State Plan Development Resource

Guidance for Developing the 2022-2026 Five Year State Plan

Developed by ITACC: Information and Technical Center for Councils on Developmental Disabilities, and NACDD: the National Association of Councils on Developmental Disabilities.

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# Introduction

The State Plan Development Resource was created to assist DD Councils in developing the 5- year State Plan. It is organized to guide DD Councils through a strategic planning process tied to the requirements in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PL 106-402) (the DD Act).

This document has been compiled from a variety of sources, including the DD Act and information ITACC has gathered from State/Territory DD Councils on a variety of topics related to State Plan development. The information is a reflection of methods and ideas that DD Councils throughout the network have found successful. This document is not intended to be prescriptive. Each DD Council is required to work within their State/Territory structure and must adapt the process to local requirements.

Throughout the process for developing the State Plan, DD Councils should keep in mind three key concepts:

1. DD Council member engagement in the planning process: The DD Act empowers DD Council members to be the driving force behind the State plan. Throughout the planning process, strategies should be used to fully support and involve members in all aspects of developing the plan.
2. Collaboration with the DD Network and other partners: DD Councils understand and appreciate the importance of partnering with others in all aspects of their work, including the development of the State plan. Such collaboration allows for DD Councils to ensure various perspectives, needs, and priorities are included in the State plan.
3. Stakeholder input on state needs and the proposed plan: Stakeholder input on state needs and the proposed plan: DD Councils should solicit and consider the public's view on service gaps and priorities, as well as how well the DD Council's proposed plan addresses state needs.

*The State Plan Development Resource* is organized into the following sections that are color coded for ease of use:

What does the DD Act Say? Any reference in The State Plan Development Resource to language in the DD Act has an **ORANGE** header.

Developing the State Plan. Information for DD Councils to use in developing the plan has a **BLUE** header.

Information on State Plan Assurances has a **PURPLE** header.

References to additional information are marked with “Find out more” in **GREEN**.

# What Does the DD Act Say?

The DD Act requires DD Councils to develop their state plan based on data-driven strategic planning. The DD Act does not mandate one form of strategic planning over another.

Three basic components of strategic planning:

1. Review of progress
2. Identification of needs based on data analysis and review
3. Development of goals based on the data

Strategic planning steps:

1. Evaluate current work and initiatives
2. Discover current needs
3. Reach agreement on vision for the future that provides a framework for the goals and results to be achieved
4. Conduct review of current and projected resources for addressing needs to achieve results
5. Reach agreement on goals, objectives, activities, and opportunities for achieving desired outcomes and results.

The DD Act requirements for the State Plan appear in Figure 1 as well as [on the Administration for Community Living website](https://acl.gov/sites/default/files/about-acl/2016-12/dd_act_2000.pdf).

Find out more: See Strategic Planning Tips in Appendix A

### DD Act Requirements for the State Plan – Sec. 124

**Figure 1:**

(a) IN GENERAL. -Any State desiring to receive assistance under this subtitle shall submit to the Secretary, and obtain approval of, a 5-year strategic State plan under this section.

(b) PLANNING CYCLE. -The plan described in subsection (a) shall be updated as appropriate during the 5-year period.

**(c)** **STATE PLAN REQUIREMENTS.** -In order to be approved by the Secretary under this section, a State plan shall meet each of the following requirements:

(1) STATE COUNCIL. -The plan shall provide for the establishment and maintenance of a Council in accordance with section 125 and describe the membership of such Council.

(2) DESIGNATED STATE AGENCY. -The plan shall identify the agency or office within the State designated to support the Council in accordance with this section and section 125(d) (referred to in this subtitle as a ''designated State agency'').

(3) COMPREHENSIVE REVIEW AND ANALYSIS. -The plan shall describe the results of a comprehensive review and analysis of the extent to which services, supports, and other assistance are available to individuals with developmental disabilities and their families, and the extent of unmet needs for services, supports, and other assistance for those individuals and their families, in the State. The results of the comprehensive review and analysis shall include-

(A) ) a description of the services, supports, and other assistance being provided to individuals with developmental disabilities and their families under other federally assisted State programs, plans, and policies under which the State operates and in which individuals with developmental disabilities are or may be eligible to participate, including particularly programs relating to the areas of emphasis, including-

(i) medical assistance, maternal and child health care, services for children with special health care needs, children's mental health services, comprehensive health and mental health services, and institutional care options;

(ii) training, job placement, worksite accommodation, and vocational rehabilitation, and other work assistance programs; and

(iii) social, child welfare, aging, independent living, and rehabilitation and assistive technology services, and such other services as the Secretary may specify;

(B) ) a description of the extent to which agencies operating such other federally assisted State programs, including activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), pursue interagency initiatives to improve and enhance community services, individualized supports, and other forms of assistance for individuals with developmental disabilities;

(C) ) an analysis of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities, especially with regard to their ability to access and use services provided in their communities, to participate in opportunities, activities, and events offered in their communities, and to contribute to community life, identifying particularly-

(i) the degree of support for individuals with developmental disabilities that are attributable to either physical impairment, mental impairment, or a combination of physical and mental impairments;

(ii) criteria for eligibility for services, including specialized services and special adaptation of generic services provided by agencies within the State, that may exclude individuals with developmental disabilities from receiving services described in this clause;

 (iii) the barriers that impede full participation of members of unserved and underserved groups of individuals with developmental disabilities and their families;

(iv) the availability of assistive technology, assistive technology services, or rehabilitation technology, or information about assistive technology, assistive technology services, or rehabilitation technology to individuals with developmental disabilities;

(v) the numbers of individuals with developmental disabilities on waiting lists for services described in this subparagraph;

(vi) description of the adequacy of current resources and projected availability of future resources to fund services described in this subparagraph;

(vii) description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive (based in part on each independent review (pursuant to section 1902(a)(30)(C) of the Social Security Act (42 U.S.C. 1396a(a)(30)(C))) of an Inter-mediate Care Facility (Mental Retardation) within the State, which the State shall provide to the Council not later than 30 days after the availability of the review); and

(viii) to the extent that information is available, a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c))) receive;

(D) a description of how entities funded under subtitles C and D, through interagency agreements or other mechanisms, collaborated with the entity funded under this sub-title in the State, each other, and other entities to con-tribute to the achievement of the purpose of this subtitle; and

(E) the rationale for the goals related to advocacy, capacity building, and systemic change to be undertaken by the Council to contribute to the achievement of the purpose of this subtitle

(4) PLAN GOALS. -The plan shall focus on Council efforts to bring about the purpose of this subtitle, by-

(A) specifying 5-year goals, as developed through data driven strategic planning, for advocacy, capacity building, and systemic change related to the areas of emphasis, to be undertaken by the Council, that-

(i) are derived from the unmet needs of individuals with developmental disabilities and their families identified under paragraph (3); and

(ii) include a goal, for each year of the grant, to-

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

(II) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and

(III) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions; and

(B) for each year of the grant, describing-

(i) the goals to be achieved through the grant, which, beginning in fiscal year 2002, shall be consistent with applicable indicators of progress described in section 104(a)(3);

(ii) the strategies to be used in achieving each goal; and

(iii) the method to be used to determine if each goal has been achieved.

(5) ASSURANCES.-

(A) IN GENERAL. -The plan shall contain or be sup-ported by assurances and information described in subparagraphs (B) through (N) that are satisfactory to the Secretary.

(B) ) USE OF FUNDS. -With respect to the funds paid to the State under section 122, the plan shall provide assurances that-

(i) not less than 70 percent of such funds will be expended for activities related to the goals described in paragraph (4);

(ii) such funds will contribute to the achievement of the purpose of this subtitle in various political sub-divisions of the State;

(iii) such funds will be used to supplement, and not supplant, the non-Federal funds paid under section 122 are provided;

(iv) such funds will be used to complement and augment rather than duplicate or replace services for individuals with developmental disabilities and their families who are eligible for Federal assistance under other State programs;

(v) part of such funds will be made available by the State to public or private entities;

(vi) the request of any State, a portion of such funds provided to such State under this subtitle for any fiscal year shall be available to pay up to 1 /2 (or the entire amount if the Council is the designated State agency) of the expenditures found to be necessary by the Secretary for the proper and efficient exercise of the functions of the designated State agency, except that not more than 5 percent of such funds provided to such State

for any fiscal year, or $50,000, whichever is less, shall be made available for total expenditures for such purpose by the designated State agency; and (vii) not more than 20 percent of such funds will be allocated to the designated State agency for service demonstrations by such agency that-

(I) ) contribute to the achievement of the purpose of this subtitle; and

(II) are explicitly authorized by the Council.

(C) STATE FINANCIAL PARTICIPATION. -The plan shall provide assurances that there will be reasonable State financial participation in the cost of carrying out the plan.

(D) CONFLICT OF INTEREST. -The plan shall provide an assurance that no member of such Council will cast a vote on any matter that would provide direct financial benefit to the member or otherwise give the appearance of a conflict of interest.

(E) URBAN AND RURAL POVERTY AREAS. -The plan shall provide assurances that special financial and technical assistance will be given to organizations that provide community services, individualized supports, and other forms of assistance to individuals with developmental disabilities who live in areas designated as urban or rural poverty areas.

(F) PROGRAM ACCESSIBILITY STANDARDS. -The plan shall provide assurances that programs, projects, and activities funded under the plan, and the buildings in which such programs, projects, and activities are operated, will meet standards prescribed by the Secretary in regulations and all applicable Federal and State accessibility standards, including accessibility requirements of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), section 508 of the Rehabilitation Act of 1973 (29 U.S.C. 794d), and the Fair Housing Act (42 U.S.C. 3601 et seq.).

(G) INDIVIDUALIZED SERVICES. -The plan shall provide assurances that any direct services provided to individuals with developmental disabilities and funded under the plan will be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individual.

(H) HUMAN RIGHTS. -The plan shall provide assurances that the human rights of the individuals with develop-mental disabilities (especially individuals without familial protection) who are receiving services under programs assisted under this subtitle will be protected consistent with section 109 (relating to rights of individuals with developmental disabilities).

(I) MINORITY PARTICIPATION. -The plan shall provide assurances that the State has taken affirmative steps to assure that participation in programs funded under this subtitle is geographically representative of the State, and reflects the diversity of the State with respect to race and ethnicity.

(J) EMPLOYEE PROTECTIONS. -The plan shall provide assurances that fair and equitable arrangements (as deter-mined by the Secretary after consultation with the Secretary of Labor) will be provided to protect the interests of employees affected by actions taken under the plan to provide community living activities, including arrangements designed to preserve employee rights and benefits and provide training and retraining of such employees where necessary, and arrangements under which maximum efforts will be made to guarantee the employment of such employees.

(K) STAFF ASSIGNMENTS. -The plan shall provide assurances that the staff and other personnel of the Council, while working for the Council, will be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and will not be assigned duties by the designated State agency, or any other agency, office, or entity of the State.

(L) NONINTERFERENCE. -The plan shall provide assurances that the designated State agency, and any other agency, office, or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development, or plan implementation of the Council, except that the designated State agency shall have the authority necessary to carry out the responsibilities described in section 125(d)(3).

