



National Independent Study of the Administration on Developmental Disabilities Programs

Final Report – Volume II. Appendixes

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on Developmental Disabilities Programs**

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Appendix A. Memorandum From Director of OMB



EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

THE DIRECTOR

August 17, 2011

M-11-30

MEMORANDUM FOR THE HEADS OF DEPARTMENTS AND AGENCIES

FROM: Jacob J. Lew
Director 

SUBJECT: Fiscal Year 2013 Budget Guidance

The President has defined our fiscal challenge as demonstrating that we can live within our means so that we can invest in job creation and economic growth now and in the long term. In April, he proposed a balanced framework for \$4 trillion in deficit reduction that would put us on path to achieve fiscal sustainability by the middle of this decade. Over the summer, in negotiations with the Congress, the President pursued deficit reduction of this magnitude. Once it was clear a bipartisan agreement could not yet be reached, the President signed into law a down payment toward this goal: the Budget Control Act of 2011. This legislation set ceilings on total discretionary spending and a target of \$2.4 trillion in total deficit reduction over the next decade.

In light of the tight limits on discretionary spending starting in 2012, your 2013 budget submission to OMB should provide options to support the President's commitment to cut waste and reorder priorities to achieve deficit reduction while investing in those areas critical to job creation and economic growth. Unless your agency has been given explicit direction otherwise by OMB, your overall agency request for 2013 should be at least 5 percent below your 2011 enacted discretionary appropriation. As discussed at the recent Cabinet meetings, your 2013 budget submission should also identify additional discretionary funding reductions that would bring your request to a level that is at least 10 percent below your 2011 enacted discretionary appropriation.

By providing budgets pegged to these two scenarios, you will provide the President with the information to make the tough choices necessary to meet the hard spending targets in place and the needs of the Nation. These 5 and 10 percent reductions from the 2011 enacted level should not be achieved by proposing across-the-board reductions or reductions to mandatory spending in appropriations bills, reclassifications of existing discretionary spending to mandatory, or enactment of new user fees to offset existing spending. The latter types of proposals may be included in your package as separate proposals on their merits or for consideration as alternatives to other cuts proposed in the main request. You may also submit priority add-backs with your request.

At the same time as your submission shows lower spending overall, you should identify programs to "double down" on because they provide the best opportunity to enhance economic growth. Finding the savings to support these investments will be difficult, but it is possible if budgets cut or eliminate low-priority and ineffective programs while consolidating duplicative ones; improve program efficiency by driving down operational and administrative costs; and support fundamental program reforms that generate the best outcomes per dollar spent.

Consistent with these guidelines, I ask that your 2013 budget and management plans address the following mechanisms for efficiency increases:

- If relevant, identify priority investments related to economic growth which the Department proposes to expand or protect, stating the strongest possible case for the positive economic impact.
- Identify and include in the budget submission cost-saving efforts that will improve operational efficiency and improve the rate of return to taxpayers, including more program integration, reorganizations within and between agency components, and realignment of resources (such as information technology, facilities, and staff) to improve service delivery to the public.
- To drive long-term productivity increases, your 2013 budget and management plans should explain how your agency will acquire, analyze, evaluate, and use data to improve policy and operational decisions, and how you will reallocate and strengthen your analytic and evaluation capacity to set outcome-focused priorities, identify the most effective and cost-effective practices and programs, and speed their adoption.
- Finally, agency submissions should take into consideration areas of duplication or overlap identified by the Government Accountability Office, as well as others.

I expect this year's budget formulation process to be a collaborative dialogue between OMB and agencies that emphasizes the best options for improving the Government's effectiveness while lowering costs. OMB will strive to offer ideas and assistance to agencies where we can, and to facilitate problem-solving on issues that cross agencies. In addition, I invite agencies to recommend ways that OMB or other Government-wide processes or requirements can be modernized and improved to help your agency meet its objectives more cost-effectively.

I know this will be a difficult year, but it will also offer an opportunity to make the hard decisions to invest where we can get the most done and pare back in other areas.

Appendix B. Working Version of Measurement Matrices (Benchmarks, Indicators, and Examples of Performance Standards)

- B1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES**
- B2. PROTECTION AND ADVOCACY SYSTEMS**
- B3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE**
- B4. COLLABORATION**

Appendix B1. State Councils on Developmental Disabilities

- B1-1. State Plan Development**
- B1-2. Self-Advocacy and Leadership Development**
- B1-3. Community Capacity Development**
- B1-4. Identification of Promising and Effective Practices**
- B1-5. Systems Change Through Advocacy**
- B1-6. Governance and Management**

B1-1. State Plan Development

As required by law, all State Councils on Developmental Disabilities (DD Councils) carry out a planning function through the development of a 5-year State Plan and amendments to the plan.

The process for developing the State Plan begins with a comprehensive review and analysis of the availability of and gaps in services and supports for people with developmental disabilities and their families in the State. DD Councils seek wide input from a variety of stakeholders, including people with developmental disabilities, their families, the State Protection and Advocacy (P&A) system, University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs), advocacy organizations, service providers, and DD Council members and staff. They also collect, review, and analyze existing data from a variety of sources (e.g., waiting lists for supports and services, the Census, surveys, State agency reports, and UCEDD and P&A reports) to validate, support, and expand upon stakeholder input.

DD Councils use the results of this comprehensive review and analysis to develop a draft 5-year State Plan and make the draft plan available for public review and comment. The DD Council then revises the plan, submits it to a designated state agency (DSA) for assurances of financial participation and consistency with state law, and then submits it to the Administration on Developmental Disabilities (ADD) for approval by the Secretary of Health and Human Services. At the end of each grant year, DD Councils review their progress in achieving the goals of the State Plan and determine whether there is a need for amendments.

The primary target audience of State Plan development is the DD Council itself. Other important audiences consist of state governments, P&As and UCEDDs, DD Council grantees and potential grantees, and individuals and organizations that may wish to use the State Plan (particularly the comprehensive review and analysis) to inform their own planning process.

Both the approved State Plan and amendments are expected to be used as a blueprint for DD Council's work. All other DD Council activities flow from their priorities, goals, and objectives. DD Councils conduct activities to meet the goals of the State Plan (with staff and collaborators), issue requests for proposals (RFPs) to identify grantees to conduct activities that are consistent with the State Plan, and/or obtain additional funding to achieve the goals in the State Plan. Moreover, DD Councils use the State Plan to guide strategies and identify potential collaborators.

Benchmarks and Indicators

- 1.1 DD Council State Plans represent key issues, priorities, and needs of people with developmental disabilities and their families.
- 1.1.1 The process DD councils use to develop the State Plan:
- Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families;
 - Enables those in both urban and rural communities to participate;
 - Provides opportunities for those who have never participated before to participate, particularly those who are typically unserved or underserved;¹
 - Enables people with developmental disabilities to participate;
 - Includes the use of feedback about current programs and activities (e.g., from participants in DD council-funded programs; staff or grantee feedback); and
 - Includes the use of reliably collected, timely, and valid data.²
- 1.1.2 DD Council State Plans reflect the input and data provided on the needs, priorities, and interests of people with developmental disabilities and their families.
- 1.2 DD Council planning drives DD Council activities.
- 1.2.1 DD Council planning results in stated long-term systems change goals that are consistent with the DD Act and results in strategies to accomplish the goals.
- 1.2.2 Self-advocacy and leadership development activities³ are consistent with the goals and objectives in the State Plan and amendments.
- 1.2.3 Community capacity development activities⁴ are consistent with the goals and objectives in the State Plan and amendments.

¹“The term ‘unserved and underserved’ includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life” [Section 102(32) of the DD Act].

²Validity refers to the degree to which the data are measuring the concept that researchers set out to measure

³Self-advocacy and leadership activities include the support or provision of education, training, technical assistance, outreach, and public awareness. These activities provide people with developmental disabilities and family members with knowledge and skills to obtain supports and services and advocate for systems change so that their choices can meet desired lifestyle goals, including integration into the community, choice and independence.

- 1.2.4 Promising practices that DD Councils identify, evaluate, promote, and disseminate are consistent with the goals and objectives in the State Plan and amendments.
- 1.2.5 Advocacy activities⁵ are consistent with the goals and objectives in the State Plan and amendments.
- 1.2.6 DD Councils address new and emerging issues not covered in the State Plan.

⁴Community capacity development activities provide communities with the capacity to support the inclusion of people with developmental disabilities in every aspect of community life. Capacity building includes increasing community awareness, knowledge, skills, and abilities and improving the infrastructure for service delivery throughout the State.

⁵ Advocacy activities include writing and disseminating white papers and other reports, meeting with legislators and other policy makers, preparing legislative briefs, providing testimony and personal stories at committee meetings and other venues, and obtaining press/media coverage.

