include but are not limited to major depressive disorder, bipolar disorder, anxiety disorders, and psychotic illnesses, among others. People with I/DD and mental health conditions often experience symptoms that lead to the requirement of services within the mental health care framework. Most mental health professionals do not receive sufficient training on the needs of the diverse population.

The NGCDD recognizes the challenges that policymakers and administrators face in addressing the current needs of Mental Healthcare in Nevada. Presently available treatment options in Nevada are not sufficient to serve the current needs of this community. Increased access to mental health services is necessary to meet the needs of those with intellectual and/or developmental disabilities and mental health conditions.

*Policy Recommendations:*

* Support initiatives that fund programs to provide multiple levels of assistance, therapy, primary care, long-term medical oversight, and individualized support that people with these co-occurring conditions need to live, work, and lead regular lives in the community.
* Support initiatives that ensure greater access to quality care.
* Ensure leadership has active oversight of and participation in the coordination of care for individuals with co-occurring conditions requiring specialized services.
* Expansion of support furnished under the Center for Medicare & Medicaid Services, including Home & Community-Based Medicaid Waiver programs and state funding of improved crisis services and increased access to mental health services.
* Community living - The primary goal and outcome of service delivery should be to enable people with co-occurring disabilities to have friends and to live, attend school, and/or work in the community, consistent with Title II of the Americans with Disabilities Act and the Supreme Court’s Olmstead ruling.
* Design of mental health facilities must be in accordance with the universal design and have language access, that encompasses the unique needs of those with physical and developmental disabilities.
* Knowledge and expertise - Systems change should involve the recipients of support and services and their family members, and advocates in conjunction with key state officials, providers, and subject matter experts with experience in providing and funding high-quality services and support to children and adults with co-occurring disabilities. All of these individuals should be included in the design of new services, support, and funding options. Consideration should be given to including representatives of diverse cultural and linguistic groups.
* All planning for services should be person-centered and individualized.
* Expansion of current programs or addition of new programs must include people with disabilities at the planning table.
* Provisions should be made to specify required qualifications and training expectations for staff members (which should include individuals with lived experiences and family members) who treat children and adults with co-occurring disabilities.
* Support shall be made available for family and friends who provide care to those with co-occurring disorders. Services and support include respite care, integrated care coordination, preventive behavioral support, and crisis intervention.
* Prevention and stabilization must be designed to address the needs of recipients of services and their family members throughout their lives.
* Training and skills development should be provided to leadership, staff, and providers including those who provide peer support.
* Support initiatives that study the current impact of neurodegenerative, other co-occurring, and mental health conditions on those with I/DD.
* Encourage service providers to accept patients who use Medicaid or are un/underinsured, and to provide preventative, as well as rehabilitative care to these individuals.

### **3.2.9. Position on Public Transportation Systems**

Within our society, freedom of movement is a fundamental right. However, it remains a largely unfulfilled promise for citizens with disabilities. Millions of Americans with developmental disabilities have difficulties obtaining transportation services that serve as a vital lifeline to employment, education, health care, and community life.

The NGCDD believes that all publicly funded and/or regulated transportation service systems must be: seamlessly coordinated among all modes of transportation; expanded in suburban, urban, rural, and unincorporated areas to connect places people live with places they work, shop, socialize, worship, attend school, access health care, etc.; incorporated with mobility management and training services for individuals with developmental disabilities; designed to appropriately address insurance and liability of vehicles and operators who serve in a coordinated transportation environment, including non-profit providers); based on principles of universal design; supported by stable and adequate funding; and fully accessible to all people with developmental disabilities.

*Policy Recommendations:*

* Increase funding for mass transit programs (including paratransit).
* Encourage pooled use of vehicles purchased so that underutilized vehicles may be shared.
* Simplify the coordinated planning process for the programs that serve people with developmental disabilities and create transparency and accountability.
* Promote incentives that encourage greater mobility for people with developmental disabilities.
* Advocate that transportation providers have up to 15% of their fleet consisting of accessible vans/taxi cabs – and require training for drivers on how to assist passengers with developmental disabilities.
* Support coordinated human services and public transportation planning process and its structure.
* Encourage the use of uniform data collection to evaluate customer satisfaction and to support the coordination of transportation efforts.

### **3.2.10. Position on Sexual Health**

Historically, people with I/DD have been thought to be asexual without needing to have loving and fulfilling relationships with others. Their rights to sexuality, which is essential to human health and well-being, have been denied and this has negatively affected people with I/DD in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. People with I/DD historically lack access to appropriate sexuality education which may cause them to engage in inappropriate sexual activity because of manipulation, loneliness, or physical force instead of an expression of their sexuality. Lack of accurate information being provided on sexuality and sexual health is a key factor in higher rates of abuse for people with I/DD.

The NGCDD believes that every person has the right to exercise choices regarding relationships and sexual expression regardless of the presence of I/DD or the severity of their diagnosis. Thus, having I/DD does not justify the loss of rights related to sexuality, sexual education, and sexual health.

The NGCDD supports the position of the World Health Organization on the sexual rights of people living with a disability. These include the right to:

* be recognized as having a sexual nature just like anyone else.
* be protected from sexual harassment, exploitation, and physical, sexual, and emotional abuse (regardless of the diagnosis of the individual abused or the person doing the abusing).
* be protected from forced sterilization solely because of their disability.
* explore and express their gender and sexuality.
* have relationships based on consent, respect, and safety.
* choose when, whether or not, to have sexual experiences.
* learn lessons from life’s experience, with support and skill development where required.
* control decisions that affect their sexual and reproductive health and relationships as much as possible.