(M) STATE QUALITY ASSURANCE. -The plan shall provide assurances that the Council will participate in the planning, design or redesign, and monitoring of State quality assurance systems that affect individuals with developmental disabilities.

(N) OTHER ASSURANCES. -The plan shall contain such additional information and assurances as the Secretary may find necessary to carry out the provisions (including the purpose) of this subtitle.

(d) PUBLIC INPUT AND REVIEW, SUBMISSION, AND APPROVAL.-

(1) PUBLIC INPUT AND REVIEW. -The plan shall be based on public input. The Council shall make the plan available for public review and comment, after providing appropriate and sufficient notice in accessible formats of the opportunity for such review and comment. The Council shall revise the plan to take into account and respond to significant comments.

(2) CONSULTATION WITH THE DESIGNATED STATE AGENCY.- Before the plan is submitted to the Secretary, the Council shall consult with the designated State agency to ensure that the State plan is consistent with State law and to obtain appropriate State plan assurances.

(3) PLAN APPROVAL.-The Secretary shall approve any State plan and, as appropriate, amendments of such plan that comply with the provisions of subsections (a), (b), and (c) and this subsection. The Secretary may take final action to disapprove a State plan after providing reasonable notice and an opportunity for a hearing to the State.

# Developing the State Plan

## Step 1: Generating a Timeline and Reviewing Progress

### 2022 – 2026 DD Council State Plan Developing a Planning Timeline

Depending on the structure and resources of each Council, a timeline of approximately 12 to 18 months has been drafted to develop a new five-year State plan. However, some Councils reported the planning process to be longer.

When developing the timeline, consider how long it will take Council members and staff to assess progress on the current state plan, conduct a comprehensive review and analysis of services, supports, and other assistance available to people with DD and their families, gather public input on needs, and develop the goals, objectives, and strategies for the plan. In addition, using the due date as a starting point when developing the timeline will help Council staff determine how early the planning process needs to begin and will help inform Council members and/or committees about the potential need for additional meetings to accomplish state plan development.

Below is a sample timeframe for consideration when developing the State plan. It may be helpful to expand on each activity to include a breakdown of tasks with assignments to individual Councils staff and Council members or committees (as applicable). Assignments may help clarify roles and responsibilities and potentially reduce duplication of tasks.

### State Plan Development Timeline Example 1 (table form):

|  |  |
| --- | --- |
| **Activity** | **Timeline** |
| Review mission and mission, assess progress on current State plan. | 12 – 18 months  |
| Gather information from various sources to address the sections of the comprehensive review and analysis. | 12 – 24 months |
| Gather public input on issues of importance to your State or Territory.  | 12 – 24 months |
| Analyze the data collected and develop meaningful summaries to inform the Council about services, supports and other assistance available and the extent of unmet needs for services to people with DD and their families.  | 12 – 18 months |
| Identify areas of importance to guide the development of goals, objectives, and strategies for the plan that are developed by data driven strategic planning and result from the unmet needs of people with DD and their families in the State or Territory. | Typically, 4 or 6 meetings prior to the due date, meetings of the Council or a planning Committee of the Council would meet to determine the goals, objectives, and strategies.  |
| Approve a public review draft of the State Plan and publish for comment.  | Three to four meetings prior to the Plan being due. |
| Public Comment Period  | 45 days minimum or longer depending on what is required statutorily by your State/Territory. |
| Review public comments to determine if any modifications should be made to the draft Plan and either approve or modify the draft Plan. If the Council modifies the draft Plan, a second public comment period would be required. | Two meetings prior to the Plan being due. |
| Council approval of the final Plan.  | One meeting prior to the Plan being due. |
| **Submit plan to AIDD in the ACL Reporting System** | **August 15, 2021 for all Councils**. |

### State Plan Development Timeline Example 2 (graphic):



### Step 1 (Continued): Reviewing Progress and "Where are we now?”

As the current 5-year State plan is closing, it is important to evaluate the status of progress towards current goals and objectives. For each goal and objective that has not been fully addressed, DD Councils will want to ask: "Should we consider continuing this goal/objective in our next Five Year Plan?"

The final decision about whether or not to continue a goal/objective (and which new ones to add) will be determined later in the planning process. This is also an ideal time to review the DD Council’s vision and mission to ensure they are current and relevant. DD Councils will want to evaluate how closely their goals and objectives are aligned with the DD Council mission, vision, the DD Act’s purpose, and policies.

For a complete listing of the DD Act’s purpose and policies that appear in Section 101 (b) and (c), see figures 2 and 3 below.

### DD Act – Section 101(b) and (c)

**Figure 2: DD Act Purposes**

**Section 101 (b)**

(b) PURPOSE. -The purpose of this title is to assure that individuals with developmental disabilities and

their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized under this title, including specifically-

(1) State Councils on Developmental Disabilities in each State to engage in advocacy, capacity building, and systemic change activities that-

(A) are consistent with the purpose described in this subsection and the policy described in subsection (c); and

(B) contribute to a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system that includes needed community services, individualized supports, and other forms of assistance that promote self-determination for individuals with developmental disabilities and their families;

(2) protection and advocacy systems in each State to protect the legal and human rights of individuals with developmental disabilities;

(3) University Centers for Excellence in Developmental Disabilities Education, Research, and Service-

(A) to provide interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of States and communities to achieve the purpose of this title;

(B) to provide community services-

(i) that provide training and technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community; and

(ii) that may provide services, supports, and assistance for the persons described in clause (i) through demonstration and model activities;

(C) to conduct research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families; and

(D) to disseminate information related to activities undertaken to address the purpose of this title, especially dissemination of information that demonstrates that the network authorized under this subtitle is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances; and

(4) funding for-

(A) national initiatives to collect necessary data on issues that are directly or indirectly relevant to the lives of individuals with developmental disabilities;

(B) technical assistance to entities who engage in or intend to engage in activities consistent with the purpose described in this subsection or the policy described in sub-section (c); and

(C) other nationally significant activities.

**Figure 3: DD Act Policies**

**Section 101 (c)**

(c) POLICY. -It is the policy of the United States that all pro-grams, projects, and activities receiving assistance under this title shall be carried out in a manner consistent with the principles that-

(1) individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life, but often require the provision of community services, individualized supports, and other forms of assistance;

(2) individuals with developmental disabilities and their families have competencies, capabilities, and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individuals;

(3) individuals with developmental disabilities and their families are the primary decision makers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decision making roles in policies and programs that affect the lives of such individuals and their families;

(4) services, supports, and other assistance should be pro-vided in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences;

(5) specific efforts must be made to ensure that individuals with developmental disabilities from racial and ethnic minority backgrounds and their families enjoy increased and meaningful opportunities to access and use community services, individualized supports, and other forms of assistance available to other individuals with developmental disabilities and their families;

(6) recruitment efforts in disciplines related to developmental disabilities relating to pre-service training, community training, practice, administration, and policymaking must focus on bringing larger numbers of racial and ethnic minorities into the disciplines in order to provide appropriate skills, knowledge, role models, and sufficient personnel to address the growing needs of an increasingly diverse population;

(7) with education and support, communities can be accessible to and responsive to the needs of individuals with developmental disabilities and their families and are enriched by full and active participation in community activities, and contributions, by individuals with developmental disabilities and their families;

(8) individuals with developmental disabilities have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, communities, and States, and the Nation;

(9) efforts undertaken to maintain or expand community-based living options for individuals with disabilities should be monitored in order to determine and report to appropriate individuals and entities the extent of access by individuals with developmental disabilities to those options and the extent of compliance by entities providing those options with quality assurance standards;

(10) families of children with developmental disabilities need to have access to and use of safe and appropriate child care and before-school and after-school programs, in the most integrated settings, in order to enrich the participation of the children in community life;

(11) individuals with developmental disabilities need to have access to and use of public transportation, in order to be independent and directly contribute to and participate in all facets of community life; and

(12) individuals with developmental disabilities need to have access to and use of recreational, leisure, and social opportunities in the most integrated settings, in order to enrich their participation in community life.

## Step 2: Data Collection and Analysis for the Comprehensive Review and Analysis

The Comprehensive Review and Analysis (CRA) should demonstrate a thorough understanding and analysis of the extent to which:

* Services, supports, and other assistance are available to individuals with developmental disabilities and their families.
* There are unmet needs for services, supports, and other assistance for those individuals and their families.
* How Council members and members of the public provided input into the development of the plan and how their feedback was used to develop the goals and objectives.

For the DD Act requirements for the Comprehensive Review and Analysis, see Figure 4 - Section 124 (c)(3)(C) below:

### DD Act – Section 124 (c)(3)(C)

**Figure 4: Comprehensive Review and Analysis**

**Section 124 (c)(3)(C)**

The results of the comprehensive review and analysis shall include-

(A) ) a description of the services, supports, and other assistance being provided to individuals with developmental disabilities and their families under other federally assisted State programs, plans, and policies under which the State operates and in which individuals with developmental disabilities are or may be eligible to participate, including particularly programs relating to the areas of emphasis, including-

(i) medical assistance, maternal and child health care, services for children with special health care needs, children's mental health services, comprehensive health and mental health services, and institutional care options;

(ii) training, job placement, worksite accommodation, and vocational rehabilitation, and other work assistance programs; and

(iii) social, child welfare, aging, independent living, and rehabilitation and assistive technology services, and such other services as the Secretary may specify;

(B) ) a description of the extent to which agencies operating such other federally assisted State programs, including activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), pursue interagency initiatives to improve and enhance community services, individualized supports, and other forms of assistance for individuals with developmental disabilities;

(C) ) an analysis of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities, especially with regard to their ability to access and use services provided in their communities, to participate in opportunities, activities, and events offered in their communities, and to contribute to community life, identifying particularly-

(i) the degree of support for individuals with developmental disabilities that are attributable to either physical impairment, mental impairment, or a combination of physical and mental impairments;

(ii) criteria for eligibility for services, including specialized services and special adaptation of generic services provided by agencies within the State, that may exclude individuals with developmental disabilities from receiving services described in this clause;

 (iii) the barriers that impede full participation of members of unserved and underserved groups of individuals with developmental disabilities and their families;

(iv) the availability of assistive technology, assistive technology services, or rehabilitation technology, or information about assistive technology, assistive technology services, or rehabilitation technology to individuals with developmental disabilities;

(v) the numbers of individuals with developmental disabilities on waiting lists for services described in this subparagraph;

(vi) description of the adequacy of current resources and projected availability of future resources to fund services described in this subparagraph;

(vii) description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive (based in part on each independent review (pursuant to section 1902(a)(30)(C) of the Social Security Act (42 U.S.C. 1396a(a)(30)(C))) of an Inter-mediate Care Facility (Mental Retardation) within the State, which the State shall provide to the Council not later than 30 days after the availability of the review); and

(viii) to the extent that information is available, a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c))) receive;

(D) a description of how entities funded under subtitles C and D, through interagency agreements or other mechanisms, collaborated with the entity funded under this sub-title in the State, each other, and other entities to con-tribute to the achievement of the purpose of this subtitle; and

(E) the rationale for the goals related to advocacy, capacity building, and systemic change to be undertaken by the Council to contribute to the achievement of the purpose of this subtitle

### Step 2 (continued): Tips for Collecting Data

As part of the data collection process, a DD Council will want to ask for input from people with developmental disabilities and their families, stakeholders and the public in their State/Territory to identify needs.