Indicators and Performance Standards

1.1 DD Council State Plans represent key issues, priorities, and needs of people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
<p>1.1.1 The process DD Councils use to develop the State Plan:</p> <ul style="list-style-type: none"> ▪ Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families; ▪ Enables those in both urban and rural communities to participate; ▪ Provides opportunities for those who have never participated before to participate, particularly those who are typically unserved or underserved; ▪ Enables people with developmental disabilities to participate. ▪ Includes the use of feedback about current programs and activities (e.g., from participants in DD Council-funded programs; staff or grantee feedback). ▪ Includes the use of reliably collected, timely, and valid data; and 	<p>In the last planning cycle, the DD Council:</p> <ul style="list-style-type: none"> ▪ Sought input on the needs of people with developmental disabilities and their families from a variety of stakeholders (e.g., people with developmental disabilities, family members, self-advocacy groups, advocates for people with developmental disabilities and family members, service providers, UCEDDs, P&As); ▪ Sought input from both urban and rural communities in the state; ▪ Sought input from individuals and groups from unserved or underserved populations or communities, such as people: <ul style="list-style-type: none"> ▪ from racial/ethnic minorities; ▪ with limited ability to understand English; and ▪ others who fall within the definition of typically unserved or unserved populations or communities; ▪ Provided accommodation to those who needed it in order to participate; ▪ Made requests for input in ways that were meaningful to people with developmental disabilities; ▪ Examined feedback from program activities (e.g., from participants in DD Council-funded programs; staff or grantee feedback); ▪ Used reliably collected, timely, and valid data and reports to identify the needs of people with developmental disabilities and their families.
<p>1.1.2 DD Council State Plans reflect the input and data provided on the needs, priorities, and interests of people with developmental disabilities and their families.</p>	<ul style="list-style-type: none"> ▪ In the last planning cycle, the DD Council analyzed and synthesized reliable and valid data (e.g., input from stakeholders, reliably collected data from surveys; state statistics; reports from the P&A and other sources; state agency reports). ▪ The goals and objectives in the State Plan reflect the findings from the planning process.

1.2 DD Council planning drives DD Council activities.

Indicators	Examples of Performance Standards
<p>1.2.1 DD Council planning results in stated long-term systems change goals that are consistent with the DD Act and results in strategies to accomplish the goals.</p>	<ul style="list-style-type: none"> ▪ The DD Council can provide planning materials that contain long-term systems change goals,⁶ short-term objectives,⁷ and targets. ▪ DD Council systems change goals contained in the State Plan are consistent with the principles and goals of the DD Act.
<p>1.2.2 Self-advocacy and leadership development activities are consistent with the goals and objectives in the State Plan and amendments.</p>	<ul style="list-style-type: none"> ▪ The DD Council can demonstrate that self-advocacy and leadership development activities in the past year reflected the goals and objectives in the State Plan or amendments.
<p>1.2.3 Community capacity development activities are consistent with the goals and objectives in the State Plan and amendments.</p>	<ul style="list-style-type: none"> ▪ The DD Council can demonstrate that community capacity development activities in the past year reflected the goals and objectives in the State Plan or amendments.
<p>1.2.4 Promising practices that DD Councils identify, evaluate, promote, and disseminate are consistent with the goals and objectives in the State Plan and amendments.</p>	<ul style="list-style-type: none"> ▪ The DD Council can demonstrate that DD Council projects selected to test, promote, or disseminate promising practices in the past year were consistent with the goals and objectives in the State Plan or amendments.
<p>1.2.5 Advocacy activities are consistent with the goals and objectives in the State Plan and amendments.</p>	<ul style="list-style-type: none"> ▪ The DD Council can demonstrate that advocacy activities in the past year reflected the goals and objectives in the State Plan or amendments.
<p>1.2.6 DD Councils address new and emerging issues not covered in the State Plan.</p>	<ul style="list-style-type: none"> ▪ The DD Council has procedures for taking on new or emerging issues not covered in the State Plan. ▪ The DD Council is able to provide a rationale for taking on new or emerging issues in the past year not covered in the State Plan or amendments.

B1-2. Self-Advocacy and Leadership Development

The DD Act contains several sections that authorize the DD Council to provide and/or support self-advocacy and leadership development for people with developmental disabilities, as well as for State self-advocacy organizations led by people with developmental disabilities.

⁶ Long-term goals cover a multiple-year period (e.g., 5 years or more).

⁷ Short-term objectives are developed to achieve long-term goals. They are explicit and are intended to be accomplished over a maximum period of 1 year.

Based on the availability of resources and opportunities and priority issues addressed in the State Plan, DD Councils plan and implement strategies for self-advocacy and leadership development. Activities include the support or provision of education, training, technical assistance, outreach, and public awareness. These activities provide people with developmental disabilities and family members with knowledge and skills to obtain supports and services and advocate for systems change so that their choices can meet desired lifestyle goals, including integration into the community, choice and independence. Knowledge includes, but is not limited to, knowledge about existing supports and services, understanding the possible supports and services that could exist, and processes that could be used to increase, improve, or maintain supports and services, community inclusion, choice, and independence. Skills include, but are not limited to, the provision of public testimony, meeting with public officials, writing letters, and other advocacy techniques.

The target audience for this key function consists of people with developmental disabilities and/or their families. The expected outcomes are knowledgeable and skilled people with developmental disabilities and family members who use their knowledge and skills to advocate for themselves and others; provide leadership to the developmental disabilities community and the community at large; and serve as mentors to others with developmental disabilities. As a result, an increased number of people with developmental disabilities and family members are expected to actively participate in advocacy activities that would influence policy and practice in the State. Furthermore, it is expected that some would become members or the Chair of the DD Council, members or leaders of organizations that advocate on behalf of people with disabilities, or members or leaders of other community agencies or organizations.

Benchmarks and Indicators

- 2.1 DD Councils provide and/or support advocacy and leadership development for people with developmental disabilities and/or their families.
 - 2.1.1 DD Councils provide and/or support self-advocacy and leadership development through education, training, and technical assistance for people with developmental disabilities and/or their families.
 - 2.1.2 Participants in DD Council-supported self-advocacy and leadership development through education, training, and technical assistance represent a wide variety of groups and communities typically considered to be unserved or underserved.

- 2.1.3 DD Councils establish or strengthen “a program for the direct funding of a State self-advocacy organization led by people with developmental disabilities.”
- 2.2 Participants in self-advocacy and leadership activities provided or supported by DD Councils use their knowledge and skills to advocate for themselves, advocate for others, and provide leadership to the developmental disabilities community and the community at large.
- 2.2.1 DD Councils and grantees evaluate DD Council-supported self-advocacy and leadership development activities to improve their programs.
- 2.2.2 Participants in DD Council-supported self-advocacy and leadership development activities:
- Are nominated to become members of the DD Council;
 - Become leaders or sub-committee members of the DD Council;
 - Become members or leaders of other organizations that advocate on behalf of people with disabilities;
 - Become members or leaders of other community organizations;
 - Participate in DD Council or other advocacy efforts;
 - Become an employee or volunteer of a disability advocacy organization; and
 - Use the knowledge and skills they obtained to enhance their lives and become self-sufficient.
- 2.2.3 DDC-supported programs led by people with developmental disabilities [(Section 124(c)(4)(A)(ii)(I)] grow and become stronger.

Indicators and Performance Standards

2.1 DD Councils provide and/or support self-advocacy and leadership development for people with developmental disabilities and/or their families.

Indicators	Examples of Performance Standards
<p>2.1.1 DD Councils provide or support self-advocacy and leadership development through education, training, and technical assistance for people with developmental disabilities and/or their families.</p>	<ul style="list-style-type: none"> ▪ In the past year, the DD Council provided or supported self-advocacy and leadership development through education, training, or technical assistance activities for people with developmental disabilities and/or their families. ▪ The DD Council kept track of the number of people who participated in DD Council-supported education, training, and technical assistance in the past year to examine indicators that demonstrate the DD Council's commitment to self-advocacy and leadership development.
<p>2.1.2 Participants in DD Council-supported self-advocacy and leadership development through education, training, and technical assistance represent a wide variety of groups and communities typically considered to be unserved or underserved.</p>	<ul style="list-style-type: none"> ▪ In the past year, the DD Council identified the unserved and underserved populations and communities in the state. ▪ In the past year, the DD Council recruited members of populations and communities in the state identified as unserved and underserved to participate in self-advocacy and leadership development through education, training, and technical assistance.
<p>2.1.3 DD Councils establish or strengthen "a program for the direct funding of a State self-advocacy organization led by people with developmental disabilities."</p>	<ul style="list-style-type: none"> ▪ In the past year the DD Council established or strengthened a State self-advocacy organization led by people with developmental disabilities in a variety of ways, such as: ▪ provided funding to an organization led by people with developmental disabilities; ▪ provided grant writing training and/or assistance; ▪ helped to identify public and/or private funding opportunities; ▪ provided opportunities for members of self-advocacy organizations to participate in DD Council advocacy activities or advocacy activities of other organizations; or ▪ Other.

2.2 Participants in self-advocacy and leadership activities supported by DD Councils use their knowledge and skills to advocate for themselves, advocate for others, and provide leadership to the developmental disabilities community and the community at large.