*Policy Recommendations:*

* School districts, medical personnel, first responders, and other trusted members of the I/DD community shall promote the sharing of accurate information about sexuality, sexual health, sexual choices including orientation, and other various sexual health-related topics to people with I/DD, their family members, other service providers, and those outside of the I/DD community in order to promote safe and consensual sexual health.
* School districts, medical personnel, first responders, family members, and other trusted members of the I/DD community shall be educated about the important topics listed above for people with I/DD in order to promote safe and consensual sexual health and to provide care that is supported and well informed.
* Implement training that provides education on safe behaviors in relationships, including sexual and non-sexual relationships.
* Implement policies that promote providing information on options, rights, and services available to people with I/DD in order to ensure safe and consensual sexual health.
* Implement policies that are welcoming and inclusive of all sexualities and relationship styles.
* Implement policies that promote the empowerment of people living with a disability to participate as fully as they are able in pursuit of their own sexual and reproductive health, and in achieving a healthy relationship with both their own sexuality and with other people.
* Discourage the use of guardianships or positions of power to control or manipulate relationships.
* Discourage abuse of power in situations or relationships that may negatively influence another person’s desires, identity, orientation, or other relationships.
* Discourage unsupportive or negative behaviors in relationships of a romantic and non-romantic nature.
* Implement policies that promote the sharing of information about dating and relationships. This information shall include various types of relationships, including sexual and non-sexual in nature.
* Implement policies and procedures that support marriage, child-rearing, and adoption for people with disabilities.
* Implement policies and procedures that encourage safe relationships including those online and long-distance.
* Discourage unsafe dating practices and encourage meeting potential partners in safe situations.
* Discourage negative stigmas and beliefs surrounding the fact that people with disabilities are sexual beings (just as billions of other humans are) with desires and needs.
* All individuals, regardless of their disability or diagnosis, shall have the right to make their own informed decisions regarding sterilization and birth control. For patients with impaired decision-making capacity or understanding, a representative may be used. This representative’s decisions must be made in the best interests of the patient, not the interests of others, including carers, other family members, or the community.
* People with I/DD who are also intersex, transgender, and/or gender diverse should have equitable access to quality sexual and reproductive health care, and to health services that are inclusive, free of discrimination and stigmas, and responsive to their individual health care needs.
* People with I/DD should have access to accurate medical information on gender affirmation when requested and access to medical providers who can accurately provide medical advice on gender affirmation.
* Encourage implementation of policies that protect the right to reproductive health care regardless of the person’s diagnosis or abilities.

### **3.2.11. Position on Transparency, Accountability, and Inclusion**

Transparency, accountability, and inclusion are essential to ensure those with disabilities receive quality services. This involves advocacy, capacity building, and systemic change activities resulting in improved choice in consumer and family-centered services for individuals with developmental disabilities. Activities include interagency coordination and collection of data resulting in improved services, support, and other assistance. Such activities promote self-determination, independence, productivity, and inclusion in all aspects of community life for individuals with developmental disabilities.

The NGCDD believes individuals with developmental disabilities must define their own quality of life/services. All service systems, such as education, employment, health, housing, childcare, recreation, transportation, and any other system that impacts persons with developmental disabilities, should provide transparency with the services they provide. This includes identifying problems and making improvements that enhance the quality of life for people with developmental disabilities.

*Policy Recommendations:*

* Support compliance with all laws, certification requirements, licensing standards, and contractual obligations.
* Promote and support individuals to find and maintain relationships with people in their communities beyond paid providers and caregivers.
* Ensure access to home and community-based services and support that are planned and implemented in keeping with each individual’s unique needs, expressed preferences, and decisions concerning his/her life in the community.
* Empower individuals by embracing the principles of self-determination and applying person-centered practices.
* Demand statewide transparency from information management systems that assist in the collection, tracking, trending, and analysis of meaningful personal outcomes.
* Ensure access to information and support necessary to affect public policy at the local, State, and national levels.
* Ensure access to information about services and support that individuals and families need to make informed choices.
* Empower individuals by supporting the independent living philosophy which is based on the belief that persons with disabilities have the same basic human rights as persons without disabilities to participate in and contribute to community life.

### **3.2.12. Position on Transportation**

Within our society, freedom of movement is a fundamental right. However, it remains a largely unfulfilled promise for citizens with disabilities. Millions of Americans with developmental disabilities have difficulties obtaining transportation that serves as a vital lifeline to employment, education, health care, and community life.

The NGCDD believes that all publicly funded and/or regulated transportation service systems must be: seamlessly coordinated among all modes of transportation; expanded in suburban, urban, rural, and unincorporated areas to connect places people live with places they work, shop, socialize, worship, attend school, access health care, etc.; incorporated with mobility management and training services for individuals with developmental disabilities; designed to appropriately address insurance and liability of vehicles and operators who serve in a coordinated transportation environment, including non-profit providers); based on principles of universal design; supported by stable and adequate funding; and fully accessible to all people with developmental disabilities.

*Policy Recommendations:*

* Increase funding for mass transit programs (including paratransit).
* Encourage pooled use of vehicles purchased so that underutilized vehicles may be shared.
* Simplify the coordinated planning process for the programs that serve people with developmental disabilities and create transparency and accountability.
* Promote incentives that encourage greater mobility for people with developmental disabilities.
* Advocate that transportation providers have up to 15% of their fleet consisting of accessible vans/taxi cabs – and require training for drivers on how to assist passengers with developmental disabilities.
* Support coordinated human services and public transportation planning process and its structure.
* Encourage the use of uniform data collection to evaluate customer satisfaction and to support the coordination of transportation efforts.