### Stakeholders may include:

1. People who have developmental disabilities and family members of people with developmental disabilities (including representatives from culturally diverse groups);
2. Service providers, and;
3. Other people concerned with services for people with developmental disabilities.

### DD Councils have indicated the following types of data are useful when engaging in strategic planning:

1. Data/trends gleaned from phone calls to the DD Council office;
2. Service agency reports analyzed by area of emphasis to identify gaps in service
3. Barriers for unserved and underserved populations
4. Data collected and used by other agencies and/or organizations in their State plans,
5. including the P&A and UCEDD; and
6. Public input on needs.

### DD Councils have reported using a variety of strategies to collect data, including the following:

1. Planning focus groups in conjunction with other events or organizations.
2. Holding public forums with DD network partners.
3. Gathering input from State agency representatives currently serving on the DD Council.
4. Using existing consortium groups or coalition groups to solicit public input.
5. Developing a survey based on the areas of emphasis to determine stakeholder’s needs.
6. Participating in disability conferences, annual meetings, etc. to distribute or conduct surveys.
7. Gathering data from organizations that DD Council members belong to.
8. Using natural opportunities such as self-advocacy or family support meetings to ask for input.
9. Working with focus groups of organizations without a disability focus. (faith-based, community resource centers for diverse populations etc.)
10. Holding public forum sessions in conjunction with DD Council meetings.
11. Calling people who do not routinely get out of their homes.
12. Rotating DD Council meetings to different regions of the state to solicit public input.
13. Using a sampling method to assess needs in specific geographic areas of the State.
14. Conducting a focus group made up of a culturally diverse group of people with developmental disabilities and their families.
15. Using different formats to solicit public input on needs, such as mail-in surveys, email surveys, and phone calls.

Find out more: *See Appendix C, pages 46 - 54 for data sources categorized by specific subsections as required by the DD Act.*

### Step 2 (continued): Determining un-served and under-served populations

Part of the comprehensive review and analysis must address the needs of the unserved and underserved (see Figure 5).

### DD Act – Section 124 (c)(C)(iii)

**Figure 5: Un-served and Underserved**

**Section 124 (c)**

(C) an analysis of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities, especially with regard to their ability to access and use services provided in their communities, to participate in opportunities, activities, and events offered in their communities, and to contribute to community life, identifying particularly-

(iii) the barriers that impede full participation of members of unserved and underserved groups of individuals with developmental disabilities and their families;

First, analyze the populations served, which can be identified by internal program data or by using the general US Census categories.

Populations can include but are not limited to:

1. Lesbian Gay, Bi-Sexual, Transgender, Queer and Questioning (LGBTQQ)
2. Disadvantaged individuals, people who speak a primary language other than English Individuals from underserved geographic areas (rural or urban)
3. Specific groups of individuals from the population of individuals with developmental disabilities, including individuals who required assistive technology in order to participate in and contribute to community life, or some other group.

Second, utilize a variety of sources to identify the barriers for people from un-served and underserved groups. For example, state bureau of statistics; state department of public health; academic databases; and members of the DD Network.

The needs of people who are un-served and under-served can be also analyzed based on geographic location of your State/Territory; type of disability; age group within a specific disability group or other criteria a DD Council may choose to identify.

### Step 2 (continued): Collaboration

Describe how the P&A, UCEDD and other key stakeholders collaborated with the DD Council in the State/Territory to achieve the DD Act purpose (see Figure 6).

### DD Act – Section 124 (c)(D)

**Figure 6: DD Network Collaboration**

**Section 124(c)**

(D) a description of how [the P&A and UCEDD], through interagency agreements or other mechanisms, collaborated with the [DD Council] in the State, each other, and other entities to contribute to the achievement of the purpose of this subtitle;

Some strategies are listed below.

1. Member participation in DD Council meetings
2. State DD Network meetings
3. Review of P&A Statement of Goals and Priorities
4. Review of UCEDD 5-year applications
5. Review of agency reports and plans

### Step 2 (continued): DD Council Member Involvement

DD Council members can be involved with the data collection process in developing the State Plan. Some strategies are listed below.

1. Attending meetings in their geographic areas to share input and data collection surveys
2. Attend scheduled "listening sessions" to receive comments
3. Ask organizations and groups they are involved with to share DD Council input surveys with their contacts

### Step 2 (continued): Data Analysis and Presentation to Council Members

Once the data has been collected, DD Council staff are responsible for translating the information into materials that the DD Council can use to develop goals for the plan.
Some strategies are listed below.

1. Using the current 5-Year State Plan as a base, identifying information that is new, information that has changed, and information still relevant.
2. Compiling information by the Areas of Emphasis in the DD Act
3. Cross-referencing data from State sources and external sources.
4. Compiling information from public forums and surveys into a reader friendly document.
5. Using workgroups to synthesize information and make it meaningful for all.
6. Using small group round table discussions to react to and discuss data results.
7. Organizing the information into smaller units so it is manageable and useable for planning.
8. Listing issues that emerged from the analysis by priority to identify the most pressing needs.
9. Developing spreadsheets that summarize the information gained from surveys.
10. Distilling all information, defining common themes, and providing a summary report.
11. Aligning agency information with Council member agencies.

## Step 3: Developing the Plan by Envisioning the Future

Once the data has been collected and reviewed, the Council will develop the plan by determining specific goals, objectives and activities to address the needs and gaps in services. In doing so, DD Councils should consider the related areas of emphasis and the types of activities, initiatives, and partners needed to reach the desired results.

Throughout this part of the planning process, the DD Council can be guided by the following two questions:

Question 1: "What should the future be like for people with developmental disabilities and their families?"

Question 2: “What can we do to make that future a reality?”

The information gathered through data collection and input from stakeholders, including but not limited to, DD Council members, self-advocates, parents or guardians of children with developmental disabilities, and immediate relatives or guardians of adults with developmental disabilities who cannot advocate for themselves, will help the DD Council to answer these questions and develop state plan goals, objectives, and activities.

### Step 3 (continued): Strategies for Developing the Plan

DD Councils can use various strategies for developing the State plan, including:

1. Devoting time during each DD Council meeting for State Plan Development.
2. Convening a planning retreat of the DD Council to explain the process, make sure everyone understands expectations, research, and brainstorm.
3. Conducting a large facilitated meeting for the DD Council, stakeholders and agencies.
4. Using a facilitator or consultant to engage DD Council members in a discussion, to generate ideas, and to assist the DD Council with reviewing survey data and selecting goals/objectives.
5. Hiring a strategic planner to assist with developing the plan.
6. Using DD Council member expertise to build on what was revealed from the data analysis.

### Step 3 (continued): Prioritizing

In developing the State plan goals, a first important step is identifying priority areas. There are a number of considerations for DD Councils to explore in identifying priority areas and determining focus, goals, objectives, related areas of emphasis (see Figure 7), and use of funds, including the following:

1. Information from the needs assessment.
2. Staffing levels and funding amounts in relation to the breadth of the State plan.
3. Current agency efforts, especially those the agency is particularly invested in to avoid overlap
4. Trends (demographic, political, social, and economic) that impact the priorities.
5. Areas of emphasis related to the greatest unmet needs (see Figure 7).

### DD Act – Section 102 (2)

**Figure 7: Areas of Emphasis**

**Section 102 (2)**

* Quality assurance
* Employment
* Child care
* Health and healthcare
* Education and early intervention
* Housing
* Transportation
* Recreation
* Other formal and informal community supports

DD Councils use a variety of strategies to assist with setting priorities, including:

1. Checklists to clarify important criteria for decision making (see Figure 8).
2. DD Council members to point out restrictions on resources.
3. Public input on priorities once the needs assessment is completed.
4. DD Council Committees will develop information and present priorities.
5. Brainstorming sessions on priority areas with the DD Council, and further researching those areas

|  |
| --- |
| **Figure 8: Sample Checklist For Screening Goals and Objectives** |
| *Instructions: Score goals and objectives ("yes", "no", "maybe") based on how well they meet the criteria listed across the top of this table.* |
|  | Aligned with purpose of DD Act | Aligned with Council mission, values, vision | Impact is measurable | Rationale is supported by data |
| Goal/objective |  |  |  |  |
| Goal/objective |  |  |  |  |
| Goal/objective |  |  |  |  |
| Goal/objective |  |  |  |  |

### Step 3 (continued): Developing the Goals

Information from the comprehensive review and analysis, which may include information from various sources (e.g., public input, surveys, organization and agency annual reports, needs assessments) should provide the basis of the rationale for the goals.

It is also important to review the goals in the DD Council's current State Plan, and use it to identify what needs to change and what can stay the same. DD Councils should pay attention to emerging issues and modify the plan accordingly.

The goals will focus on advocacy, capacity building and systemic change related to the areas of emphasis that are derived from the unmet needs of individuals with developmental disabilities and their families. The DD Council is required to have at least one goal related to self-advocacy and leadership development of people with development disabilities. The self-advocacy goal has three components. All three components must be addressed each year of the 5 Year State Plan cycle (see Figure 9).

### DD Act – Section 124 (c)

**Figure 9: DD Act Requirements for State Plan Goals**

**Section 124 (c)**

(4) PLAN GOALS. -The plan shall focus on Council efforts to bring about the purpose of this subtitle, by-

(A) specifying 5-year goals, as developed through data driven strategic planning, for advocacy, capacity building, and systemic change related to the areas of emphasis, to be undertaken by the Council, that-

(i) are derived from the unmet needs of individuals with developmental disabilities and their families identified under paragraph (3); and

(ii) include a goal, for each year of the grant, to-

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

(II) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and

(III) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions;

As goals are identified, determine strategies the DD Council will utilize to meet the goal. Section 125(c)(5)(A-L) of the DD Act identifies specific strategies a DD Council may utilize, such as outreach, training, informing policy makers, coalitions, etc. in implementing the goals in the State Plan (see Figure 10).

### DD Act – Section 125 (c)

**Figure 10: Strategies for Implementing the State Plan**

**Section 125 (c)**

(5) STATE PLAN IMPLEMENTATION.-

(A) IN GENERAL. -The Council shall implement the State plan by conducting and supporting advocacy, capacity building, and systemic change activities such as those described in subparagraphs (B) through (L).

(B) OUTREACH.-The Council may support and conduct outreach activities to identify individuals with develop-mental disabilities and their families who otherwise might not come to the attention of the Council and assist and enable the individuals and families to obtain services, individualized supports, and other forms of assistance, including access to special adaptation of generic community services or specialized services.

(C) TRAINING. -The Council may support and conduct training for persons who are individuals with develop-mental disabilities, their families, and personnel (including professionals, paraprofessionals, students, volunteers, and other community members) to enable such persons to obtain access to, or to provide, community services, individualized supports, and other forms of assistance, including special adaptation of generic community services or specialized services for individuals with developmental disabilities and their families. To the extent that the Council supports or conducts training activities under this subparagraph, such activities shall contribute to the achievement of the purpose of this subtitle.