Indicators	Examples of Performance Standards
<p>2.2.1 DD Councils and grantees evaluate DD Council-supported self-advocacy and leadership development activities to improve their programs.</p>	<ul style="list-style-type: none"> ▪ The DD Council or grantees assessed participant satisfaction with DD Council-supported advocacy and leadership development activities implemented in the past year. ▪ Participants in DD Council-supported advocacy and leadership development activities implemented in the past year were satisfied or very satisfied with the activity in which they participated (i.e., report 4 or 5 on a scale of 1 – 5). ▪ The DD Council can provide examples of ways in which it used results of evaluations to make changes to self-advocacy and leadership development activities in the past year.
<p>2.2.2 Participants in DD Council-supported self-advocacy and leadership development activities:</p> <ul style="list-style-type: none"> ▪ Are nominated to become members of the DD Council; ▪ Become leaders or sub-committee members of the DD Council; ▪ Become members or leaders of other organizations that advocate on behalf of people with disabilities; ▪ Become members or leaders of other community organizations; ▪ Participate in DD Council or other advocacy efforts; ▪ Become an employee or volunteer of a disability advocacy organization; and ▪ Use the knowledge and skills they obtained to enhance their lives and become self-sufficient. 	<ul style="list-style-type: none"> ▪ The DD Council has a prescribed methodology for following up participants in DD Council-supported self-advocacy and leadership development activities to determine ways in which participants benefited from the activity. ▪ The DD Council or grantees followed up participants of self-advocacy and leadership development activities implemented in the past year after the activity ended to determine ways in which participants benefited from the activity. ▪ The DD Council can provide examples in which participants in DD Council-supported self-advocacy and leadership development activities in the past 5 years benefited, such as: <ul style="list-style-type: none"> – Were nominated to become the Chair of the DD Council or of a DD Council sub-committee; – Became a leader or sub-committee member of the DD Council; – Became a member or leader in other organizations that advocate on behalf of people with disabilities; – Became a member or leader in other community organizations;

Indicators	Examples of Performance Standards
	<ul style="list-style-type: none"> - Participated in DD Council or other advocacy efforts on behalf of people with developmental disabilities; - Helped a peer or mentored another person with a disability; - Became an employee or volunteer of a disability advocacy organization; or - Used the knowledge and skills they obtained to enhance their lives and become self-sufficient.
<p>2.2.3 DD Council-supported programs led by people with developmental disabilities [(Section 124(c)(4)(A)(ii)(I)] improve.</p>	<p>The DD Council can give examples from the past 5 years that demonstrate the improvement of DD Council-supported self-advocacy organizations led by people with developmental disabilities (e.g., increase in the number of organizations, increase in size, financial independence, receipt of a grant).</p>

B1-3. Community Capacity Development

Under Sec. 121(1) of the DD Act, one of the purposes of DD Councils is to “engage in advocacy, capacity building, and systemic change activities...” by providing communities with the capacity to support the inclusion of people with developmental disabilities in every aspect of community life. Capacity building includes increasing community awareness, knowledge, skills, and abilities and improving the infrastructure for service delivery throughout the State. Each DD Council works with appropriate collaborators or grantees to develop and implement strategies and activities for community capacity building, including provision or support of seminars, forums, workshops, demonstration projects, technical assistance, outreach, and public awareness.

The target audience for the development of community capacity includes people not necessarily considered to be part of the developmental disabilities community (e.g., dentists, physician specialists, and teachers) but nevertheless are in a position to have an impact on the inclusion into the community of people with developmental disabilities and on the choices they have available.

The expected outcomes of this key function include knowledgeable and skilled individuals who are in a position to improve supports, inclusion, and choice for people with developmental disabilities and their families. People with developmental disabilities and families are the ultimate beneficiaries of the changes and improvements in community capacity that accrue from this key function. They

benefit in a variety of ways, including access to competent health care, employment opportunities, and public transportation and services, and increased inclusion and choice in living a fulfilled life.

Benchmarks and Indicators

- 3.1 DD Councils provide or support community capacity development activities that target those who potentially have an influence on the choice, inclusion, and integration of people with developmental disabilities into the community.
 - 3.1.1 DD Councils provide or support community capacity development through information, training, demonstration projects, and technical assistance to individuals and organizations that are in a position to provide people with developmental disabilities choice and inclusion in the community.
 - 3.2 Information, training, demonstration projects and technical assistance provided or supported by DD Councils are responsive to the needs of people with developmental disabilities and to their families.
 - 3.2.1 DD Councils and grantees evaluate DD Council-supported community capacity development activities to improve their programs.
 - 3.2.2 Recipients of DD Council-supported information, training, and technical assistance activities:
 - Transfer the knowledge and skills they obtained to their work;
 - Improve their effectiveness in providing services or supports to people with developmental disabilities; and
 - Improve the effectiveness of the community in including people with developmental disabilities in all aspects of life.

Indicators and Performance Standards

- 3.1 DD Councils provide or support community capacity development activities that target those who potentially have an influence on the choice, inclusion, and integration of people with developmental disabilities into the community.**

Indicators	Examples of Performance Standards
<p>3.1.1 DD Councils provide or support community capacity development through information, training demonstration projects, and technical assistance to individuals and organizations that are in a position to provide people with developmental disabilities choice and inclusion in the community.</p>	<ul style="list-style-type: none"> ▪ In the past year, the DD Council provided or supported community capacity development through education, training, demonstration projects, or technical assistance activities for people with developmental disabilities and/or their families. ▪ The DD Council kept track of the number of people who participated in DD Council-supported education, training, and technical assistance in the past year to examine indicators that demonstrate the DD Council's commitment to community capacity development.⁸

- 3.2 Information, training, demonstration projects and technical assistance provided or supported by DD Councils are responsive to the needs of people with developmental disabilities and to their families.**

Indicators	Examples of Performance Standards
<p>3.2.1 DD Councils and grantees evaluate DD Council-supported community capacity development activities to improve their programs.</p>	<ul style="list-style-type: none"> ▪ The DD Council or grantees assessed participant satisfaction with DD Council-supported community capacity development activities implemented in the past year. ▪ Participants in DD Council-supported community capacity development activities implemented in the past year were satisfied or very satisfied with the activity in which they participated (i.e., report 4 or 5 on a scale of 1 – 5). ▪ The DD Council can provide examples of ways in which it used results of evaluations to make changes to community capacity development activities in the past year.

⁸ Examples of indicators include: number of people who participated in community capacity development programs per population of the state; number of people who participated in community capacity development programs per DD Council budget.

Indicators	Examples of Performance Standards
<p>3.2.2 Recipients of DD Council-supported information, training, and technical assistance:</p> <ul style="list-style-type: none"> ▪ Transfer the knowledge and skills they obtained to their work; ▪ Improve their effectiveness in providing services or supports to people with developmental disabilities; and ▪ Improve the effectiveness of the community in including people with developmental disabilities in all aspects of life. 	<ul style="list-style-type: none"> ▪ The DD Council or grantees followed up participants in community capacity development activities implemented in the past year after the activity ended to determine ways in which participants benefited from the activity. ▪ The DD Council can provide examples in which participants in DD Council-supported community capacity development activities in the past 5 years: <ul style="list-style-type: none"> - Transferred the knowledge and skills they obtained to their work; - Improved their effectiveness in providing services to people with developmental disabilities; or - Improved the effectiveness of the community in including people with developmental disabilities in all aspects of life.

B1-4. Identification of Promising and Effective Practices

As a means of filling gaps in services and supports and overcoming barriers to people with developmental disabilities and their families, DD Councils fund or conduct demonstration projects on new approaches to delivering services and supports. If these approaches have not yet been evaluated, they are known as “promising practices.”

DD Councils identify and test promising practices⁹ and promote and disseminate information on those promising practices that have been found to be effective. Negative findings may also be disseminated so organizations will not continue to use ineffective practices. DD Councils award funding, secure funding from other sources, assist community organizations in obtaining funding, monitor progress of those engaged in testing and promoting promising practices, and disseminate project results.

The target audience for this key function includes the DD Council itself (which uses the results of the projects it funds), policy makers, as well as people in the community who have an influence on

⁹ We use the term “test” as an umbrella term to include evaluation with rigorous and less rigorous methods for observing the results of trying out a promising practice.

the inclusion of people with developmental disabilities into the community and their ability to have choices (e.g., employers, dentists, physician specialists, and teachers). Grantees, who are often funded by DD Councils to perform the work of testing promising practices and implementing those known to be effective are also key players in this key function.

DD Council efforts to identify and test promising practices and promote and disseminate effective ones are expected to result in new and effective approaches to services and supports for people with developmental disabilities and their families and changes to community practices. Findings which result from this key function can also be used to guide future DD Council efforts to make changes to systems that deliver services and supports and include people with developmental disabilities in the community and provide them with choices.

Benchmarks and Indicators

- 4.1 DD Councils identify and test promising practices.
 - 4.1.1 DD Councils identify and test promising practices in a variety of ways.
- 4.2 **Promising practices identified and tested by DD Councils improve supports and services for people with developmental disabilities and their families and increase inclusion and choice in the community.**
 - 4.2.1 DD Councils disseminate results of efforts to identify and test promising practices.
 - 4.2.2 Effective practices identified by DD Councils increase inclusion and choice in the community.
 - 4.2.3 Promising and effective practices identified by DD Councils guide future DD Council activities (e.g., become an advocacy issue).