### **3.2.13. Position on Voting**

Voting is a fundamental civil right for Americans to have a voice in choosing the elected officials whose decisions impact our lives, families, and communities. Individuals with intellectual and developmental disabilities (I/DD) are more likely to experience difficulties in registering to vote, requesting absentee ballots, and casting their vote, compared to persons without disabilities. Even with limited access to Americans with Disabilities Act (ADA) compliant machines, many poll workers are unfamiliar with and unable to provide instruction to someone with a disability on how to properly use the machine. When assistance is provided, it is often without the privacy of the individual’s vote in mind.

Several federal laws recognize and protect the right of people with disabilities to vote. They set standards to ensure access to polling places and to permit assistance to voters where it is needed. The **Help America Vote Act of 2002 (HAVA)**requires jurisdictions responsible for conducting federal elections to provide at least one accessible voting system for individuals with disabilities at each polling place in federal elections. The accessible voting system must provide the same opportunity for access and participation—including privacy and independence—that other voters receive. Universal accessibility creates a world that does not separate anyone based on their abilities. The fundamental problem is that voters with disabilities are being offered a “separate but equal” approach to voting, yet in this case “separate” is **not** equal.

The NGCDD advocates for accessible, effective, and efficient election processes at all levels, that have a universal design for all voters.

*Policy Recommendations:*

Voting for people with disabilities must adequately include the following:

* Access to working ADA-compliant machines at all polling locations, with polling workers trained and available to assist, if requested.
* Access to private and equal locations for individuals to cast their ballots.
* Ensure all policies and programs result in the creation of equal treatment and access to all universally designed voting services for all individuals.
* Access to reasonable voting hours and expanded transportation hours to accommodate public transportation users and/or voters who work.
* Develop and strengthen inclusive laws that protect the right to vote, easy access to voting machines, easy voter registration and absentee ballot requests, reasonable hours to vote which reflect the needs of working voters, and elimination of government ID barriers to voting.
* Beginning in youth, encourage inclusion of individuals with I/DD in all levels of voting and education on voting rights in schools.
* Develop and strengthen all currently available polling locations and machines in Nevada.
* Strengthen and encourage the use of currently available Nevada's Effective Absentee System for Elections (NVEASE), which can be accessed at [www.nvease.gov](http://www.nvease.gov).
* Support the development and continuation of voting options that provide people with I/DD with multiple options to register to vote, request absentee ballots, and cast their ballots.
* Provide education to law and policymakers on the needs of individuals with I/DD regarding all aspects of voting.

# 4. MEMORANDUM OF UNDERSTANDING (MOU)

Memorandum of Understanding Between the NGCDD and The Department of Health and Human Services Director's Office.

## 4.1. Purpose

The purpose of this Agreement is to specify the relationship and responsibilities of the Director's Office within the Department of Health and Human Services (DHHS) and Nevada's Governor's Council on Developmental Disabilities (NGCDD) (the Council) and to detail the roles of DHHS as Designated State Agency (the DSA) and the Council in implementing the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106.402 (the DD Act).

It is assumed that the agreement in place will be followed to the fullest extent. Changes cannot be made to this document or the authority within the document without consent by the Council or Executive Committee in the event the full Council cannot convene in a reasonable amount of time. No changes may be made without explanation or merit.

In like manner, it is DHHS's intent to be responsive to the intent of the DD Act that provides for the Council to determine the numbers and types of staff necessary to carry out NGCDD responsibilities and activities.

The NGCDD will work cooperatively with the DSA to establish procedures for the processing of the NGCDD grants, contracts, and personnel actions, recognizing that state and federal law vest fiscal, personnel, and rulemaking authority in the Council concerning activities carried out with funds available to the NGCDD. Federal law establishes that the DSA, and any other agency, office, or entity of the State, will not interfere with the advocacy, capacity building, systemic change activities, budget, personnel, State plan development, or plan implementation of the Council.

The DSA will provide administrative support services to the NGCDD as detailed in this MOU. The provision of these services is subject to DSA’s then-current operating procedures and systems. Nothing in this MOU obligates the DSA to provide or purchase for the NGCDD any administrative service or support not regularly available or provided by the DSA. Any requests by the NGCDD for modification to DSA services or support shall be subject to negotiation at the time of the request and to additional reimbursement as allowed by the DD Act. The NGCDD agrees to cooperate with the DSA in providing any information needed by the DSA to carry out its duties.

## 4.2. Background

The DD Act provides a formula grant to accomplish comprehensive planning for people with developmental disabilities, develop a State Plan, and implement selected activities contained in the State Plan. Functions related to the implementation of activities are performed by the NGCDD, the Department of Health and Human Services, and other State agencies. The Director's Office within the Department of Health and Human Services and the Council recognize and agree to the Congressional intent that the Council must be free to act as an "independent advocate for people with developmental disabilities", and that the activities of DHHS as the Designated State agency under Sec. 125(d)(3) shall be "expressly limited to ensuring that expenditures are made in a manner consistent with State Law regarding grants and contracts, proper accounting, bookkeeping, and other fiscal controls, the provision of assurances and the provisions of administrative support services for this program."