(D) TECHNICAL ASSISTANCE. -The Council may support and conduct technical assistance activities to assist public and private entities to contribute to the achievement of the purpose of this subtitle.

(E) SUPPORTING AND EDUCATING COMMUNITIES. -The Council may support and conduct activities to assist neighborhoods and communities to respond positively to individuals with developmental disabilities and their families-

(i) by encouraging local networks to provide informal and formal supports;

(ii) through education; and

(iii) by enabling neighborhoods and communities to offer such individuals and their families access to and use of services, resources, and opportunities.

(F) INTERAGENCY COLLABORATION AND COORDINATION.- The Council may support and conduct activities to promote interagency collaboration and coordination to better serve, support, assist, or advocate for individuals with developmental disabilities and their families.

(G) COORDINATION WITH RELATED COUNCILS, COMMITTEES, AND PROGRAMS. -The Council may support and conduct activities to enhance coordination of services with-

(i) other councils, entities, or committees, authorized by Federal or State law, concerning individuals with disabilities (such as the State interagency coordinating council established under subtitle C of the Individuals with Disabilities Education Act (20 U.S.C. 1431 et seq.), the State Rehabilitation Council and the Statewide Independent Living Council established under the Rehabilitation Act of 1973 (29 U.S.C. 701 et seq.), the State mental health planning council established under subtitle B of title XIX of the Public Health Service Act (42 U.S.C. 300x-1 et seq.), and the activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), and entities carrying out other similar councils, entities, or committees);

(ii) parent training and information centers under part D of the Individuals with Disabilities Education Act (20 U.S.C. 1451 et seq.) and other entities carrying out federally funded projects that assist parents of children with disabilities; and

(iii) their groups interested in advocacy, capacity building, and systemic change activities to benefit individuals with disabilities.

(H) BARRIER ELIMINATION, SYSTEMS DESIGN AND REDESIGN. -The Council may support and conduct activities to eliminate barriers to access and use of community services by individuals with developmental disabilities, enhance systems design and redesign, and enhance citizen participation to address issues identified in the State plan.

(I) COALITION DEVELOPMENT AND CITIZEN PARTICIPATION.- The Council may support and conduct activities to educate the public about the capabilities, preferences, and needs of individuals with developmental disabilities and their families and to develop and support coalitions that support the policy agenda of the Council, including training in self-advocacy, education of policymakers, and citizen leadership skills.

(J) INFORMING POLICYMAKERS. -The Council may support and conduct activities to provide information to policy-makers by supporting and conducting studies and analyses, gathering information, and developing and disseminating model policies and procedures, information, approaches, strategies, findings, conclusions, and recommendations. The Council may provide the information directly to Federal, State, and local policymakers, including Congress, the Federal executive branch, the Governors, State legislatures, and State agencies, in order to increase the ability of such policymakers to offer opportunities and to enhance or adapt generic services to meet the needs of, or provide specialized services to, individuals with developmental disabilities and their families.

(K) DEMONSTRATION OF NEW APPROACHES TO SERVICES AND SUPPORTS.-

(i) IN GENERAL. -The Council may support and conduct, on a time-limited basis, activities to demonstrate new approaches to serving individuals with developmental disabilities that are a part of an overall strategy for systemic change. The strategy may involve the education of policymakers and the public about how to deliver effectively, to individuals with developmental disabilities and their families, services, supports, and assistance that contribute to the achievement of the purpose of this subtitle.

(ii) SOURCES OF FUNDING. -The Council may carry out this subparagraph by supporting and conducting demonstration activities through sources of funding other than funding provided under this subtitle, and by assisting entities conducting demonstration activities to develop strategies for securing funding from other sources.

(L) OTHER ACTIVITIES.-The Council may support and conduct other advocacy, capacity building, and systemic change activities to promote the development of a coordinated, consumer- and family-centered, consumer- and family-directed, comprehensive system of community services, individualized supports, and other forms of assistance that contribute to the achievement of the purpose of this subtitle.

## Step 4: Developing the Evaluation Plan

The DD Council must identify an evaluation method to determine if the goals have been achieved. Figure 11 shows the provisions in the DD Act for the State Plan goals with regard to evaluation.

In addition, the DD Act provides requirements with regard to the DD Council Annual Report and indicates the types of information that should be included as part of the DD Council's evaluation plan for measuring progress on goals (see Figure 12).

### DD Act – Sections 124 (c)(4) and 125 (c)

**Figure 11: State Plan Goals**

**Section 124(c)(4)**

(B) for each year of the grant, describing-

(i) the goals to be achieved through the grant, which, beginning in fiscal year 2002, shall be consistent with applicable indicators of progress described in section 104(a)(3);

(iii) the method to be used to determine if each goal has been achieved.

**Figure 12: Council Annual Report**

**Section 125 (c)**

(7) REPORTS. -Beginning in fiscal year 2002, the Council shall annually prepare and transmit to the Secretary a report. Each report shall be in a form prescribed by the Secretary by regulation under section 104(b). Each report shall contain information about the progress made by the Council in achieving the goals of the Council (as specified in section 124(c)(4)), including-

(A) a description of the extent to which the goals were achieved;

(B) a description of the strategies that contributed to achieving the goals;

(C) to the extent to which the goals were not achieved, a description of factors that impeded the achievement;

(D) separate information on the self-advocacy goal described in section 124(c)(4)(A)(ii);

(E) (i) as appropriate, an update on the results of the comprehensive review and analysis described in Section 124(c)(3); and

(ii) information on consumer satisfaction with Council supported or conducted activities;

(F) (i) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities in Intermediate Care Facilities (Mental Retardation) receive; and

(ii) a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c)) receive;

(G) an accounting of the manner in which funds paid to the State under this subtitle for a fiscal year were expended;

(H) a description of-

(i) resources made available to carry out activities to assist individuals with developmental disabilities that are directly attributable to Council actions; and

(ii) resources made available for such activities that are undertaken by the Council in collaboration with other entities; and

(I) a description of the method by which the Council will widely disseminate the annual report to affected constituencies and the general public and will assure that the report is available in accessible formats.

## Step 5: Public Review

DD Councils must demonstrate that citizens in the State/Territory have had an opportunity to review the draft State Plan (see Figure 13). The DD Act states that a DD Council shall revise the Plan to take into account and respond to significant comments [Section 124(d)(1)]. This is true for the first round of public review and any subsequent rounds of public review needed to address possible revisions.

Frequently, DD Councils want to know, after the draft Plan has been presented for public review, what constitutes a significant comment to warrant a change to the draft Plan. Further, DD Councils want to know if changes to the draft Plan then go back out for public review again.

There is no definitive answer to this question however, if comments received from the public review are significant enough and substantiated in data, then the DD Council will most likely need to change a goal or goals in the draft State Plan. This amended draft Plan would need to go out again for public review to ensure that changes to any goals and/or objectives are acceptable to the public.

A DD Council is expected to be able to make changes to objectives, activities and/or strategies without necessarily having to give the public an opportunity for review. However, if a DD Council is going to change a goal or goals, the DD Council has an obligation to make sure the public has been given an opportunity to review the changes.

### DD Act – Section 124 (d)

**Figure 13: Public Review**

**Section 124(d)**

(1) PUBLIC INPUT AND REVIEW. -The plan shall be based on public input. The Council shall make the plan available for public review and comment, after providing appropriate and sufficient notice in accessible formats of the opportunity for such review and comment. The Council shall revise the plan to take into account and respond to significant comment

## Step 6: Budget

The DD Council should consider the resources available to implement the Plan. The DD Council will want to ensure that its plan can be implemented and achieved utilizing the funds available, either though the DD Act allotment or other sources.

Section 124 of the DD Act on State Plans does not include specific requirements for developing the budget as part of the State planning process. It only asks for the following assurances related to the use of funds (see Figure 14).

### DD Act – Section 124 (5)

**Figure 14: Assurances Related to the Use of Funds**

**Section 124(5)**

**(5) ASSURANCES.-**

(B) USE OF FUNDS. -With respect to the funds paid to the State under section 122, the plan shall provide assurances that-

(i) not less than 70 percent of such funds will be expended for activities related to the goals described in paragraph (4);

(ii) such funds will contribute to the achievement of the purpose of this subtitle in various political sub-divisions of the State;

(iii) such funds will be used to supplement, and not supplant, the non-Federal funds that would other-wise be made available for the purposes for which the funds paid under section 122 are provided;

(iv) such funds will be used to complement and augment rather than duplicate or replace services for individuals with developmental disabilities and their families who are eligible for Federal assistance under other State programs;

(v) part of such funds will be made available by the State to public or private entities;

(vi) the request of any State, a portion of such funds provided to such State under this subtitle for any fiscal year shall be available to pay up to 1 /2 (or the entire amount if the Council is the designated State agency) of the expenditures found to be necessary by the Secretary for the proper and efficient exercise of the functions of the designated State agency, except that not more than 5 percent of such funds provided to such State for any fiscal year, or $50,000, whichever is less, shall be made available for total expenditures for such purpose by the designated State agency; and (vii) not more than 20 percent of such funds will be allocated to the designated State agency for service demonstrations by such agency that-

(I) contribute to the achievement of the purpose of this subtitle; and

(II) are explicitly authorized by the Council.

Section 125(c)(8)(A-C) of the law states that DD Councils should develop budgets (see Figure 15). It is recommended to develop budgets for each year of the 5 year State Plan, based on the activities (staff and grant) that will be undertaken each year. Updates to proposed budgets can be made annually when State plan amendments are due.

### DD Act – Section 125 (c)

**Figure 15: Budget Section**

**125(c)(8)(A-C)**

(8) BUDGET. -Each Council shall prepare, approve, and implement a budget using amounts paid to the State under this subtitle to fund and implement all programs, projects, and activities carried out under this subtitle, including

(A) (i) conducting such hearings and forums as the Council may determine to be necessary to carry out the duties of the Council; and

(ii) determined in Council policy-

(I) 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;

(II) paying a stipend to a member of the Council, if such member is not employed or must forfeit wages from other employment, to attend Council meetings and perform other Council duties;

(III) supporting Council member and staff travel to authorized training and technical assistance activities including in-service training and leadership development activities; and

(IV) trying out appropriate subcontracting activities;

(B) hiring and maintaining such numbers and types of staff (qualified by training and experience) and obtaining the services of such professional, consulting, technical, and clerical staff (qualified by training and experience), consistent with State law, as the Council determines to be necessary to carry out the functions of the Council under this subtitle, except that such State shall not apply 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 the functions of the Council under this subtitle; and

(C) directing the expenditure of funds for grants, contracts, interagency agreements that are binding contracts, and other activities authorized by the State plan approved under section 124.

### Tips on filling out the proposed budget:

Provide the budget, broken down into three cost categories (Goals, General Management, and DSA functions) for the first year of the grant only. The Council will submit budget for subsequent years of the grant through the State Plan Amendments.

Subtitle B $

This column should represent the amount of federal funds the Council has planned to use on specified goals, general management, and functions of the DSA.

Break down the costs associated with the goals of the plan by each goal. For example, if the Council has 5 goals, there should be 5 line items identifying the budget amount for each goal. The budget amounts for the goals may vary and should be based on the planned activities. Section 124(c)(5) requires that not less than 70 percent of the funds available to the Council will be expended for activities related to the goals.