Indicators and Performance Standards

4.1 DD Councils identify and test promising practices.

Indicators	Examples of Performance Standards
<p>4.1.1 DD Councils identify and test promising practices in a variety of ways.</p>	<p>The DD Council can provide examples in which it identified or tested promising practices in the past 5 years by:</p> <ul style="list-style-type: none"> ▪ Issuing requests for proposals to identify promising practices; ▪ Issuing requests for proposals to test promising practices using DD Council funds; ▪ Securing external funding to identify or test promising practices; ▪ Assisting community organizations in obtaining funding to identify or test promising practices; ▪ Partnering with other agencies or organizations to identify or test promising practices; or ▪ Other.

4.2 Promising practices identified tested by DD Councils improve supports and services for people with developmental disabilities and their families and increase inclusion and choice in the community.

Indicators	Examples of Performance Standards
<p>4.2.1 DD Councils disseminate results of efforts to identify and test promising practices.</p>	<ul style="list-style-type: none"> ▪ The DD Council can provide examples in which it promoted, in the past 5 years, promising practices shown to be effective through DD Council-supported efforts. ▪ The DD Council can provide examples in which it disseminated, in the past 5 years, information on promising practices shown to be effective through DD Council-supported efforts. ▪ The DD Council can provide examples in which it disseminated information on tests of promising practices that showed that the practices were ineffective.
<p>4.2.2 Effective practices identified by DD Councils increase inclusion and choice in the community.</p>	<p>The DD Council can provide examples of promising or effective practices identified through DD Council-supported efforts in the past 5 years that:</p> <ul style="list-style-type: none"> ▪ are currently being utilized by service providers and others in the community; and ▪ increase inclusion and choice in the community.

Indicators	Examples of Performance Standards
4.2.3 Promising and effective practices identified by DD Councils guide future DD Council activities (e.g., become an advocacy issue).	The DD Council can provide examples of promising or effective practices identified through DD Council-supported efforts in the past 5 years that have guided current DD Council activities.

B1-5. Systems Change Through Advocacy

Systems change for the purpose of greater community inclusion and choice is a major goal of the DD Council, and advocacy is an important means of reaching that goal. DD Council advocacy efforts consist of activities to facilitate changes to the service delivery and support systems in the state in order to improve community access and promote self-determination and independence for people with developmental disabilities and their families. Councils engage in advocacy activities to make changes to (or sometimes to maintain) policies and practices; foster attitudes that support access to full inclusion of people with developmental disabilities in society; eliminate barriers to access; and engage key policy makers and people with developmental disabilities in advocacy activities.

In order to develop and implement a plan of action, Councils work with partners and key stakeholders [e.g., people with developmental disabilities and their family members, advocates), other DD Network programs (UCEDDs and P&As), members of the DD Council, and DD Council staff] to identify and assign roles for systems change activities. Advocacy activities described here include writing and disseminating white papers and other reports, meeting with legislators and other policy makers, preparing legislative briefs, providing testimony and personal stories at committee meetings and other venues, and obtaining press/media coverage.

The target audiences of these advocacy efforts include the legislative and administrative arms of local, state, and federal government; human services agencies; educational institutions; the medical community; the business community; the media; and other groups and organizations that can have an impact on supports and services for people with developmental disabilities and their choice and inclusion in the community.

Expected outcomes include changes to (or maintenance of) federal, state and local policies, legislation, practices, or procedures; improved access to existing community services and supports; and increased knowledge of policy makers about people with developmental disabilities and the barriers that prevent them from living a fully inclusive life.

Benchmarks and Indicators

- 5.1 DD Councils address systems change issues that have an impact on the lives of people with developmental disabilities and their families and promote inclusion and choice for people with developmental disabilities.
 - 5.1.1 DD Councils use a variety of advocacy strategies to meet systems change goals and objectives.
 - 5.1.2 DD Councils collaborate with local and state agencies, organizations, individuals, disability networks, coalitions, and other DD Network programs to achieve systems change goals and objectives through advocacy.
- 5.2 DD Council systems change efforts through advocacy facilitate changes to or maintenance of legislative, administrative, and/or organizational actions, policies, and practices that positively impact the lives of people with developmental disabilities and their families.
 - 5.2.1 DD Council advocacy efforts support changes to or maintenance of legislation or public or social policy.
 - 5.2.2 DD Council advocacy efforts support changes to community practice that lead to inclusion in the community, independence, and increased choice.

Indicators and Performance Standards

- 5.1 DD Councils address systems change issues that impact the lives of people with developmental disabilities and their families and promote inclusion and choice for people with developmental disabilities.

Indicators	Examples of Performance Standards
5.1.1 DD Councils use a variety of advocacy strategies to meet systems change goals and objectives.	The DD Council can provide examples in which it used advocacy strategies in the past 5 years to meet systems change goals and objectives. For example: <ul style="list-style-type: none"> ▪ Provided funding to support systems change (or maintenance) efforts; ▪ Wrote position papers or other reports; ▪ Obtained press coverage; ▪ Informed policy makers; ▪ Gave public testimony; ▪ Drafted legislation; or ▪ Other.

Indicators	Examples of Performance Standards
<p>5.1.2 DD Councils collaborate with local, state, and federal agencies, organizations, individuals, disability networks, coalitions, and other DD Network programs to achieve systems change goals and objectives through advocacy.</p>	<ul style="list-style-type: none"> ▪ The DD Council can describe the roles played by collaborators in system change efforts they led or participated in the past year. ▪ DD Council collaborators can describe the roles the DD Council played on system change efforts led or participated in by the DD Council in the past year.

5.2 DD Council systems change efforts through advocacy facilitate changes to or maintenance of legislative, administrative, and/or organizational actions, policies, and practices that positively impact the lives of people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
<p>5.2.1 DD Council advocacy efforts support changes to or maintenance of legislation or public or social policy.</p>	<p>The DD Council can provide examples in which DD Council advocacy efforts supported (or prevented) changes to legislation or public or social policy in the past 5 years.</p>
<p>5.2.2 DD Council advocacy efforts support changes to community practice which lead to inclusion in the community, independence, and increased choice.</p>	<ul style="list-style-type: none"> ▪ The DD Council can provide examples in which DD Council advocacy efforts supported changes to community practice in the past 5 years. ▪ The DD Council can provide examples in which DD Council advocacy efforts led to inclusion in the community, independence, and increased choice.

B1-6. Governance and Management

The goals of DD Council governance and management are to ensure that each of the key functions for which DD Councils are responsible – State Plan development; self-advocacy and leadership development; community capacity development; identification of promising and effective practices; and systems change through advocacy -- are carried out efficiently and effectively.

The direct target audience of governance and management is the funding agency (ADD) whose role is to administer efficient and effective programs that have an impact on people with developmental disabilities, family members, service providers, and State programs. Other beneficiaries of successful governance and management include people with developmental disabilities and their families, community organizations, and the governor and state government.

The expected outcome for this key function is an efficient, effectively functioning and professional DD Council with strong ties to the developmental disabilities community.

Benchmarks and Indicators

- 6.1 DD Councils have the capacity to fulfill their roles and responsibilities.
 - 6.1.1 DD Council members collectively have the areas of expertise required to be an effective Council.
 - 6.1.2 DD Council members learn about their roles and responsibilities, the intent of the DD Act, and the DD Council in a variety of ways.
 - 6.1.3 DD Council members consistently attend DD Council meetings.
 - 6.1.4 DD Council staff provides members with support so they can consistently and meaningfully participate in meetings and fulfill their responsibilities.
 - 6.1.5 DD Councils assess their own efficiency and effectiveness in meeting their goals and objectives.
- 6.2 DD Councils use a fair and transparent process to select competent and experienced grantees to implement goals and objectives in the State Plan and amendments.
 - 6.2.1 DD Councils have a written policy or procedures for selecting competent and experienced grantees.
 - 6.2.2 DD Councils utilize review committees composed of people who have an understanding of issues concerning people with developmental disabilities and family members and experience in selecting and monitoring grantees.
 - 6.2.3 DD Councils have a policy or procedures for handling unsolicited proposals.¹⁰
- 6.3 DD Councils administer the work of grantees in a professional manner.
 - 6.3.1 DD Councils issue contracts to grantees.
 - 6.3.2 DD Council-supported grantees meet the requirements of their contracts.

¹⁰ An unsolicited proposal means one that is independently developed and submitted rather than one submitted in response to a solicitation or request for proposal (RFP).

Indicators and Performance Standards

6.1 DD Councils have the capacity to fulfill their roles and responsibilities.

Indicators	Examples of Performance Standards
6.1.1 DD Council members collectively have the areas of expertise required to be an effective Council.	<p>In addition to complying with the DD Act on the composition of the DD Council, the DD Council collectively includes individuals who:</p> <ul style="list-style-type: none"> ▪ Are representative of the state population and where the population resides; ▪ Have an understanding of policy or legal issues; ▪ Have financial or business expertise; and ▪ Have demonstrated leadership.
6.1.2 DD Council members learn about their roles and responsibilities, the intent of the DD Act, and the DD Council in a variety of ways.	<ul style="list-style-type: none"> ▪ New DD Council members receive an orientation within a few months of becoming a member. ▪ DD Council members learn about their roles and responsibilities in a variety of ways, such as: <ul style="list-style-type: none"> – Attend national meetings; – Participate in or chair a DD Council sub-committee; – Attend a community meeting on behalf of the DD Council; and – Participate in or observe Council activities. ▪ DD Council members are able to communicate about the Council mission and some of the goals and objectives in the current State Plan.
6.1.3 DD Council members consistently attend DD Council meetings.	The DD Council has a written policy on attendance that requires attendance at a minimum number of DD Council meetings.