## 4.3. Objectives

The objective of this Agreement is to formally establish a basis for an effective working relationship between the Council and DHHS, hereby referred to as the DSA. This can be accomplished through a clear and mutually agreed upon assignment of authority and responsibility in the following areas:

* + - 1. Identification/Designation of the Administering Agency.
      2. Provision of operating and administrative support.
      3. State Plan Development Activities
      4. Review of Designation and Re-Designation.
      5. Dispute Resolution
      6. Modification or Termination of Agreement
      7. Other Understandings

## 4.4. Statement Of Agreement

The Council and the Department of Health and Human Services (DHHS) agree to the following:

### **4.4.1. Identification/Designation of the Administering Agency**

The Department of Health and Human Services was established on July 1, 2009, as the designated State agency for implementation of the Developmental Disabilities Program as defined by the DD Act. DHHS and the Council agree that DHHS will help implement this Agreement by providing administrative and fiscal services and support, and by acting in partnership with the Council to carry out its mission and activities.

The recognition of the provision of the DD Act, the Council and the DHHS hereby agree that there shall be no conflict of interest regarding the Council's ability to act as an independent advocate for people with developmental disabilities. If, at any time, a simple majority of the total non-state agency members of the Council finds that such a conflict exists, they shall inform the Council Chairperson who shall resolve the conflict with the Director of the Department of Health and Human Services. If it remains unresolved, the Council Chairperson shall report the findings to the Administration on Developmental Disabilities and the Governor for appropriate action to resolve the matter so that no conflict of interest exists.

### **4.4.2. Provisions of Operating and Administrative Support**

*Fiscal Administration*

**Budget Development:** It shall be the responsibility of the Council to develop its budget for annual receipt of Federal funds. It is the joint responsibility of the Council and DHHSto translate the Council's Federal budget into a particular format which may be necessary to ensure timely access to Council funds through the State system. This budget will then be reflected in the biennial Executive Budget.

It is the responsibility of the DSA to receive, account for, and disburse funds on behalf of the NGCDD in accordance with state and federal law and as authorized by the NGCDD staff, provided that the DSA shall not encumber funds available to the NGCDD, transfer funds between the NGCDD budget categories or from the NGCDD to any other entity, or otherwise initiate changes or expenses against funds available to the NGCDD without specific authorization in advance by the NGCDD.

**Accounting, Reporting, and Expenses:** DHHS shall process payment of Council expenses incurred through the day-to-day operation of the Council and appropriate activities of Council sub-grantees. The DSA shall keep and provide access to such records as the Secretary of Health and Human Services and the Council may determine to be necessary, and shall submit an expenditure report to the Councils quarterly. The DSA shall provide fiscal controls and fund accounting procedures necessary for proper disbursement of and accounting for the NGCDD funds. The DSA shall provide or assist the NGCDD in securing the non-federal share of the cost of projects as required by federal law.

**In-Kind Match:** DHHS shall assist the Council in ensuring the provision of adequate in-kind matching funds and certification of such matches, in compliance with Federal requirements.

**Operational Requirements:** Both office space and equipment of the Council shall be purchased in accordance with the approved Council budget and relevant State policies and procedures. The location of all facilities and leases related to the Council's operation will be subject to Council approval and shall not be located on the site of any other state or private service/fund providing agency for people with disabilities. DHHS will ensure access to such support services as are afforded by Executive Branch agencies in the State of Nevada.

*Personnel Administration*

Council employees, including the Executive Director, while working for the Council, shall be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and shall not be assigned duties by the DSA or any other agency or entity of the State. Council employees shall be considered State employees only to the extent necessary in order to ensure efficient and full compliance with the DD Act and shall receive pay and benefits through the State Personnel System. The Council will be exempt from any hiring freezes, reductions in force, prohibitions on travel, or other policies to the staff of the Council, to the extent that such policies would impact the staff or functions funded with Federal funds or would prevent the Council from carrying out its functions under the DD Act.

**Recruitment and Employment of the Director of the Council**: The Council shall, by way of the Ad-Hoc Interview Committee in conjunction with the Council Chair, consistent with State law, recruit and hire a Director of the Council, should the position of Director become vacant, and supervise and annually evaluate the Director. Council recruitment, hiring, and dismissal of staff shall be conducted in a manner consistent with Federal and State nondiscrimination laws. Dismissal of personnel shall be conducted in a manner consistent with State law and personnel policies. The Director of DHHS will act as the appointing authority per the requirements of the State Administrative Code.

**Recruitment and Employment of Staff:** The Director of the Council shall, consistent with the State law, be responsible for the recruitment, hiring, evaluation, and termination of all Council staff. The Director of the Council shall participate in the selection of the Director of DHHSshould that position become vacant.

**Performance Evaluation and Supervision:** All Council Members shall jointly undertake the Annual Performance Evaluation from the Director in accordance with the DD Act and State Personnel policies and procedures. The Director of the Council shall conduct the Performance Evaluations and supervision of other Council staff. All Annual Performance Evaluations shall be conducted in compliance with the Council State Plan and the Nevada Department of Personnel policies and procedures.

**Personnel Policies:** Staff assigned to support Council activities through grants or contracts authorized by the Council, shall be supervised by the Director of the Councilin relationship to the Council's State Plan and the requirements of such grants and contracts.

*State Plan Development Activities*

The Council shall perform assessments of services and needs relevant to persons with developmental disabilities; determine service gaps and identify unserved or underserved populations; obtain data regarding consumer and family satisfaction; establish objectives and areas of emphasis for addressing service needs; and implement and evaluate identified action plans.

The Council shall develop and submit the Council State Plan to the Secretary of Health and Human Services after consultation with the DSA under the State plan. Such consultation shall be solely for the purposes of obtaining State assurances and ensuring consistency of the plan with State law. The Council will monitor, review, and evaluate annually, the implementation of such Council State Plan; submit to the Secretary of Health and Human Services, through the Governor, such periodic reports on its activities as the Secretary of Health and Human Services may make a reasonable request, and keep such records and afford access thereto as the Secretary of Health and Human Services finds necessary to verify such reports.