Other(s) $

This column should represent the amount of other funds the Council has planned to use on specified goals, general management, and functions of the DSA.

Total

This column should be the total of columns Subtitle B$ and Other(s) $.

The “General management” item refers to the administrative costs for the Council. Show the amount of money budgeted for administrative type functions. This may include personnel, budget, finance, and reporting administrative functions that are not related specifically to a state plan goal or goals.

The “Functions of the DSA” item refers to the amount of money a DSA can request for reimbursement of costs to support the Council. Federal funds cannot exceed 5% of Council grant award or $50,000, whichever is less, up to ½ of expenses found to be necessary for the proper and efficient exercise of the functions of the Designated State Agency). Costs in this category are considered administrative costs.

The Subtitle B$ amount for General management and Functions of the DSA cannot exceed 30% of the Council’s annual award.

|  |
| --- |
| **Figure 16: Budgeting Chart** |
| **Goal** | **Subtitle B $** | **Other(s) $** | **TOTAL** |
| **1. Goal** |  |  |  |
| **2. Goal** |  |  |  |
| **3. Goal** |  |  |  |
| **4. Goal** |  |  |  |
| **5. Goal** |  |  |  |
| **6. General management (Personnel, Budget, Finance, Reporting)** |  |  |  |
| **7. Functions of the DSA** |  |  |  |
| **8. TOTAL** | $ | $ | $ |

# Assurances

DD Councils should obtain the appropriate signatures for the Assurances for the 5 Year State plan. Councils will keep a copy of the Assurances on file should OIDD request them. Assurances only have to be obtained and kept on file at the beginning of the 5 Year plan, unless there have been substantive changes to the plan or the Council Chairperson or Designated State Agency has changed since the assurances were last signed. (see Figure 16).

### Who exactly signs the assurances?

The Designated State Agency (DSA) signs the assurances since they receive the money for the DD Council. If a DD Council is operating as their own DSA, typically, the DD Council Chairperson signs the assurances.

### DSA Consultation

Section 124 (d)(2) references consultation with the Designated State Agency. This is only to ensure that the Council State Plan is consistent with State law. This is not to gain the DSA's "approval" of the Plan, including the goals and objectives.

### DD Act – Section 124 (c)(5)

**Figure 17: Assurances**

**Section 124 (c)(5)**

(A) IN GENERAL. -The plan shall contain or be sup-ported by assurances and information described in subparagraphs (B) through (N) that are satisfactory to the Secretary.

(B) USE OF FUNDS. -With respect to the funds paid to the State under section 122, the plan shall provide assurances that-

(i) not less than 70 percent of such funds will be expended for activities related to the goals described in paragraph (4);

(ii) such funds will contribute to the achievement of the purpose of this subtitle in various political sub-divisions of the State;

(iii) such funds will be used to supplement, and not supplant, the non-Federal funds paid under section 122 are provided;

(iv) such funds will be used to complement and augment rather than duplicate or replace services for individuals with developmental disabilities and their families who are eligible for Federal assistance under other State programs;

(v) part of such funds will be made available by the State to public or private entities;

(vi) the request of any State, a portion of such funds provided to such State under this subtitle for any fiscal year shall be available to pay up to 1 /2 (or the entire amount if the Council is the designated State agency) of the expenditures found to be necessary by the Secretary for the proper and efficient exercise of the functions of the designated State agency, except that not more than 5 percent of such funds provided to such State for any fiscal year, or

$50,000, whichever is less, shall be made available for total expenditures for such purpose by the designated State agency; and (vii) not more than 20 percent of such funds will be allocated to the designated State agency for service demonstrations by such agency that-

(I) contribute to the achievement of the purpose of this subtitle; and

(II) are explicitly authorized by the Council.

(C) STATE FINANCIAL PARTICIPATION. -The plan shall provide assurances that there will be reasonable State financial participation in the cost of carrying out the plan.

(D) CONFLICT OF INTEREST. -The plan shall provide an assurance that no member of such Council will cast a vote on any matter that would provide direct financial benefit to the member or otherwise give the appearance of a conflict of interest.

(E) URBAN AND RURAL POVERTY AREAS. -The plan shall provide assurances that special financial and technical assistance will be given to organizations that provide community services, individualized supports, and other forms of assistance to individuals with developmental disabilities who live in areas designated as urban or rural poverty areas.

(F) PROGRAM ACCESSIBILITY STANDARDS. -The plan shall provide assurances that programs, projects, and activities funded under the plan, and the buildings in which such programs, projects, and activities are operated, will meet standards prescribed by the Secretary in regulations and all applicable Federal and State accessibility standards, including accessibility requirements of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), section 508 of the Rehabilitation Act of 1973 (29 U.S.C. 794d), and the Fair Housing Act (42 U.S.C. 3601 et seq.).

(G) INDIVIDUALIZED SERVICES. -The plan shall provide assurances that any direct services provided to individuals with developmental disabilities and funded under the plan will be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individual.

(H) HUMAN RIGHTS. -The plan shall provide assurances that the human rights of the individuals with develop-mental disabilities (especially individuals without familial protection) who are receiving services under programs assisted under this subtitle will be protected consistent with section 109 (relating to rights of individuals with developmental disabilities).

(I) MINORITY PARTICIPATION. -The plan shall provide assurances that the State has taken affirmative steps to assure that participation in programs funded under this subtitle is geographically representative of the State, and reflects the diversity of the State with respect to race and ethnicity.

(J) EMPLOYEE PROTECTIONS. -The plan shall provide assurances that fair and equitable arrangements (as deter-mined by the Secretary after consultation with the Secretary of Labor) will be provided to protect the interests of employees affected by actions taken under the plan to provide community living activities, including arrangements designed to preserve employee rights and benefits and provide training and retraining of such employees where necessary, and arrangements under which maximum efforts will be made to guarantee the employment of such employees.

(K) STAFF ASSIGNMENTS. -The plan shall provide assurances that the staff and other personnel of the Council, while working for the Council, will be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and will not be assigned duties by the designated State agency, or any other agency, office, or entity of the State.

(L) NONINTERFERENCE. -The plan shall provide assurances that the designated State agency, and any other agency, office, or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development, or plan implementation of the Council, except that the designated State agency shall have the authority necessary to carry out the responsibilities described in section 125(d)(3).

(M) STATE QUALITY ASSURANCE. -The plan shall provide assurances that the Council will participate in the planning, design or redesign, and monitoring of State quality assurance systems that affect individuals with developmental disabilities.

(N) OTHER ASSURANCES. -The plan shall contain such additional information and assurances as the Secretary may find necessary to carry out the provisions (including the purpose) of this subtitle

Find out more*:* The 2022-2026 Assurances are posted for download on the [ITACChelp.org website’s Federal Reporting & Resources page under Five Year State Plan/Assurances](https://itacchelp.org/federal-reporting-resources/five-year-state-plan/). The Council should obtain signed assurances and keep a copy for their own records. Be sure to check the box in the ACL system that assurances are signed. No need to mail a copy of the assurances to the Office of Intellectual and Developmental Disabilities (OIDD).

# Appendices

## Appendix A: Strategic Planning Tips and Information

Strategic planning has a basic overall framework. Not to oversimplify the strategic planning process, but by placing all the parts of a plan into the following three areas, you can clearly see how the pieces of your plan fit together:

* Where are we now? Review your current strategic position and clarify your mission, vision, and values.
* Where are we going? Establish your competitive advantage and your vision. Clearly see the direction your organization is headed.
* How will we get there? Lay out the road to connect where you are now to where you’re going. Set your strategic objectives, goals, and action items and how you’ll execute your plan.

Find out more: You can find a guide on how to write a strategic plan [on the “mystrategicplan” website](http://mystrategicplan.com/resources/how-to-write-a-%20%20%20strategic-plan/).

(Erica Olsen – 2008)

## Appendix B: DD Prevalence Rate Resources

|  |  |  |
| --- | --- | --- |
| Source | Rate | Description |
| Steinmetz, E. (2006, May). Americans with disabilities: 2002. Washington, DC: U.S. Census Bureau Household Economic Studies. [Accessed 7/31/06 at: http://www.census.gov/prod/2006 pubs/p70-107.pdf] , Tables 2& 7 | 1.7% | A U.S. Census Bureau report reporting on 2002 data indicated that there were 1.221 million individuals with "mental retardation" living in the US aged 15 years and older; 0.225 million children with developmental delay aged under 3 years and 0.376 million aged 3-5 years, .226 million with children with "mental retardation", and .256 million with "other developmental disability" aged 6-14 years. Thus, the census study indicated that 0.8% of the U.S. population of 288 million persons in 2002 were individuals with "mental retardation". |
| Centers for Disease Control and Prevention. (1996, January 26). State-specific rates of mental retardation -- United States, 1993. MMWR Weekly, 45(03), 61-65.[Accessed 7/31/06 at: http://www.cdc.gov/mmwr/previe w/mmwrhtml/00040023.htm] | 0.76% | In 1996, the Center for Disease Control and Prevention (CDC) issued a report on "State- Specific Rates of Mental Retardation -- United States, 1993". That study identified a prevalence rate of 7.6 per 1,000 population (0.76%). |
| Larson, S.A., Lakin, K.C., Anderson, L., Kwak, N., Lee, J., & Anderson, D. (2001). Prevalence of mental retardation and developmental disabilities: Estimates from the 1994/1995 National Health Interview Survey Disability Supplements. American Journal on Mental Retardation, 106(3), 231-252. | 1.58% | The prevalence of "mental retardation" and closely related developmental disabilities was determined to be 1.58% of the general population based on the National Health Interview Survey- Disability Supplement (NHIS-D). This analysis reported an "MR only" prevalence rate of 0.78% for all ages, and prevalence for persons with MR and DD over 18 years of age of 7.9 per 1,000 (0.79%) (p. 244). This rate is used in the "State of the States in Developmental Disabilities", which states there are 4.7 million people with intellectual and developmental disabilities in the U.S. |

## Appendix C: Comprehensive Review and Analysis Resources

### CRA Part 1: State Information, State Disability Characteristics, and Demographic Information

|  |  |
| --- | --- |
| Census Data | 1. United States Census – [Statistical Atlas/Overview of the United States](https://statisticalatlas.com/United-States/Overview) (This data is derived from the US Census)
 |
| Languages Spoken at Home | 1. Census Bureau Report – [At Least 350 Languages Spoken in U.S. Homes](https://www.census.gov/newsroom/press-releases/2015/cb15-185.html)
2. MLA Modern Language Association – [A language map](https://www.mla.org/Resources/Research/MLA-Language-Map) with 2010 being the most recent year of data
3. To search for languages by State, region, City, County, Town or Zip Code, you can use [the MLA Language Map Data Center](https://apps.mla.org/map_data)
 |
| Territory Data | This is a select group of links and reports that include data from some or all of the five territories. (Note: There are not Disability Status Reports for other territories at this time.)1. For data on school aged children with DD: [IDEA data tables, which includes all territories](https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#ccc).
2. [A 2017 Microsoft Excel spreadsheet](https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/part-b-data/child-count-and-educational-environments/bchildcountandedenvironments2017-18.csv) breaking down youth served by Special Education by State, disability, age, race, ethnicity and more. Child Count and Educational Environments
3. The Puerto Rico [2017 Disability Status Report](http://www.disabilitystatistics.org/StatusReports/2017-PDF/2017-StatusReport_PR.pdf?CFID=20854252&CFTOKEN=7f06e1379e068f7d-C96C6270-E6F5-3D9F-4117AFA0C8A612F1)
4. The Virgin Islands [2010 Disability Status Report](http://www.disabilitystatistics.org/reports/2010/English/2010-PDF/2010-StatusReport_USVI.pdf)
 |