Indicators	Examples of Performance Standards
<p>6.1.4 DD Council staff provides members with support so they can consistently and meaningfully participate in meetings and fulfill their responsibilities.</p>	<ul style="list-style-type: none"> ▪ DD Council members receive supports from DD Council staff, such as: <ul style="list-style-type: none"> - Reimbursement for Council-related travel and expenses; - Provision of a stipend; - Receipt of accessible materials in advance of all meetings; - Provision of a personal assistant or other supports to help with preparation and understanding before and during meetings for those who may require it; and/or - Other accommodations, if required. ▪ DD Council members are satisfied or highly satisfied (i.e., report 4 or 5 on a scale of 1 – 5) with the support they receive in order to meaningfully participate in meetings and fulfill their responsibilities.
<p>6.1.5 DD Councils periodically conduct self-evaluations.</p>	<p>In the past 5 years, the DD Council:</p> <ul style="list-style-type: none"> ▪ Evaluated itself; ▪ Evaluated the Designated State Agency; ▪ Evaluated the Executive Director.
<p>DD Councils assess their own efficiency and effectiveness in meeting their goals and objectives.</p>	<p>In the past year, the DD Council:</p> <ul style="list-style-type: none"> ▪ Reviewed the performance of all DD Council permanent staff; ▪ Provided an orientation to newly-hired DD Council staff; ▪ Provided technical assistance to grantees on the principles and goals in the DD Act; and/or ▪ Other

6.2 DD Councils use a fair and transparent process to select competent and experienced grantees to implement goals and objectives in the State Plan and amendments.

Indicators	Examples of Performance Standards*
6.2.1 DD Councils have a written policy or procedures for selecting competent and experienced grantees.	<p>The DD Council policy or procedures for selecting competent and experienced grantees includes:</p> <ul style="list-style-type: none"> ▪ A requirement for a review committee; and ▪ Stated review criteria.
6.2.2 DD Councils utilize review committees composed of people who have an understanding of issues concerning people with developmental disabilities and family members and have experience in selecting and monitoring grantees.	<p>The DD Council committee that reviews proposals and makes recommendations to the Council on grantees to select consists of people:</p> <ul style="list-style-type: none"> ▪ With a developmental disability and/or who are family members; ▪ With an understanding of project management; ▪ Who have evaluation/research expertise; ▪ Understand the subject matter being discussed; and ▪ Other.
6.2.3 DD Councils have a policy or procedures for handling unsolicited proposals.	If the DD Council accepts unsolicited proposals, it uses the same criteria for making decisions on funding unsolicited proposals as it uses for solicited proposals.

6.3 DD Councils administer the work of grantees in a professional manner.

Indicators	Examples of Performance Standards
6.3.1 DD Councils issue contracts to grantees.	<p>DD Council contracts issued to grantees within the past year contained the following:</p> <ul style="list-style-type: none"> ▪ A description of the scope of work; ▪ A description of the methodology or process; ▪ Expected outcomes; ▪ Deliverables and deliverable dates; ▪ Reporting requirements; ▪ A budget; ▪ Start and end dates; and ▪ Other state requirements.
6.3.2 DD Council-supported grantees meet the requirements of their contracts.	<p>DD Council-supported grantees funded in the past year:</p> <ul style="list-style-type: none"> ▪ Met deadlines; and ▪ Submitted all deliverables listed in the contract.

Appendix B2. Protection and Advocacy Systems

- B2-1. Planning and Priority Setting**
- B2-2. Intake and Assistance**
- B2-3. Individual Advocacy**
- B2-4. Systemic Advocacy**
- B2-5. Community Outreach and Education**
- B2-6. Governance and Management**

B2-1. Planning and Priority Setting

All state Protection and Advocacy (P&A) systems carry out a planning and priority setting function. With the help of well-informed individuals (e.g., people with developmental disabilities, family members, service providers, advocacy organizations) and reliably collected, timely, and valid data, P&As identify barriers in supports and services for people with developmental disabilities and their families and infringements of basic human and legal rights.

The planning and priority setting function should result in a number of different products, including the Statement of Goals and Priorities (SGP) required by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). Other products may include plans with goals, measurable objectives, and budgets. The planning process ultimately results in a widespread understanding of the important needs of people with developmental disabilities and their families and the strategies the P&As will use to address those needs.

The primary target audience of planning and priority setting is the P&A itself, which uses the planning and priority setting process and its results to guide its activities. Except for emerging issues and emergency issues that arise suddenly, all other P&A activities flow from the goals, priorities, and targets identified in the SGP and other policy documents. Moreover, part of the planning and priority setting process requires feedback on the current year's activities and an understanding of progress in achieving P&A goals.

Benchmarks and Indicators

1.1 P&A Statements of Goals and Priorities (SGPs) represent key issues, priorities, and needs of people with developmental disabilities and their families.

1.1.1 The P&A process for planning and priority setting:

- Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families;
- Enables those in both urban and rural communities to participate;
- Provides opportunities for those who have never participated before to participate;
- Enables people with developmental disabilities to participate.

- Includes the use of feedback from current programs and activities (e.g., intake information, caseload statistics, staff feedback);
 - Includes the use of reliably collected, timely, and valid data; and
- 1.1.2 SGPs reflect the stakeholder¹¹ input and data obtained on the needs, priorities, and interests of people with developmental disabilities and their families.
- 1.2 P&A planning drives P&A activities.
- 1.2.1 P&A priorities are integrated into the full range of materials provided to internal staff, Board of Directors/Commission, and the public.
- 1.2.2 P&A individual advocacy¹² caseloads are determined by the priorities in the SGP [see indicator 3.1.1].
- 1.2.3 Systemic advocacy¹³ activities reflect the goals and priorities in the SGP.
- 1.2.4 Community outreach¹⁴ activities reflect the goals and priorities in the SGP.
- 1.2.5 Community education¹⁵ activities reflect the goals and priorities in the SGP.
- 1.2.6 P&As prepare for and respond to emerging and emergency issues not covered in the SGP that have an impact on people with developmental disabilities and their families.

¹¹ An individual or group that has an interest in a particular decision. For instance, in the case of the development of a 5-Year State Plan, stakeholders include, but are not limited to, people with developmental disabilities, their family members, Council members and staff, the P&A, UCEDDs, advocacy organizations, and service providers.

¹² Individual advocacy: Intervention strategies used in serving individuals (e.g., negotiation, mediation/alternative dispute resolution, administrative hearings, litigation).

¹³ Systemic advocacy: Systems change efforts that include activities on behalf of groups (e.g., group advocacy, investigations, monitoring, court-ordered monitoring, systemic or class action litigation) and result in changes to infrastructure, legislation, or policy.

¹⁴Community outreach: Efforts made to connect or bring awareness of the P&A and P&A services to organizations, groups, or the general public. One goal of outreach is to identify typically unserved and underserved populations who might benefit from P&A services and programs.

¹⁵Community education consists of informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.

Indicators and Performance Standards

1.1 P&A Statements of Goals and Priorities (SGPs) represent key issues, priorities, and needs of people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
<p>1.1.1 The P&A process for planning and priority setting:</p> <ul style="list-style-type: none"> ▪ Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families; ▪ Enables those in both urban and rural communities to participate; ▪ Provides opportunities for those who have never participated before to participate; ▪ Enables people with developmental disabilities to participate. ▪ Includes the use of feedback about current programs and activities (e.g., intake information, caseload statistics, staff and contractor feedback); ▪ Includes the use of reliably collected, timely, and valid data; and 	<p>The P&A can give examples from the last planning cycle in which it:</p> <ul style="list-style-type: none"> ▪ Sought input on the needs of people with developmental disabilities and their families from a variety of stakeholders [e.g., people with developmental disabilities, family members, advocates for people with developmental disabilities and family members, service providers, DD Councils, UCEDD(s)]; ▪ Sought input from both urban and rural communities in the state; ▪ Sought input from those not typically heard from (e.g., individuals from ethnic/minority groups, those with difficulty understanding English). ▪ Provided accommodation to those who needed it in order to participate; ▪ Made requests for input in ways that were meaningful to people with developmental disabilities; ▪ Examined feedback about program activities (e.g., information on recipients' satisfaction with P&A-supported programs; staff and contractor feedback); ▪ Used reliably collected, timely, and valid data and reports to identify the needs of people with developmental disabilities and their families; and
<p>1.1.2 SGPs reflect the stakeholder input and data obtained on the needs, priorities, and interests of the developmental disabilities community.</p>	<ul style="list-style-type: none"> ▪ In the last planning cycle, the P&A analyzed and synthesized reliable and valid data (e.g., input from stakeholders, reliable, valid, and representative survey data; state statistics; reports from the UCEDD and other sources; state agency reports). ▪ The goals and priorities in the SGP reflect the findings from the planning process.