The DSA shall support the NGCDD in developing required state plans, strategic plans, performance measures, and related items (and other state reporting).

*Review of Designation and Re-Designation:*

The Council may request a review of and change in the designation of the Designated State Agency by the Governor. Re-designation of Designated State Agency may be made only after all of the following conditions as outlined in **Sec. 124(c)(d)(2)(C)** of the DD Act have been met:

* The Council requests a review of and change in the designation of the designated State agency by the Governor. The Council shall provide documentation concerning the reason the Council desires a change to be made and make a recommendation to the Governor regarding a preferred designated State agency.
* The Governor considers the comments and recommendations of the general public and a simple majority of the total non-State agency members of the Council with respect to the designation of the State agency.
* The Governor makes an independent assessment that the designation of such a State agency will not interfere with the budget, personnel, priorities, or other action of the Council, and the ability of the Council to serve as an independent advocate for people with developmental disabilities.

*Dispute Resolution*

Disputes concerning the implementation of this MOU between the NGCDD and the DSA must first be resolved at the executive staff level if possible. If either party determines that the dispute cannot be resolved at the executive staff level, the NGCDD and the DSA agree to pursue resolution through the use of communication between the State of Nevada Deputy Attorney General and/or the Information and Technical Assistance Center for Councils on Developmental Disabilities (ITACC). ITACC is a federally funded training and technical assistance project that is overseen by the Administration on Disability (AOD)/Office of Intellectual and Developmental Disabilities (OIDD). **Section 129(b)** of **PL 106-402** provides that funding be made available to provide technical assistance to entities funded under the DD Act (**PL 106-402**). ITACC is the entity providing technical assistance to Councils on Developmental Disabilities.

*Modification or Termination of Agreement:*

This agreement shall become effective upon the signature of all parties and may be modified or terminated with a thirty-day notice and with written agreement by all parties: NGCDD and Department of Health and Human Services. This MOU will be reviewed annually by all parties and may be expanded, modified, or amended at any time upon the mutual written agreement as stated above. In the event there is a new Council Chair, Council Vice Chair, Executive Director, or Designated State Agency Representative, this agreement shall be re-signed by all parties.

In the event that either party would like to take action to terminate or modify this agreement, such actions do not alone affect the status of the Governor’s designation of the Department of Health and Human Services as the NGCDD’s designated state agency pursuant to provisions of the DD Act. In the event that any provisions of this agreement become unenforceable or void, such will not invalidate any other provisions of this agreement.

*Other Understandings*

The NGCDD agrees to reimburse the DSA for the services provided under the MOU in accordance and alignment with the provisions listed in the DD Act. The NGCDD will reimburse the DSA at not more than 5% or $50,000, whichever is less, each fiscal year for basic services of accounting, budgeting, purchasing, and HR services provided.

# 5. OUR 5-YEAR STATE PLAN

## 5.1. Goals, Objectives & Activities

Each 5-year plan is reviewed and updated annually. An Annual Program Performance Report is submitted indicating Council activities and progress made toward each identified Goal. The Goals, Objectives, and Activities established by the Council to be addressed during the 5-year period, October 1, 2021, through September 30, 2026, are:

### **5.1.1. GOAL 1**

“Individuals with I/DD and/or family members of individuals with I/DD will be able to make more informed decisions about their lives by improving access to information on services, support, and rights.”

Areas of Emphasis and identified barriers addressed:Quality Assurance,not knowing what services are available, not enough or can't access services, targeted disparity (racial/ethnic and rural communities).

*Objectives*

**1.1 In-house** Council members and staff will provide and participate in public education activities that increase Nevadans’ awareness of disability services, policies, and practices.

Activities:

1. The self-advocacy coordinator will create and distribute a statewide quarterly newsletter in English and Spanish via email, direct mailing, and social media that provides resources, information, and support in plain language on advocacy, current policy issues, health, mental health, social services, housing, transportation, employment, education, transition, quality assurance and other subjects relevant to the North, South, and Rural areas of the State.
2. The self-advocacy coordinator will regularly collect input to gauge impact and inform future newsletters.
3. Council members and staff will participate in at least 5 Public Awareness Events in communities across the State to inform individuals with developmental disabilities, their families, and professionals about resources and/or topics of concern identified through public input for this State Plan.

**1.2 In-house** Council members and staff will participate in a minimum of 6 (councils/committees/coalitions) to promote communication within and between agencies to ensure cohesive information about services and support is available to more individuals and families dealing with I/DD.

Activities:

1. Council members and staff will participate in statewide committees and councils comprised of multiple agency representatives.
2. Council members and staff will regularly report on information gathered to Council members and self-advocates. The self-advocacy coordinator will include this information in the quarterly newsletter.

**1.3 Grant** Reduce identified barriers to accessing technology and digital information for individuals with I/DD representing racial and/or ethnic disparities, Deaf/Hard of Hearing, Blind/Visually Impaired, and/or those living in rural communities.

Activities:

1. Use information gathered from Council efforts and other stakeholder input to educate technology service providers and policymakers on the barriers faced by people with I/DD and provide recommendations on best practices for systems change.
2. Work with digital service providers and policymakers to implement best practice recommendations.
3. Provide ongoing, coordinated outreach to Hispanic, Blind/Visually Impaired, Deaf/Hard of Hearing, and Rural communities statewide on resources and support for accessing digital information needed to make informed decisions, and track outcomes to inform future needs.