### Part 1 (continued): General Resources to Inform the Comprehensive Review and Analysis

|  |  |
| --- | --- |
| Organization or Project | Resource link and/or description |
| The Administration for Community Living (ACL)’s Office on Intellectual and Developmental Disabilities (OIDD) | ACL/Office of Intellectual and Developmental Disabilities (OIDD) Data Collection projects are on-going efforts to examine federally funded services for people with developmental disabilitiesACL – Webinar on Longitudinal Data Projects of National Significance: Data for the DD Council’s 5-year plans. You can download the [PowerPoint](https://itacchelp.org/wp-content/uploads/2019/09/DataProjects-DD-Councils-2019-08-06.pdf) as well as the [Webinar Recording](https://register.gotowebinar.com/recording/8380385668601340685). |
| The State of the States in Intellectual and Developmental Disabilities | You can access nationwide longitudinal financial and programmatic trends in intellectual and developmental disabilities services by going to the [State Profiles](http://stateofthestates.org/index.php/view-state-profiles) and [Create a Chart](http://stateofthestates.org/index.php/create-idd-chart) webpages at the [State of the State website](http://stateofthestates.org). |
| The Residential Information Systems Project (RISP) | RISP is [a longitudinal study of long-term supports and services (LTSS)](http://www.rtc.umn.edu/risp/build/index.asp19) that people with intellectual and developmental disabilities (IDD) receive. An annual survey of state IDD agencies is used to gather information about the settings in which LTSS recipients live, federal and state funding mechanisms used, residential setting type and size, age of recipients, and expenditures. |
| StateData | The [StateData website](https://www.statedata.info/) promotes [Employment First](http://www.apse.org/employmentfirst/statement.cfm) and systems change efforts nationwide by supporting outcome-based management and planning. Since the mid-1980s, the Institute for Community Inclusion has collected data from state intellectual and developmental disability (IDD) agencies, the vocational rehabilitation (VR) system, and other agencies such as the Social Security Administration, the U.S. Census, and the U.S. Department of Labor, to describe trends in day and employment services for individuals with developmental disabilities. |
| USA.Gov | USA.Gov is the official site of the US government. Find [data and statistics about the US](https://www.usa.gov/statistics#item-37157), such as maps population, demographic and economic data.  |
| The Census Bureau | [The Census Bureau](http://www.census.gov) provides data on disability based on four primary sources: the Survey of Income and Program Participation (SIPP), the decennial census of population, the Current Population Survey (CPS), and American Community Survey (ACS). |
| The Bureau of Labor Statistics | [The Bureau of Labor Statistics](http://www.bls.gov) is the principal fact-finding agency for the Federal Government in the broad field of labor economics and statistics. |
| Disability Statistics | [Disability Statistics: An Online Resource for U.S. Disability Statistics](http://www.disabilitystatistics.org/) provides access to comprehensive, up-to-date U.S. disability statistics via graphs and charts, tables, and written descriptions. Currently, all statistics are estimated by Cornell University using the Census Bureau's Current Population Survey - Annual Demographic Supplement. This website also contains [The Disability Status Report webinar materials](http://www.disabilitystatistics.org/resources/2017_Disability_Status_Report_Rollout.pdf) (January 2019). |
| National Core Indicators (NCI) | [The NCI website](https://nacddonline.sharepoint.com/sites/NACDDShared/Shared%20Documents/03%20-%20Technical%20Assistance/AOD_OIDD/1.%20%20TTA%20Contract%202017-2021/8.%20FY%2020%20State%20Plan%20Development/FINAL%20DRAFTS/The%20National%20Core%20Indicator%20website) contains many resources, including the [At-A-Glance Report In-Person Survey](https://www.nationalcoreindicators.org/upload/core-indicators/NCI_AtAGlanceReport_1718_Final_May2019.pdf) (formerly called the Adult Consumer Survey). |
| The American Association on Intellectual and Developmental Disabilities (AAIDD) | [AAIDD](https://www.aaidd.org/) promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities. |
| The Annual Disability Statistics Compendium | [Annual Disability Statistics Compendium 2018](https://disabilitycompendium.org/sites/default/files/user-uploads/2018_Compendium_Accessible_AbobeReaderFriendly.pdf) |

### CRA Part 2: Portrait of the State Services [Section 124(c)(3)(A)(B)]:

Use the following sub-sections to describe the state’s services, supports, and other assistance available to people with developmental disabilities and their families. In your description, include information specific to individuals with developmental disabilities from culturally and linguistically diverse backgrounds. Only some of the fields in this section are required, as noted by an asterisk.

TA Tip: In addition to the general CRA resources linked above, consider the following sources for information related to*each* area of emphasis:

1. State plans, research reports and annual reports from DD Network partners.
2. UCEDD Needs Assessments: UCEDDs may have reports/surveys related to a specific area of emphasis. (Obtain a copy or see if a joint report/survey can be developed.)
3. State agency annual reports, topical papers, presentations and publications related to the area of emphasis. (Visit State agency websites for more information)
4. Progress reports and other data from DD Council grant projects.

|  |
| --- |
| **Subject Area**Description |
| Links to Specific Websites | Other General Resource Ideas |
| **Recreation**Provide information on recreational, leisure, and social activities in communities that are available to individuals with developmental disabilities. (Optional) |
| 1. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
2. [State of the States in DD](http://www.stateofthestates.org/)
3. [National Recreation and Park Association (NRPA)](https://www.nrpa.org/our-work/partnerships/initiatives/parks-for-inclusion/)
4. [The Arc of the United States](http://www.thearc.org/NetCommunity/Page.aspx?pid=1646)
 | * Advocacy organizations – both statewide and local
* Statewide and local Arc groups
* State and local newspapers
* State and local recreation boards and programs
 |
| **Transportation**Provide information on accessible public transportation services, paratransit services, and/or programs that promote community accessibility. (Optional) |
| 1. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
2. [State of the States in DD](http://www.stateofthestates.org/)
3. [ICI State Data](http://www.statedata.info/)
4. [ACL Transportation Page](https://acl.gov/programs/transportation/transportation) (Check right column for links)
5. [National Aging and Disability Transportation Center (NADTC)](https://www.nadtc.org/)
 | * Advocacy organizations – both statewide and local
* Statewide and local Arc groups
* State and local newspapers
 |
| **Housing**Provide information on the availability of affordable, accessible, integrated housing; housing supports and services; and services related to renting, owning, or modifying a residence. (Optional) |
| 1. [US Census Data](http://www.census.gov)
2. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
3. [State of the States in DD](http://www.stateofthestates.org/)
4. [ICI State Data](http://www.statedata.info/)
5. [Residential Information Systems Project (RISP) State Profiles Page](https://risp.umn.edu/state-profiles)
6. [Priced Out – The Housing Crisis for People with Disabilities](http://www.tacinc.org/media/59493/priced-out-in-2016.pdf)
7. [Cornell University – Disability Status Report](http://www.disabilitystatistics.org/)
 | * Interagency Agreements
* Statewide provider organizations
* State and local recreation boards and programs
 |
| **Child Care**Provide information on before-school, after-school, and early care services in communities. (Optional) |
| 1. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
2. [US Census Data](http://www.census.gov)
3. [Cornell University – Disability Status Report](http://www.disabilitystatistics.org/)
4. [Easter Seals – Autism Profiles for States](http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles)
5. [Center for Law and Social Policy – Head Start by the Numbers](http://www.clasp.org/)
 | n/a |
| **Interagency Initiatives**To the extent available, include information on other state collaborations, such as the state early learning councils required under the Head Start program, State Interagency Coordinating Councils required under Part C of IDEA, Work Investment Boards, and Centers for Independent Living, State Rehabilitation Council, Aging and Disability Resource Centers and other relevant state-established Councils, Committees, and/or Cabinets. (Required)\* |
| 1. [US Census Data](http://www.census.gov)
2. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
3. [State of the States in DD](http://www.stateofthestates.org/)
4. [Center on Budget Policy and Priorities](https://www.cbpp.org/archiveSite/9-8-08sfp.htm)
5. [Cornell University – Disability Status Report](http://www.disabilitystatistics.org/)
6. [Annual Disability Statistics Compendium](https://disabilitycompendium.org/)
 | * Interagency agreements
* State agency services needs assessment or gaps in services reports
* State agency Resource Mapping reports
* Statewide Direct Support Professional group66
* Policy updates from partners
* Council staff activities (I.e. information from interagency Boards and Coalitions that staff serve on)
 |
| **Quality Assurance**Provide information on monitoring of services, supports, and assistance to prevent abuse, neglect, sexual or financial exploitation, violation of legal or human rights, and inappropriate use of restraints or seclusion; interagency coordination and systems integration efforts that result in improved and enhanced services, supports, and other assistance; access to person-centered planning services; and training in leadership, self-advocacy, and self-determination. (Optional) |
| 1. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
2. [State of the States in DD](http://www.stateofthestates.org/)
3. [Institute on Community Integration (UCEDD/Minnesota)](https://cl.ici.umn.edu/our-work/self-determination-and-self-direction)
4. [University of Wisconsin, Population Health Institute, 2019 County Health Rankings Report](https://www.countyhealthrankings.org/reports/2019-county-health-rankings-key-findings-report)
5. [Center on Budget Policy and Priorities](https://www.cbpp.org/archiveSite/9-8-08sfp.htm)
6. [Easter Seals – Autism Profiles for States](http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles)
7. [Cornell University – Disability Status Report](http://www.disabilitystatistics.org/)
8. [Center for Law and Social Policy](http://www.clasp.org/)
9. [The Arc of US – Public Policy Goals for the 116th Congress](https://thearc.org/policy-advocacy/public-policy-goals/)
10. [Annual Disability Statistics Compendium](https://disabilitycompendium.org/)
 | * Statewide provider association
* State agency annual/topical reports, presentations and publications on Quality Assurance.
* State agency publications, websites, satisfaction surveys, needs assessments and reports.
 |
| **Health/Healthcare**Describe available medical assistance, maternal and child health care, services for children with special health care needs, mental health services for children and adults, institutional care options, and other comprehensive health and mental health services. (Required)\* |
| 1. [US Census Data](http://www.census.gov)
2. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
3. [State of the States in DD](http://www.stateofthestates.org/)
4. [Institute on Community Integration (UCEDD/Minnesota)](https://cl.ici.umn.edu/our-work/health-and-wellness)
5. [National Center on Health Statistics](http://www.cdc.gov/nchs/)
6. [National Core Indicators (NCI)](https://www.nationalcoreindicators.org/)
7. [Henry J. Kaiser Family Foundation (KFF) - Data related to insurance access](http://www.kff.org/)
8. [Kaiser Commission on Medicaid Facts](http://www.kff.org/about/kcmu.cfm)
9. [Annual Disability Statistics Compendium (Rehabilitation Research and Training Center on Disability Statistics and Demographics)](https://disabilitycompendium.org/sites/default/files/user-uploads/2018_Compendium_Accessible_AbobeReaderFriendly.pdf)
10. [Disability Statistics and Demographics](https://researchondisability.org/statsrrtc)
11. [University of Wisconsin, Population Health Institute, County Health Rankings](http://www.countyhealthrankings.org/)
 | * State Rehabilitation reports, which focus highlight or include health care
* State agency annual/topical reports, presentations and publications, which highlight or include health care
* Service Provider fact sheets, data, websites, articles, reports, and evaluations focusing on health care
 |
| **Education/Early Intervention**Provide information on general and special education services; early intervention services; early childhood services; private school services; education supports; and teacher training. (Optional) |
| 1. [US Census Data](http://www.census.gov)
2. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
3. [State of the States in DD](http://www.stateofthestates.org/)
4. [National Center for Education Statistics](http://nces.ed.gov/)
5. [American Institutes for Research](https://www.air.org/topic/education/special-education)
6. [Office of Special Education and Rehabilitative Services (OSERS)](https://www2.ed.gov/about/offices/list/osers/osep/index.html)
7. [40th Annual Report to Congress on the Implementation of the IDEA (2018)](https://www2.ed.gov/about/reports/annual/osep/2018/parts-b-c/40th-arc-for-idea.pdf)
 | * Search State Interagency Coordinating Councils for Education/Early Intervention in your State/Territory
 |
| **Employment**Describe job training, job placement, worksite accommodation, vocational rehabilitation, and other work assistance incentive and benefits programs that are available to people with developmental disabilities. You may choose to include information about “school to work” transition efforts.**To the extent available also include information on competitive, integrated employment efforts; sheltered workshops; Employment First policies/efforts; and sub- minimum wage.****To the extent available, include data regarding the number of youth and adults with developmental disabilities receiving each type of such employment services and supports. (Required)\*** |
| 1. [US Census Data](http://www.census.gov)
2. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
3. [State of the States in DD](http://www.stateofthestates.org/)
4. [ICI State Data](http://www.statedata.info/)
5. [The Bureau of Labor Statistics](http://www.bls.gov)
6. [National Council on Independent Living](https://www.ncil.org/)
7. [National Association of Workforce Boards](http://www.nawb.org/)
8. [State Employment Leadership Network](http://www.selnhub.org/home)
 | * State agency publications, websites, satisfaction surveys, needs assessments and reports related to employment.
* Statewide provider associations.
 |
| **Other Informal and Formal Services and Supports**Describe available social, child welfare, aging, independent living, and other such services not described elsewhere that are available to people with developmental disabilities and their families.* To the extent available, also include information on family support efforts/policies, peer support initiatives, faith-based community efforts, volunteer activities, home and community-based services, and long term services and supports.
* To the extent available, include data regarding the number of children and adults with developmental disabilities and, as applicable, their families receiving each type of such services and supports. (Required)\*
 |
| 1. [US Census Data](http://www.census.gov)
2. [American Community Survey](https://www.census.gov/programs-surveys/acs/)
3. [State of the States in DD](http://www.stateofthestates.org/)
4. [Institute on Community Integration (UCEDD/Minnesota)](https://cl.ici.umn.edu/our-work/long-term-supports-and-services)
5. [Residential Information Systems Project (RISP) State Profiles Page](https://risp.umn.edu/state-profiles)
6. [Priced Out – The Housing Crisis for People with Disabilities](http://www.tacinc.org/media/59493/priced-out-in-2016.pdf)
7. [University of Wisconsin, Population Health Institute, County Health Rankings](http://www.countyhealthrankings.org/)
8. [Easter Seals – Autism Profiles for States](http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles)
9. [Cornell University – Disability Status Report](http://www.disabilitystatistics.org/)
10. [Center for Law and Social Policy – Head Start by the Numbers](http://www.clasp.org/)
11. [Annual Disability Statistics Compendium (Rehabilitation Research and Training Center on Disability Statistics and Demographics)](https://disabilitycompendium.org/sites/default/files/user-uploads/2018_Compendium_Accessible_AbobeReaderFriendly.pdf)
12. [The Arc of the United States](http://www.thearc.org/NetCommunity/Page.aspx?pid=1646)
 | * Interagency agreements
* Statewide volunteer opportunities
* Faith based community services and supports
* Statewide People First group
* Statewide Direct Support Professional group
* Statewide and local Arc groups
* Stories from family providers
 |