1.2 P&A planning drives P&A activities.

Indicators	Examples of Performance Standards
<p>1.2.1 P&A priorities are integrated into the full range of materials provided to internal staff, members of the Board of Directors/Commission, and the public.</p>	<p>The P&A can provide examples in which forms and materials reflect the goals and priorities in the SGP (e.g., the intake form, intake training materials, Board of Directors/Commission orientation materials, outreach materials made publicly available).</p>
<p>1.2.2 P&A individual advocacy caseloads are determined by the priorities in the SGP [see indicator 3.1.1].</p>	<p>Cases of P&A advocates begun in the past year were consistent with the priorities in the SGP.</p>
<p>1.2.3 Systemic advocacy activities reflect the goals and priorities in the SGP.</p>	<ul style="list-style-type: none"> ▪ The P&A addressed the systemic advocacy priorities contained in the SGP in the past year. ▪ Systemic advocacy issues addressed by the P&A in the past year were contained in the SGP.
<p>1.2.4 Community outreach activities reflect the goals and priorities in the SGP.</p>	<p>The P&A focused community outreach activities in the past year on the populations and communities identified in the SGP.</p>
<p>1.2.5 Community education activities reflect the goals and priorities in the SGP.</p>	<p>The P&A focused community education activities in the past year on those issues, populations and communities identified in the SGP.</p>
<p>1.2.6 P&As prepare for and respond to emerging and emergency issues not covered in the SGP that have immediate impact on people with developmental disabilities.</p>	<ul style="list-style-type: none"> ▪ The P&A is able to provide examples of the ways in which they responded to emerging and/or emergency issues that arose in the past year. ▪ The P&A is able to provide a rationale for taking on an emerging or emergency issue not covered in the SGP.

B2-2. Intake and Assistance

P&A intake staff is generally the first point of contact for people seeking assistance from the P&A program. Under the DD Act, P&A programs have the authority to set up a system that includes the provision of “information on and referral to programs and services addressing the needs of individuals with developmental disabilities.” In its simplest form, assistance can consist of providing a name or a contact number for additional information or mailing information to an inquirer. Intake can also be the portal through which people with developmental disabilities and their families gain access to the full range of services P&As offer.

Through the intake process, P&A intake staff collects information from people who telephone, email, or visit the P&A in person and then routes a particular question or issue to the appropriate destination. Intake questions or issues can become the subject of individual advocacy or a systemic advocacy issue. More likely, in terms of numbers, P&A intake staff resolves the question or issue quickly by providing information, educational materials, or referral to another agency that can more appropriately provide information or services to the caller. This creates opportunities for people with developmental disabilities and their families to self-advocate for their own needs. Having well-trained and knowledgeable staff to determine the destination of a caller's inquiry is critical to having an effective intake process. To the extent that intake staff is able to communicate with people from diverse populations and communities in a culturally competent¹⁶ manner, access to the P&A is enhanced.

The primary target audiences of the intake process are people or groups who contact the P&A for information and assistance. A secondary audience is the P&A itself, which uses the information gleaned from intake interactions to identify trends among issues important to people with developmental disabilities and their families and inform P&A planning and priority setting activities.

The expected outcome of intake and assistance is that P&A intake processes meet the needs of P&A clients or constituents as P&As respond both appropriately and promptly to requests for information, resources, and assistance related to issues affecting people with developmental disabilities and their families.

Benchmarks and Indicators

- 2.1 P&As respond efficiently to requests for information, resources, and assistance related to issues affecting people with developmental disabilities and their families.
 - 2.1.1 P&As have written intake procedures that meet the needs of people with developmental disabilities and family members.
 - 2.1.2 P&A intake staff receives training on intake procedures to better provide assistance to people with developmental disabilities and their families.

¹⁶ Culturally competent is defined in the DD Act as follows: The term “culturally competent,” used with respect to services, supports, or other assistance, means services, supports, or other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved [Sec. 102(7) of the DD Act].

- 2.1.3 P&A intake staff follows intake procedures.
- 2.2 P&As respond appropriately to requests for information, resources, and assistance related to issues affecting people with developmental disabilities and their families.
 - 2.2.1 P&As periodically assess satisfaction of clients with the assistance they receive.
 - 2.2.2 P&A clients are satisfied with the assistance they receive.
 - 2.2.3 P&As provide callers and clients with information about the grievance procedure.

Indicators and Performance Standards

- 2.1 P&As respond efficiently to requests for information, resources, and assistance related to issues affecting people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
2.1.1 P&As have written intake procedures that meet the needs of people with disabilities and family members.	<ul style="list-style-type: none"> ▪ People with developmental disabilities and family members provide input to the P&A on intake procedures. ▪ P&A written intake procedures consist of: <ul style="list-style-type: none"> - Requirements for the collection of basic intake information; - Criteria for determining the amount of information to collect on each type of caller (e.g., those for whom a file is opened; those who require information and/or referral only); - Maximum response times; and - Other
2.1.2 P&A intake staff receives training on intake procedures to better provide assistance to people with developmental disabilities and their families.	<p>In the past 2 years, the P&A:</p> <ul style="list-style-type: none"> ▪ Arranged training on the intake procedures for all new intake staff; ▪ Included people with developmental disabilities in training; ▪ Arranged for existing intake staff to receive review training periodically; and ▪ Included training on cultural competency.

Indicators	Examples of Performance Standards
2.1.3 P&A intake staff follows intake procedures.	<p>In the past year, P&A senior staff:</p> <ul style="list-style-type: none"> ▪ Reviewed intake data; ▪ Reviewed intake staff performance on the extent to which they comply with intake procedures.

2.2 P&As respond appropriately to requests for information, resources, and assistance related to issues affecting people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
2.2.1 P&As periodically assess satisfaction of clients with the assistance they receive.	<ul style="list-style-type: none"> ▪ In the past two years, the P&A assessed client satisfaction with the assistance they received. ▪ The method used by the P&A to measure satisfaction of clients has a response rate that indicates that the results are representative of most P&A clients. ▪ In the past year, the P&A used feedback from client satisfaction assessments to make improvements to programs and services.
2.2.2 P&A clients are satisfied with the assistance they receive.	<ul style="list-style-type: none"> ▪ The P&A uses more than one method to determine client satisfaction. ▪ At last assessment, P&A clients surveyed were satisfied or very satisfied with the assistance they received from the P&A (e.g., 4 or 5 on a scale of 1 – 5).
2.2.3 P&As provide callers and clients with information about the grievance procedure.	<ul style="list-style-type: none"> ▪ The P&A provides information on the grievance process to those who are denied P&A services beyond information and referral. ▪ The P&A provides information on the grievance process to those who are taken on as accepted as clients.

B2-3. Individual Advocacy

Individual advocacy includes intervention strategies used in serving individuals (e.g., negotiation, mediation/alternative dispute resolution, administrative hearings, litigation). Individual advocacy involves working with people with developmental disabilities and their families or guardians, in a culturally competent manner, to access needed legal remedies. Examples of the legal remedies under the umbrella of individual advocacy are technical assistance to help people with developmental disabilities and their families advocate for themselves, short-term assistance,

investigation/monitoring, negotiation, mediation/alternative dispute resolution, administrative hearings, and litigation. Using a client's preferred mode of communication and language the client understands. P&A staff support their clients' active participation in identifying the objectives of P&A individual advocacy efforts on their behalf. They help their clients understand the issues involved in their cases and work with them to identify goals and objectives. The resolution of clients' issues is contingent upon many variables. However, regardless of whether or not clients' objectives are fully met, P&As work vigorously and effectively to ensure that their clients are afforded equal protection under the law.

The target audience of individual advocacy is the P&A client – a person with developmental disabilities and, as appropriate, a family member. The expected outcome of individual advocacy is client-centered representation that meets the client's objectives.

Benchmarks and Indicators

- 3.1 P&A client caseloads reflect the priorities and needs of people with developmental disabilities and their families.
 - 3.1.1 P&As represent individual advocacy clients on issues that are consistent with the goals and priorities in the SGA [see indicator 1.2.2].
 - 3.1.2 P&As represent people from typically unserved or underserved populations or communities.¹⁷
- 3.2 P&As provide high quality, professional representation to individuals.
 - 3.2.1 P&As provide opportunities for individual advocacy staff to discuss cases in order to share ideas and learn from one another.
 - 3.2.2 Experienced P&A legal staff reviews case files of individual advocacy staff.
 - 3.2.3 P&As maintain confidentiality at all times.
- 3.3 P&A individual advocacy meets the client's identified objectives.
 - 3.3.1 P&As communicate with clients in their chosen mode of communication in language the client can understand.

¹⁷“The term ‘unserved and underserved’ includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life” (Section 102(32) of the DD Act).

3.3.2 P&A clients and their P&A representatives have a common understanding of the issues that need to be resolved on behalf of clients and the ways in which P&A representatives will try to resolve those issues.

3.3.3 P&As meet the documented objectives of clients.

3.3.4 P&A clients are provided with information to file a grievance.

Indicators and Performance Standards

3.1 P&A client caseloads reflect the priorities and needs of people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
3.1.1 P&As represent individual advocacy clients on issues that are consistent with the goals and priorities in the SGA.	Individual advocacy cases begun in the past year were consistent with the priorities in the SGP.
P&As represent people from typically unserved or underserved populations or communities.	<ul style="list-style-type: none"> ▪ In the past year, the P&A identified the unserved and underserved populations or communities in the state. ▪ In the past year, the P&A caseload was consistent with unserved or underserved populations or communities in the state.