**1.4 In-house** Council members and staff will address emerging needs of individuals with I/DD through state, regional, or local level systemic change.

Activities:

1. Use information gathered from Council efforts and other stakeholder input to develop and implement advocacy and communication efforts in conjunction with individuals with I/DD, family members, and other key stakeholders to address needed changes to statutes, rules, policies, procedures, practices, and/or funding/staffing issues that improve outcomes for individuals with I/DD.
2. Work with key stakeholders and policymakers to implement best practice recommendations.
3. Provide ongoing, coordinated outreach to Access and Functional Needs communities statewide on resources and support for emerging needs and track outcomes to inform future needs.

### **5.1.2. GOAL 2**

“Individuals with I/DD will have the information, education, and training necessary to participate in local and state advocacy and policy-making activities.”

Areas of Emphasis and identified barriers addressed: Quality Assurance, Education (school-age through college), DD Act Mandates for Advocacy, DD Network Collaboration, Youth and Leadership.

*Objectives*

**2.1 In-house** Council members and staff will establish or strengthen a minimum of one State self-advocacy organization led by individuals with I/DD in Nevada (DD Act Mandate).

Activities:

1. Support individuals with I/DD to participate in Legislative sessions by providing information on current policy initiatives and meeting with their legislators to educate them on issues important to them.
2. Provide annual funding opportunities for individuals with I/DD to attend disability-related conferences and summits to increase their knowledge and share that knowledge with other Nevadans with developmental disabilities.
3. The self-advocacy coordinator will collaborate with DD Network Partners and other DD stakeholders to facilitate a DD Network Statewide Self-Advocacy Summit every other year, led by individuals with I/DD for individuals with I/DD, to identify common barriers, and enhance advocacy skills, knowledge and connections to create a stronger unified voice within the I/DD community.

**2.2 In-house** Council members and staff will annually support individuals with I/DD who are considered leaders, to provide leadership training to 15 individuals with I/DD who may become leaders (DD Act Mandate).

Activities:

1. The self-advocacy coordinator will annually implement curriculums such as the NGCDD Youth Empowering Students (Y.E.S.) peer-to-peer education model in a total of 3 schools throughout the state (North, South, and Rural) to provide students and teachers with information on self-determination, advocacy, post-secondary education, employment, and other transition options upon graduation.
2. Council members will participate in the implementation of curriculums as appropriate.

**2.3 In-house** Council members and staff will support people with I/DD to participate in cross-disability and culturally diverse Coalitions(DD Act Mandate).

Activities:

1. The self-advocacy coordinator will work with Council members and advocacy groups to annually identify 5 individuals with I/DD representing North, South, and Rural areas of the state who want to participate in cross-disability and culturally diverse Coalitions.
2. The self-advocacy coordinator will work with Council members to support identified individuals in finding Coalitions that would best fit their interests and support education to those Coalitions on the benefits of including individuals with I/DD, and the best way to include them.

**2.4 In-house** DD Network Partners: NGCDD and Council members; Nevada Center for Excellence in Disabilities (NCED); Nevada Disability Advocacy and Law Center (NDALC), will annually support leadership training for a minimum of 20 individuals with I/DD and/or family members of individuals with I/DD (DD Act Mandate).

Activities:

1. Council staff will facilitate training.
2. Council members will participate in training as appropriate.
3. DD Network Partners will provide support and sponsorship as appropriate.
4. DD Network Partners will recruit and promote training.
5. DD Network Partners will provide staff as needed.

### **5.1.3. GOAL 3**

“Develop and strengthen systems that improve quality services and access to quality services, and support for individuals with I/DD and their families.”

Areas of Emphasis and identified barriers addressed:Quality Assurance, Employment, Health, Education (transition services in high school), Transportation and Housing,not knowing what services are available, not enough, or can't access services.

*Objectives:*

**3.1 Grant** Create systems change through the implementation of policies to reduce the barriers to transportation for people with I/DD in Nevada.

Activities:

1. Use the NGCDD Transportation Ad-Hoc Committee White Paper and other best practice findings to educate transportation providers and policymakers on the barriers faced by people with I/DD and provide recommendations on best practices for systems change.
2. Work with transportation providers and policymakers to implement best practice recommendations through the creation of a statewide transportation board(s), ensuring individuals with I/DD have prominent roles on those boards.

**3.2 Grant** Educate individuals with I/DD, their families, and community-based employers/employer groups on National best practices, and the benefits of hiring individuals with I/DD.

Activities:

1. Annually provide coordinated outreach and education to 20 community-based employers/employer groups on National best practices for employing individuals with I/DD in Nevada.
2. Annually provide coordinated outreach and education to 30 individuals with I/DD and their families on employment rights and options in Nevada.

**3.3 Grant** Improve access to quality housing options and support for individuals with I/DD Statewide.

Activities:

1. Fund initiatives to study current housing options available to individuals with I/DD.
2. Annually provide coordinated outreach and education to 30 individuals with I/DD and their families on housing options and support.

**3.4 Grant** Increase access to quality services and support for individuals with I/DD transitioning into or in adulthood.

Activities:

1. Engage Council members, Partners in Policymaking graduates, self-advocacy leaders, and DD Network Partners to annually educate a minimum of 20 professionals statewide (including teachers, and community and state agency personnel) on the rights, services, and options available to individuals with I/DD after high school.
2. Engage Council members, Partners in Policymaking graduates, self-advocacy leaders, and DD Network Partners to annually educate 15 parents statewide on the rights, services, and options available to individuals with I/DD after high school.
3. Engage Council members, Partners in Policymaking graduates, self-advocacy leaders, and DD Network Partners to annually educate a minimum of 15 individuals with I/DD statewide living in group or nursing homes on the rights, services, and options available to them.