### CRA Part 3: Analysis of State Issues and Challenges [SECTION 124(C)(3)(C)]

Waiting Lists

In general, the waiting list section includes, number of people waiting for residential services, (to the extent possible) state data on all other types of wait-lists, description of state’s wait list definition (s), how the state prioritizes individuals to be on the wait list and a summary of waiting list issues and challenges.

For a full list of the Waiting Lists requirements, refer to the State Plan Template with Guidance document. Additional Analysis of State Issues and Challenges sections have links listed below.

|  |
| --- |
| **Criteria for Eligibility of Services**The criteria for eligibility section includes an analysis of the barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families and the availability of assistive technology. (Required)\* |
| n/a | * State agency presentations presented at Council meetings or conferences
* Service Provider fact sheets, data, websites, articles, reports, and evaluations
* State and Federal agencies associated with the provision of Early Intervention Services, Special Education, employment/Vocational Rehabilitation Services and long-term services and supports.
 |
| **The Availability of Assistive Technology**Summarize the Council’s analysis of the availability of AT services, rehabilitation technology, and/or the availability of information about AT to individuals with developmental disabilities. If available, include information about access to generic technologies, such as universally designed technology, smart home-based technology, monitoring technology, etc. Also include information about the availability of AT for individuals with DD from culturally and linguistically diverse backgrounds. |
| 1. [National Assistive Technology Act Technical Assistance and Training (AT3) Center](https://www.at3center.net/stateprogram)
2. [Report by NIDILRR and Able Data – How State AT Programs Can Help You](https://abledata.acl.gov/sites/default/files/How%20State%20AT%20Programs%20Can%20Help%20You_1.pdf)
 | * State Rehabilitation reports, which include assistive technology
* State agency annual/topical reports, presentations and publications which highlight or include assistive technology
* Service Provider fact sheets, data, websites, articles, reports, and evaluations focusing on assistive technology
 |

## Appendix D: Developing Measurable Goals, Objectives, and Expected Outcomes with Examples

### Goals

A goal is a measurable statement of purpose for the desired long-term (5-year), global impact of the area of focus. Goals generally address change. Well-written goals serve as the foundation for developing objectives.

Criteria for developing a “good” goal:

* *Declarative statements*—provide a complete sentence that describes an outcome.
* *Jargon free*—use language that most people in the field outside your own agency are likely to understand.
* *Concise*—get the complete idea of your goal across as simply and briefly as possible, leaving out unnecessary detail.
* *Easily understood*—provide a goal in which the language is clear and for which there is a clear rationale.
* *Positive terms*—frame the outcomes in positive terms. Avoid the use of double negatives.
* *Framework for objectives*—provide a framework so that the objectives are stepping-stones to make progress to achieve the goals.

Example: “The DD Council will make community inclusion activities available to 50 people with developmental disabilities.”

Self-advocacy goal example: “[The DD Council will] Strengthen a program for the direct funding of a state self-advocacy organization to increase the number of people with developmental disabilities active in systems advocacy.”

### Objectives

An objective is a specific, measurable statement of the desired immediate or direct outcomes of the initiative that support the accomplishment of a goal.

Framework for developing objectives using SMART method:

* *Specific = Who?* Target population and who is doing the activity? What? (Action or broad activity for the objective)
* *Measurable* = Identifies how much change is expected.
* *Achievable* = Can be accomplished given current resources and constraints.
* *Realistic* = Addresses the DD Council’s purpose and proposes reasonable programmatic steps toward goals
* *Time-phased* = Provides a timeline indicating when the objective will be met.

Example: By 2024 the Council will provide support and training to 75 parents who have developmental disabilities to increase their participation in schools and community activities with their children.”

Self-Advocacy objective example, “By the end of each fiscal year, at least five self-advocate leaders will increase leadership skills of 20 people with developmental disabilities who want to become leaders.”

### Expected Outcomes

An Expected Outcome is what the DD Council expects to achieve as a result of doing something. This is not the same thing as the targeted performance measure.

Answer the question “if we do “x” then [insert expected outcome]

Example of an output and its coordinating expected outcome - Output: 4 newsletters will be developed and disseminated. Expected outcome: “People will have increased knowledge about and access to advocacy strategies, events and opportunities.”

### Additional Information on Writing Measurable Goals and Objectives

The ABCDEs of writing measurable goals and objectives include the following:

* Audience-Who?

The population/target audience for whom the desired outcome is intended.

* Behavior-What is to happen?

A clear statement of the behavior change/results expected.

* Condition-By when?

The conditions under which measurements will be made. This may refer to the timeframe and/or implementation of a specific intervention.

* Degree-By how much?

The quantification, or level, of results expected. This often involves measuring change in comparison to an identified baseline.

* Evidence-As measured by?

The definition of the method of measuring the expected change. The degree of change (set forth above) will be measured using a specific instrument or criterion.

To develop measurable *goals*—

1. Identify the long-term, global outcome(s) you want to achieve.
2. Identify each of the elements (A, B, C, D, E).
3. Formulate the goal statement using each of the necessary elements.

To develop measurable *objectives*—

1. Identify the short-term, more immediate outcome(s) you want to achieve.
2. Identify each of the elements (A, B, C, D, E).
3. Formulate the objective statement using each of the necessary elements.

### Additional Information on Outcomes and Measures:

Outcomes reflect the changes in service experienced by a program’s participants and progress toward the program’s goals. Outcomes also describe the consequences of your program activities or intervention.

Measures are data that can be used to determine whether program objectives have been achieved. A measure is a specific (quantitative) piece of information (i.e., data are numeric and consist of frequency counts, percentages, or other statistics) that provides evidence of your outcomes and helps you assess your program’s progress toward its stated goals. Measures are simply data that demonstrate what is occurring, not what caused the occurrence (Burt et al., 1997).

*Measuring outcomes is fundamental to program evaluation*. Essentially, it helps answer the questions, “Did the intervention work? Is your program employing the right activities to meet its program requirements, client needs, and program goals?” See example below of how to think about the relationship between outcomes and measures.

|  |
| --- |
| **EXAMPLE OF OUTCOMES AND MEASURES** |
| **Outcome** | What change are you measuring? | Increased understanding of the needs of victims. |
| **Measure** | What specific piece of data shows the change made by your program? | Number of appropriate referrals. |

### Outcomes and Measures

In identifying outcomes and measures, keep in mind the four Rs:

* Relevance: Are the expected outcomes relevant to the program? (This is the "Does it make sense?" test.)
* Reality: Can you measure what you want to know? Can you get the data you need?
* Reliability: Are the data accurate? Are the data of high quality?
* Resources: Do you have the staff, the money, and the time to gather the data?