3.2 P&As provide high quality, professional representation to individuals.

Indicators	Examples of Performance Standards
3.1.1 P&As provide opportunities for individual advocacy staff to discuss cases in order to share ideas and learn from one another.	In the past year, the P&A individual advocacy staff met periodically and consistently to share case experiences in order to share ideas and learn from one another.
3.2.2 Experienced P&A legal staff reviews case files of individual advocacy staff.	The P&A has a policy that requires experienced legal staff to review open case files of individual advocacy clients regularly and consistently.

Indicators	Examples of Performance Standards
<p>3.2.3 P&As maintain confidentiality at all times.</p>	<ul style="list-style-type: none"> ▪ The P&A uses a variety of means to protect confidentiality (e.g., private offices or rooms, password protection of electronic files, secure storage of files that contain personal/confidential information). ▪ P&A staff is trained on maintaining confidentiality. ▪ P&A staff is aware of the penalty for infringement of the policy on confidentiality. ▪ In the past year, there were no infringements of the confidentiality policy.

3.3 P&A individual advocacy meets the client’s identified objectives.

Indicators	Examples of Performance Standards
<p>3.3.1 P&As communicate with clients in their chosen mode of communication and in language the client can understand.</p>	<ul style="list-style-type: none"> ▪ The P&A has access to interpreter services (e.g., for the deaf, to translate different languages as needed, or to provide personal assistance for those with a cognitive disability). ▪ The P&A individual advocacy staff can demonstrate that it uses the client’s chosen mode of communication in language the client understands throughout the representation process (e.g., at in-person meetings, during telephone conversations, to translate letters and other documents).
<p>3.3.2 P&A clients and their P&A representatives have a common understanding of the issues that need to be resolved on behalf of clients and the ways in which P&A representatives will try to resolve those issues.</p>	<p>P&A individual advocacy case files contain a document (sometimes referred to as a representing agreement) that:</p> <ul style="list-style-type: none"> ▪ Lists the issues that the P&A will address for the client; ▪ Lists the client’s objectives; ▪ Describes the process by which the P&A will attempt to meet the client’s objectives; and ▪ Provides an estimated timeframe for the process.

Indicators	Examples of Performance Standards
<p>3.3.3 P&As meet the documented objectives of clients.</p>	<ul style="list-style-type: none"> ▪ The P&A sends each individual advocacy client a closing letter when the case is closed that contains information on: <ul style="list-style-type: none"> - What the documented objectives were; - What the P&A agreed to do; - What the P&A did; - What the estimated timeframe was; and - The results. ▪ P&A individual advocacy staff is able to articulate the objectives of each client with an open case, the steps expected to meet the objectives, and the status of each open case. ▪ In the past year the P&A met some/most/all of the documented objectives of clients.
<p>3.3.4 P&A clients are provided with information to file a grievance.</p>	<ul style="list-style-type: none"> ▪ The P&A checks with the client throughout the process to ensure the client understands the process. ▪ The P&A provides explanation of the grievance process when a case is closed.

B2-4. Systemic Advocacy

In addition to protecting the rights of individual P&A clients, P&As implement systemic advocacy activities that are intended to improve or maintain access to State systems and improve community practice.

To implement the systemic advocacy key function, P&As identify systemic advocacy issues important to people with developmental disabilities and their families and engage in collaboration with DD Councils, UCEDDs, and other organizations, agencies, individuals, coalitions and government agencies. They use group and individual litigation to meet systemic advocacy goals and objectives. P&A systemic advocacy activities include writing position papers, obtaining press coverage, informing policy makers, including people with developmental disabilities and their families, securing pro bono firms to assist, testifying before state legislatures and other bodies, drafting legislation, litigating, and other proactive work. While P&As work to address systemic advocacy issues identified in their SGPs, they also respond to emerging issues as they arise.

Primary target audiences of systemic advocacy include policy makers, legislators, the press, employers, schools, the medical community, service provider agencies, and other groups with power to influence positive change or, when necessary, prevent change on behalf of people with developmental disabilities and their families.

The expected outcomes of systemic advocacy are changes to or maintenance of legislation or statewide or local public policy or administrative, and/or organizational actions, policies, and practices that reflect the needs of people with developmental disabilities and their families.

Benchmarks and Indicators

- 4.1 P&As respond to systemic advocacy issues that meet the needs of the developmental disabilities community.
 - 4.1.1 P&As use a variety of strategies to meet systemic advocacy goals and objectives.
 - 4.1.2 P&As collaborate with Federal, State, and local agencies, organizations, individuals, networks, coalitions and other DD Network programs to implement systemic advocacy activities.
- 4.2 P&A systemic advocacy efforts help to change or maintain legislative, administrative, and/or organizational actions, policies, and practices that reflect the needs of people with developmental disabilities and their families.
 - 4.2.1 P&A systemic advocacy efforts support or enhance changes to or maintenance of legislation or statewide or local public policy.
 - 4.2.2 P&A systemic advocacy efforts support or enhance changes to or maintenance of statewide or local community practice or services.

Indicators and Performance Standards

4.1 P&As respond to systemic advocacy issues that meet the needs of the developmental disabilities community.

Indicators	Examples of Performance Standards
<p>4.1.1 P&As use a variety of strategies to meet systemic advocacy goals and objectives.</p>	<ul style="list-style-type: none"> ▪ The P&A can provide examples in which it used group or individual litigation to meet systemic advocacy goals and objectives in the past 5 years. ▪ The P&A can provide examples in which it used each of the following strategies in the past 5 years to meet systemic advocacy goals and objectives: <ul style="list-style-type: none"> - Writing position papers; - Obtaining press coverage; - Informing policy makers; - Including people with developmental disabilities and/or family members; - Providing testimony; - Securing pro bono law firms to assist; - Drafting legislation; and - Other.
<p>4.1.2 P&As collaborate with Federal, State, and local agencies, organizations, individuals, networks, coalitions, and other DD Network programs to implement systemic advocacy activities.</p>	<ul style="list-style-type: none"> ▪ The P&A leads or coordinates systemic advocacy efforts with partners and collaborators. ▪ The P&A plays a supportive role in meeting systemic advocacy goals and objectives. ▪ P&A collaborators can describe the roles they played on systemic advocacy efforts led or coordinated by the P&A in the past 5 years.
<p>4.1.3 P&A systemic advocacy efforts support or enhance changes to or maintenance of legislation or statewide or local public policy.</p>	<p>The P&A can provide examples in which P&A systemic advocacy efforts supported, enhanced, or prevented changes to legislation or statewide or local public policy in the past 5 years.</p>
<p>4.1.4 P&A systemic advocacy efforts support or enhance changes to or maintenance of statewide or local community practice or services.</p>	<p>The P&A can provide examples in which P&A systemic advocacy efforts supported, enhanced or maintained changes to statewide or local community practice or services in the past 5 years.</p>

B2-5. Community Outreach and Education

P&As use community outreach and education to reach individuals, groups, communities, and others who may benefit from the information and services P&As offer. Through outreach activities, P&As work to extend the reach of P&A services to people with developmental disabilities and their families who typically may not know about or do not seek services from the P&A. Through community education activities, P&As inform service providers, the public at large, and people with developmental disabilities and their families about the rights and value of people with developmental disabilities and specific services P&As offer.

Community outreach and education activities consist of making public presentations, interacting with the media, providing technical assistance, developing and distributing training and other informational materials, identifying targets to receive information, and engaging in other individual and group activities that deliver information in a culturally competent and understandable manner.

There are many target audiences of community outreach and education – people with developmental disabilities and their families who may be potential P&A clients, the general public, employers, service providers (e.g., direct care, health care providers, employees at residential facilities, personal assistants), and those not necessarily considered to be part of the developmental disabilities community (e.g., dentists, physicians, and teachers). Another target audience is the media, a primary vehicle for communicating the work of the P&As and keeping developmental disabilities issues in the forefront of the public consciousness.

The expected outcome of community outreach is increased numbers of people who know about the P&A and its programs, services, and expertise, especially among those populations and communities that are often unserved or underserved by the P&A. The expected outcomes of community education are increased information and improved skills for people with developmental disabilities and family members so they can advocate for themselves. In addition, recipients of P&A community education for service providers and others in the community at large are expected to use what they learn in their work and everyday lives.

Benchmarks and Indicators

- 5.1 P&As are a resource on developmental disability issues for the community.
 - 5.1.1 P&As engage in outreach activities, including outreach to those who are typically unserved or underserved.
 - 5.1.2 P&As provide or support training and education for people with developmental disabilities and family members to advocate for themselves.
 - 5.1.3 P&As provide or support information activities, training and technical assistance to the community at large to improve access, inclusion, and choice.
 - 5.1.4 P&A community outreach and education are culturally competent.
 - 5.1.5 P&A community outreach and education is understandable to people with developmental disabilities.
- 5.2 P&A outreach and community education are responsive to the requests and needs of people with developmental disabilities and their families.
 - 5.2.1 P&A outreach reaches all components of its constituency, including typically unserved or underserved populations or communities.
 - 5.2.2 Recipients of P&A community education are able to understand and use what they learned in their job or everyday life.