# 6. COMMONLY USED ACRONYMS

|  |  |
| --- | --- |
| ABLE ACT | Achieving a Better Life Experience Act |
| ABA | Applied Behavior Analysis |
| ACL | Administration for Community Living |
| ACLU | American Civil Liberties Union |
| ADA | Americans with Disabilities Act |
| ADHD | Attention Deficit Hyperactivity Disorder |
| AIDD | Administration on Intellectual & Developmental Disabilities |
| AOD | Administration on Disability |
| APSE | Association for Persons in Supported Employment |
| ARC | Known as the ARC - A statewide non-profit advocacy organization |
| ASD | Autism Spectrum Disorder |
| AT | Assistive Technology |
| AUCD | Association of University Centers on Disabilities |
| CCD | Consortium for Citizens with Disabilities |
| CEC | Council for Exceptional Children |
| CIL | Centers for Independent Living – in Nevada, they are the NNCIL, SNCIL |
| CMS | Centers for Medicare and Medicaid Services |
| CP | Cerebral Palsy |
| DD ACT | Developmental Disabilities Assistance and Bill of Rights Act |
| DD | Developmental Disability |
| DHHS | Department of Health and Human Services |
| DSA | Designated State Agency - For NV this is DHHS |
| DSM | Diagnostic and Statistical Manual of Mental Disorders |
| EI | Early Intervention |
| EIS | Early Intervention Services |
| ESY | Extended School Year |
| FAPE | Free and Appropriate Public Education |
| FERPA | Family Educational Rights Privacy Act |
| FTA | Federal Transit Administration |
| FFY | Federal Fiscal Year |
| HCBS | Home & Community Based Services |
| HUD | Housing and Urban Development. |
| ICC | Interagency Coordinating Council |
| ICF | Intermediate Care Facility |
| IDD | Intellectual/Developmental Disability |
| IEP | Individualized Education Program |
| IFC | Interim Finance Committee |
| IFSP | Individualized Family Services Plan |
| ISP | Individual Service Plan |
| JDT | Jobs and Day Training |
| LEA | Local Education Agency |
| LRE | Least Restrictive Environment |
| LTSS | Long Term Services and Support |
| NACDD | National Association of Councils on Developmental Disabilities |
| NCD | National Council on Disability |
| NCIL | National Council on Independent Living |
| NDRN | National Disability Rights Network |
| NICHCY | National Information Center for Children & Youth with Disabilities |
| NIH | National Institutes of Health |
| NOFA | Notice of Funds Available |
| OCR | Office of Civil Rights (U.S.) |
| ODEP | Office of Disability Employment Policy |
| OIDD | Office of Intellectual and Developmental Disabilities |
| OSEP | Office of Special Education Programs (U.S.) |
| OSERS | Office of Special Education and Rehabilitation Services |
| OT | Occupational Therapy |
| P&A | Protection and Advocacy System (this is the NDALC in Nevada) |
| P.L. | Public Law |
| Part C | Section of the DD Act that deals with Early Intervention |
| PAS | Personal Assistance Services |
| PBS | Positive Behavioral Support |
| PBIS | Positive Behavioral Interventions & Support |
| PCA | Personal Care Assistant/Attendant |
| PNS | Project of National Significance |
| PT | Physical Therapy |
| PTIC | Parent Training & Information Center |
| RFP | Request for Proposals |
| RSA | Rehabilitation Services Administration |
| SILC | Statewide Independent Living Council |
| SLA | Supported Living Arrangement |
| SLP | Speech Language Pathologist |
| SSA | Social Security Administration |
| SSDI | Social Security Disability Insurance |
| SSI | Supplemental Security Income |
| TA | Technical Assistance |
| UCEDD | University Center for Excellence in Developmental Disabilities (this is the NCED in Nevada) |
| VR | Vocational Rehabilitation |
| WIOA | Workforce Investment Opportunity Act |

This guide was adapted for Nevada from the ITACC Council Member Guide supported, in part by grant number **90DN0292**, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.

# 7. CONFLICT OF INTEREST POLICY

## 7.1. Purpose

The NGCDD has an approved Conflict of Interest Policy governing Council members and staff. As required by law, no Council member or staff may engage in activities that either create or give the appearance of conflict of interest. In accordance with Developmental Disabilities Assistance and Bill of Rights Act, **42 USC § 15024(c)(5)(D)**. Council must “ensure that no member of such Council will cast a vote on any matter that would provide conflict of interest.” Members representing agencies and organizations shall recuse themselves from any discussion of grants or contracts for which representatives’ departments, agencies, or programs are grantees or applicants.

Members and staff shall also comply with the Nevada Revised Statutes concerning Ethics in Government Chapter 281A.

## 7.2. Actions

Members who participate in a Notice of Funds Available (NOFA) development session(s) or apply for such funds shall not seek to influence the vote regarding the awarding of a contract or grant by the Council when that person knows that he or she has a direct or indirect financial interest in the award. Except as reimbursement for approved out-of-pocket expenses, no person may directly receive funds, including any portion of his/her salary, from any grant or contract funded by the Council without first disclosing his/her relationship to the project. That person must refrain from participating in any discussions, decisions, or reviews by the Council on that grant or contract. Following disclosure, the person may answer technical questions and provide factual information if requested by the Council.

Council members and sub-committee members who are volunteer or paid employees of organizations that have affiliated regional or local chapters or organizations shall not participate in the discussion, selection, or award of grants or contracts when the affiliated chapter or organization is an applicant or recipient.