### Developing and Generating Outcomes and Measures

Measures of outcomes represent the extent to which a program is effective in producing its intended outcomes and achieving desired results. To illustrate a broad view of program effectiveness, measures of outcomes are usually expressed as immediate or short-term, intermediate, and long-term outcomes. Immediate or short-term outcomes are the changes (e.g., knowledge, attitudes, and behaviors) that occur early in the delivery of program services or interventions. Intermediate outcomes are results that emerge after immediate outcomes, but before long-term outcomes. Long-term outcomes are the overall intended changes or results you are trying to achieve. Please keep this information in mind as you develop and generate your own outcomes and measures.

*Identify desired outcomes.* First, look to your program’s mission and goals. Ask yourself, “What activities are we doing? Why are we doing these particular activities?” The answer to the “Why” is usually an outcome. For instance, if one overall goal is to increase law enforcement’s ability to make appropriate referrals for trafficking victims, what are the benefits to your target population?

*Choose desired outcomes and prioritize them.* Specify a target goal on which to base your outcomes. For example, providing training to law enforcement on how to better identify trafficking victims may be one way of meeting your goal and prioritizing your manner of achieving a goal.

*Identify what information you need to measure the outcomes.* For example, one way of measuring whether law enforcement’s understanding of the needs of trafficking victims has increased (outcome) is to look at the number of appropriate service referrals law enforcement makes for trafficking victims after you have trained the officers (impact).

*Decide how that information can be efficiently and realistically gathered.* For example, think about what documentation (e.g., grant applications, monthly reports) or personnel can help you support your outcomes.

### Tip To Remember!

Be sure that you don’t confuse outcomes and outputs:

* *Outcomes* are the changes that result from the program or its activities (e.g., moving from a sheltered workshop to integrated/competitive employment)
* *Outputs* are units of services (e.g., the number of people trained)

## Appendix E: Logic Models and Evaluation

### Logic Models

The logic model should reflect an understanding of the relationships among the resources a DD Council has to operate, the strategies/activities the DD Council plans to implement, and the outputs, outcomes and impact the DD Council expects to achieve.

### What is a logic model?

* A diagram (and words) that shows key relationships among program elements
* A diagram that shows a direct relationship between activities and outputs and impact
* A diagram that helps people clearly see “what the DD Council does” versus “what the DD Council is trying to achieve” A diagram that shows the links in a chain of reasoning (“what causes what”)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Inputs/Resources** | **Activities** | **Outputs** | **Short Term Outcomes** | **Long-term Outcomes** | **Impact** |
| Resources are what a Council needs to operate the program. Program inputs, elements, ingredients. Resources include the human, financial organizational and community resources. E.g., funds, staff, technology. “What must this program have to operate well” | Activities are the methods (processes, tools, events) for providing the program. What the program does with the resources/inputs to fulfill its mission. E.g., training, outreach, advocacy, technology, events, actions. “What must we do to achieve our intended result?” | Outputs are service or product units produced by the program. The direct products of program activities. E.g., people trained, people served. “How many, how often, over what period of time?” | Outcomes are the changes in individuals, the community, or organizational conditions that occur as a result of the program. Specific changes in behavior, knowledge, skills status and level of functioning. Short term (1 to 3 years), changes anticipated. “So what? What difference is your program making?” | Intermediate and longer term (3 to 5 years) changes anticipated. | Impact is the fundamental intended change occurring in organizations, communities or systems as a result of DD Council program activities – the impact statement(s) should align with the 5 year goal statements (but do not have to be exact). |

### “If and then test”

Once a model is created, confirm that the model is ‘logical.’ Check this by conducting the ‘if-then’ test. Ask, “If we use all our resources/inputs and do these activities, then will we achieve our short-term outcomes? If we achieve our short-term outcomes and continue our activities then should we achieve all our intermediate outcomes?” For each activity, ask why it is being done and if it is absolutely necessary. Make sure there are no logical gaps – that all required inputs and activities are included.

### Logic model resources and references:

1. [HHS Logic Model Tip Sheet](https://www.acf.hhs.gov/sites/default/files/fysb/prep-logic-model-ts.pdf)
2. [W.W. Kellogg Foundation Logic Model Guide](http://www.wkkf.org/knowledge-center/resources/2006/02/wk-kellogg-foundation-%20%20%20logic-model-development-guide.aspx) – Clear, concise discussion of the use of logic models.
3. [CDC Resources](http://www.cdc.gov/eval/resources/index.htm#logicmodels) – A comprehensive list

### Evaluation Plan [Section 125(c)(3) and (7)]

Requested Elements:

1. Outline how the Council will examine the progress made in achieving the goals of the State Plan.
	1. The extent to which the goals were achieved
	2. The strategies that contributed to achieving the goals
	3. Factors that impeded achievement of the goals
	4. Separate info on the self-advocacy goal
	5. Updates (if appropriate) on results of CRA analysis
	6. Consumer satisfaction
2. Explain the methodology, which may be qualitative or quantitative, that will be used to determine if the needs identified and discussed are being met and if the Council results are being achieved.
	1. Define the procedures the council will use to monitor progress
	2. Discuss council activities that will measure (or address) Council's effectiveness
	3. Method or measures for determining progress?
	4. Logic model?
3. Describe the Council's role in reviewing and commenting on progress towards reaching the goals of the Plan.
4. Describe how the annual review will identify emerging trends and needs as a means for updating the Comprehensive Review and Analysis.

### Example Evaluation Plan

Over the course of the five years, the Council’s evaluation staff will implement a multi-method approach to conducting formative and summative evaluation of our Council. Two types of formative evaluation approaches will be used; process and progress evaluation. Process-based evaluation measures the extent to which a critical project activity is implemented as planned and proposed. Results of our process evaluation will be used to inform the Council and other stakeholders as to whether critical activities have been conducted within proposed timelines. The process-based evaluation will address the question of the extent implementation has differed significantly from what was planned and if changes or adjustments are needed.

The purpose of a formative evaluation plan is: (1) to determine the extent to which objectives were achieved; (2) to provide a description of the strategies that contributed to achieving the objectives; and (3) to provide a description of factors that may have impeded progress. The summative evaluation involves the collection of data that measures intended project outcomes.

Outcomes for the evaluation of Council activities will be measured through multiple methods, which incorporate culture and linguistically competent strategies, including the following:

Face-to-face/telephone interviews. In some instances, face-to-face and/or telephone interviews will be conducted with some stakeholders, particularly when the stakeholder group is a small and targeted group. Interviews will collect data not only on stakeholders’ perceptions of outcome attainment of the specific objective, but also on the needs groups have for information, education, training, technical assistance, policy revision, etc., in better serving people with developmental disabilities and their families. In the case of interviews with individuals with developmental disabilities and family members themselves, questions will also focus on how our work can better serve them.

Pre-tests will be used to measure participants’ assessments of the gains they make from participating in Council education and training programs. Pre-tests will be designed to demonstrate participants’ increased knowledge and skills, changed attitudes, and/or increased motivation in alignment with program specific outcomes.

Surveys. Outcome data will be collected through a post-course or post-workshop survey of participants. These surveys will focus on participants’ assessments of knowledge and skilled through participation in the Council activity. Other surveys will measure the extent to which the Council activity enhanced programs’/agencies/ capacity to serve individuals with developmental disabilities, and the extent to which project activities have increased consumer and stakeholder awareness of diverse issues related to areas in developmental disabilities.

Follow-up interviews will be utilized for some activities. The follow-up interviews will be developed to obtain more in-depth information regarding the outcomes of education and training and participants’ use and application of what they have gained or learned in the training.

Follow-up surveys will be administered on a widespread basis to participants of designated Council activities. Standardized survey instruments will be used to obtain data on the extent to which participants are applying knowledge and skills or applying new practices acquired through training.

Product review will be used if the primary outcome of an objective is products. Outcome attainment will be assessed by an in-depth review of the product for completion, quality and relevance through the use of Product Review instruments assessing the extent to which products address the Councils five year goals and the needs of people with developmental disabilities.

Other data will be collected and will supplement the formative and summative evaluation of the Council. Additional data will include Council member surveys, Council staff surveys, grantee and subcontractor surveys, and other data collection methods as appropriate to inform consumer satisfaction measures.

Our logic model is broad and reflects the connection between inputs, short and intermediate term outcomes related to the ultimate outcomes for the 5-Year Goals. Intermediate outcomes reflect the Council’s expectation that these short-term outcomes will translate into application of new and enriched skills, enhanced organizational capacity, improved practices and greater availability and access of higher quality services and opportunities for people with developmental disabilities and their families. In addition, intermediate outcomes are logically linked to desired impact on long-term outcomes – increasing the independence, productivity, integration and inclusion of people with developmental disabilities and their families.

The logic model serves as a guide for evaluating the five-year plan, which is linked to on-going evaluation activities, project-specific evaluation activities, Program Performance Report and Council review and commentary on the progress of the five-year plan.

All projects have evaluation activities specific to assessing their accomplishments and outcomes. Project status reports are generated quarterly. In addition, an annual evaluation summary for each project is required for Council activities. The summary has the following components, a brief description of project activities implemented during the reporting period, consumer satisfaction data, project accomplishments, project modifications due to obstacles encountered, and if applicable, emerging trends that should be addressed with within the project or through new activities.

Quarterly and annual project reports will be reviewed during regularly scheduled Council meetings. The Council review will assess the overall progress toward the accomplishment of the five-year plan, determine the status of each goal and objective as achieved, in progress, or not achieved, and make recommendations about modification to the plan in response to emerging trends and needs. The Council findings and decisions will be incorporated into applicable reports and state plan amendments.

The continuous feedback from the Council as well as the ongoing data collection of the Council will provide a strong review and identification process for emerging trends and needs as a mean for updating the CRA. The Council reviews the CRA during the annual meeting held in late spring of each year and, in collaboration with Council staff, adjusts the CRA in the Council State Plan amendment.

## Appendix F: How to Calculate a Rate (per 100,000) Formula

"Rate" simply means the number of things per some other number, in this case 100,000.

To calculate a rate, you need three pieces of information:

1. the number in the total group (for example, the total population in a State/Territory);
2. the number in the subgroup you are interested in (such as the number of people waiting for services); and;
3. the "per" number — per  100,000. The "per" number is called a multiplier.

 The formula for calculating a rate is:

(Number in subgroup ÷ Number in total group) × multiplier  = rate (per 100,000)

Example: Maryland

Total population in 2011 = 5,830,000 (58.3 per 100,000)

Total served (RISP report, Table 2.5) = 7,581

Number serviced per 100,000 state population = (7,581/5,830,000 \* 100,000) = 130.00

National average served per 100,000 = 439,146/311,800,000 x 100,000 = 141.00

We hope you find the State Plan Development Resource helpful as you engage in the planning process. To that end, we encourage your feedback and input on information and tools that would be useful to include. ***To submit content for consideration or if you need this resource in alternative format, please contact the NACDD office at 202-506-5813. For more information on State Plan Development, please contact*** [***NACDD/ITACC staff***](https://itacchelp.org/about-us/contact-us/)***.***