No Council member shall participate in the discussion, selection, award, or administration of, or seek to influence, a decision regarding a grant or contract to a recipient where that member has a financial or other interest in the award.

No Council member shall solicit, receive, or accept anything of value under circumstances in which it could reasonably be inferred that the gift was intended:

1. To influence the DD Council member in the performance of their official duties, or
2. As a reward for any official action on the DD Council member’s part.

No Council member, in their official capacity, shall engage in self-dealing in any purchase or sale and must not refer to themselves to any business or client where the origin of the relationship arises from their DD Council position.

No Council member shall divulge confidential information acquired in the course of official DD Council duties.

No DD Council member shall represent their personal opinion as that of the DD Council.

Except as reimbursement for approved out-of-pocket expenses, a DD Council member:

1. May not directly receive funds, including any portion of their salary, from any grant or contract funded by the DD Council; and
2. May not have his/her salary used as a match related to any grant or contract funded by the DD Council.

Council members who are employees of national, state, or local organizations shall not participate in the discussion, selection, award or administration of a grant or contract for which an affiliated regional or local organization is an applicant or recipient.

No former Council member shall appear before the DD Council in relation to any application in which they participated during the period of DD Council service.

## 7.3. Disclosure

Council Members must disclose their conflict of interest on the record. After disclosing that affiliation, the Council member or sub-committee member may, at the request of the Council, answer technical questions and provide factual information.

Any DD Council member who has disclosed a conflict of interest must not, in relation to the matter in conflict:

1. Participate in the DD Council while the details and specifications of Requests for Proposals are being developed;
2. Participate in the discussion, screening, or selection process for grants and contracts;
3. Vote on funding;
4. Participate in contract negotiations or administration or evaluation of grants or contracts.

Any DD Council member who has disclosed or who has been found to have a conflict of interest because some portion of their salary is being, or will be, paid by or used as a match for a grant or contract, may, at the recommendation of the DD Council Executive Committee, tender their resignation from the DD Council or be granted a temporary leave of absence pending completion of the grant or contract.

By my signature below, I acknowledge that I have read and understood, or someone has explained to me, the attached Conflict of Interest Policy.

# 8. MEMORANDUM OF UNDERSTANDING-VOLUNTEER IN STATE SERVICE

A Memorandum of Understanding between the State of Nevada acting by and through the NGCDD and Volunteer.

**WHEREAS**, it is considered that the services of Volunteers are both necessary and in the best interests of the State of Nevada;

**NOW,** THEREFORE, in consideration of the previously mentioned premises, the parties mutually agree as follows:

* + - 1. **ASSENT.** The State accepts the services of the Volunteer until such services are ended with or without cause or notice at the discretion of either party.
      2. **INCORPORATED DOCUMENTS.** The parties agree that the services to be performed shall be specifically described, including, when applicable, any certifications, licenses, and/or other credentials the Volunteer is to possess; the number of hours or the number of times the service is to be performed, or when appropriate, a description of the work product.
      3. **LIMITED STATE LIABILITY.** The State will not waive and intends to assert NRS chapter 41 liability limitations in all cases.
      4. **INDEMNIFICATION.** To the fullest extent permitted by law, the State shall indemnify, hold harmless, and defend Volunteer, as if as an employee of the State within the scope and meaning of **NRS 41.0339**, from and against all liability, claims, actions, damages, losses, and expenses, including but not limited to attorneys' fees and costs, arising out of the performance of those services set forth in Attachment A—If the act or omission on which such liability, claims, actions, damages, losses, and expenses are based appears to be within the course and scope of the public duty assumed by Volunteer, appears to have been performed or omitted in good faith, was done under the control and in direct supervision of the State, and in furtherance of the State's business.
      5. **INSURANCE.** Volunteer, as if as an employee of the State within the scope and meaning of **NRS 41.0339**, shall be treated as an employee regarding any coverage under any applicable liability insurance maintained by the State while engaged in the performance of those services set forth in Attachment A. However, the Volunteer is excluded from participation in any employee rights, benefits, or plans, including, without limitation, those found in **NRS Title 23**.
      6. **WORKERS' COMPENSATION INSURANCE.** TheVolunteer shall receive workers' compensation coverage in accordance with **NRS 616A.130** while engaged in the performance of those services set forth in Attachment A. Said volunteer understands that workers' compensation coverage is their sole remedy for personal injury.
      7. **GOVERNING LAW; JURISDICTION.** This Memorandum of Understanding and the rights and obligations of the parties hereto shall be governed by, and construed according to, the laws of the State of Nevada., and adjudicated in the Nevada district courts.
      8. **STATE OWNERSHIP OF PROPRIETARY INFORMATION.** Any reports, histories, studies, tests, manuals, instructions, photographs, negatives, blueprints, plans, maps, data, system designs, computer code, or any other documents or drawings, prepared or in the course of preparation by the Volunteer while engaged in the performance of those services set forth in Attachment A shall be the exclusive property of the State and all such materials shall be remitted to the State by Volunteer upon completion, termination, or cancellation of service. Volunteer shall not use, willingly allow, or cause to have such materials used for any purpose other than the performance of Volunteer's services under this agreement without the prior written consent of the State.
      9. **PUBLIC RECORDS.** Following **NRS 239.010**, information or documents received from the Volunteer may be open to public inspection and copying. The State will have the duty to show unless a record is made confidential by law or a common law balancing of interests.
      10. **CONFIDENTIALITY.** Volunteer shall keep confidential, all information, in whatever form: produced, prepared, observed, or received by Volunteer, to the extent that such information is confidential by law.