Indicators and Performance Standards

5.1 P&As are a resource on developmental disability issues for the community.

Indicators	Examples of Performance Standards
<p>5.1.1 P&As engage in outreach activities, including outreach to those who are typically unserved or underserved.</p>	<ul style="list-style-type: none"> ▪ The P&A implemented outreach activities within the past year. ▪ The P&A can provide examples in which it provided outreach to unserved or underserved populations or communities in the past year.

Indicators	Examples of Performance Standards
<p>5.1.2 P&As provide or support training and education for people with developmental disabilities and family members to advocate for themselves.</p>	<ul style="list-style-type: none"> ▪ The P&A can provide examples from the past year in which it provided or supported training and education for people with developmental disabilities and family members to advocate for themselves. ▪ The P&A can provide examples in which it referred people with developmental disabilities to local or state self-advocacy organizations. ▪ The P&A can provide examples in which it identified potential participants in training and education for people with developmental disabilities and family members to advocate for themselves (e.g., “Partners in Policymaking.”) ▪ P&A community education activities in the past year were accessible and understandable.
<p>5.1.3 P&As provide or support information activities, training and technical assistance to the community at large to improve access, inclusion, and choice.</p>	<p>The P&A can provide examples in which it provided or supported information activities, training or technical assistance to the community at large in the past year (e.g., presentations to employers on hiring people with developmental disabilities and reasonable accommodation; awareness training to service providers on client or patient rights; technical assistance to attorneys on disability-related legislation).</p>
<p>5.1.4 P&A community outreach and education are culturally competent.</p>	<p>The P&A can provide examples of culturally competent outreach and community education it provided or supported in the past year.</p>
<p>5.1.5 P&A community outreach and education is understandable to people with developmental disabilities.</p>	<p>People with developmental disabilities who received P&A community outreach and education information reported that they were able to understand the information provided by the P&A.</p>

5.2 P&A outreach and community education are responsive to the requests and needs of people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
<p>5.2.1 P&A outreach reaches all components of its constituency, including typically unserved or underserved populations or communities.</p>	<p>Since the previous year, the P&A increased or maintained the number of people it serves from groups or individuals:</p> <ul style="list-style-type: none"> ▪ With racial or ethnic minority backgrounds; ▪ With limited ability to understand English; and ▪ Who would fall within the definition of typically unserved or underserved populations or communities.

Indicators	Examples of Performance Standards
<p>5.2.2 Recipients of P&A community education are able to understand and use what they learned in their job or everyday life.</p>	<ul style="list-style-type: none"> ▪ People with developmental disabilities or family members who received P&A community education in the past year can provide examples in which they were able to advocate for themselves and/or others. ▪ Recipients of P&A community education in the past 5 years can provide examples in which they: <ul style="list-style-type: none"> - Improved the quality of their interactions with people with developmental disabilities and their families (e.g., classroom instruction and policies, accessibility of their workplace; accessibility of community events); - Changed policies; and - Increased the number of people with developmental disabilities they served or hired.

B2-6. Governance and Management

P&A governance and management provide an umbrella under which P&As carry out their work. In addition to providing quality assurance that their infrastructures, processes, and outputs are adequate for achieving expected outcomes, P&A governance and management systems ensure that the organizational cultures of P&As are consistent with the principles and purposes of the DD Act to preserve, enhance, and promote the human and legal rights of individuals with developmental disabilities, and support their inclusion in society.

To carry out their governance and management responsibilities, P&As maintain staffs and contractual personnel, as necessary, who are well-trained and qualified to deliver P&A services accurately, consistently, and in a culturally competent manner. In addition, P&As maintain information systems, advisory and management structures, physical work space, and the necessary communication technology to interact effectively with a broad range of stakeholders and agencies, associations, and others with whom the P&As interact to address their annual goals and priorities.

The direct target audience of governance and management is the funding agency (ADD) that requires effective, consistent, and efficient service delivery. P&As themselves benefit from the quality assurance data that informs ongoing P&A activities, operations, and planning. Effective and

efficient governance and management also enhance the agility with which P&As respond to emerging issues and emergency issues that arise suddenly. The indirect and, ultimately, the primary beneficiaries of effective governance and management are people with developmental disabilities and their families who profit from access to prompt and efficient P&A services and vigorous and effective representation.

The expected outcome of governance and management is that P&As adhere to the principles and goals of the DD Act and maintain an infrastructure that enables them to conduct all key functions efficiently and effectively.

Benchmarks and Indicators

- 6.1 P&As maintain an infrastructure that enables them to conduct all key functions efficiently and effectively.
 - 6.1.1 P&A Boards or Commissions collectively have the areas of expertise required to meet their responsibilities (e.g., legal and business expertise, understanding of the needs of rights and needs of people with developmental disabilities, advocacy).
 - 6.1.2 P&As hire and maintain qualified staff to effectively provide services, including services to typically unserved or underserved populations and communities.
 - 6.1.3 P&As are responsive to emerging issues and emergency issues that arise suddenly.
 - 6.1.4 P&As maintain sound fiscal management to support the infrastructure.
- 6.2 P&A governance adheres to the principles and goals of the DD Act.
 - 6.2.1 P&A Boards of Directors or Commissions are familiar with the mission and goals of the DD Act and the goals of the P&As.
 - 6.2.2 P&A Boards of Directors or Commissions receive support from P&As so members can meaningfully participate in meetings and fulfill their responsibilities.
 - 6.2.3 P&As operate independently from the Governor, other state agencies, and the developmental disabilities services system of their state.
 - 6.2.4 P&A programs are physically and programmatically accessible.

Indicators and Performance Standards

6.1 P&As maintain an infrastructure that enables them to conduct all key functions efficiently and effectively.

Indicators	Examples of Performance Standards
<p>6.1.1 P&A Boards or Commissions collectively have an understanding of people with developmental disabilities and areas of expertise required to meet their responsibilities.</p>	<ul style="list-style-type: none"> ▪ The P&A Board of Directors or Commission is comprised collectively of people with an understanding of and expertise on: <ul style="list-style-type: none"> - Policy and laws related to people with disabilities; - Business; - Having a developmental disability (including a cognitive disability); - Advocacy; and - State systems.
<p>6.1.2 P&As hire and maintain qualified staff to effectively provide services, including services to typically unserved and underserved populations and communities.</p>	<ul style="list-style-type: none"> ▪ The P&A conducts a staff performance review each year. ▪ The P&A uses experienced staff to assist or mentor less experienced staff. ▪ P&A staff in direct contact with people with developmental disabilities has work or personal experience with people or communities that are typically unserved or underserved (e.g., racial and ethnic minorities; people whose first language is not English). ▪ The P&A has staff members with a developmental disability, including a cognitive disability.
<p>6.1.3 P&As are responsive to emerging issues and emergency issues that arise suddenly.</p>	<ul style="list-style-type: none"> ▪ The P&A can describe the structures and processes that enable it to respond quickly to urgent issues that suddenly arise. ▪ The P&A can provide examples in which it implemented procedures that facilitated response to an emerging or emergency issue that arose suddenly within the past year.
<p>6.1.4 P&As maintain sound fiscal management to support the infrastructure.</p>	<ul style="list-style-type: none"> ▪ The P&A obtained an audit from a reputable accounting firm in the past year. ▪ The P&A's yearly audit report indicates that the P&A is financially sound.

6.2

P&A governance adheres to the principles and goals of the DD Act.

Indicators	Examples of Performance Standards
<p>6.2.1 P&A Boards of Directors or Commissions are familiar with the mission and goals of the DD Act and the goals of the P&As.</p>	<ul style="list-style-type: none"> ▪ In the past year, the Executive Director regularly reported to the Board of Directors or Commission. ▪ Board or Commission members can describe the mission and goals of the DD Act and the annual goals of the P&A. ▪ New Board or Commission members receive an orientation that covers the mission and goals of the DD Act and the goals of the P&A.
<p>6.2.2 P&A Boards of Directors or Commissions receive support from P&As so members can meaningfully participate in meetings and fulfill their responsibilities.</p>	<p>In the past year the P&A:</p> <ul style="list-style-type: none"> ▪ Reimbursed P&A Board or Commission members for all P&A-related travel when requested; ▪ Sent materials out in advance of meetings to Board or Commission members; ▪ Provided a support person to help with preparation and understanding before and during meetings for those who required it ▪ Provided other accommodations as required; and ▪ Provided an orientation to new Board or Commission members on their responsibilities, the Developmental Disabilities Act, and other governing Federal requirements.
<p>6.2.3 P&As operate independently from the Governor and the developmental disabilities service system of their state.</p>	<p>The P&A can provide examples from the past 2 years that demonstrate that:</p> <ul style="list-style-type: none"> ▪ There are no restrictions on the P&A's ability or authority to litigate; and ▪ The P&A is not financially encumbered by the office of the Governor of the state or the state developmental disabilities service system.
<p>6.2.4 P&A programs are physically and programmatically accessible.</p>	<ul style="list-style-type: none"> ▪ The P&A implemented its programs and services in accessible facilities. ▪ The P&A can provide examples in which P&A programs are programmatically accessible [e.g., staff uses technology, translators, and alternate forms of materials (e.g., Braille, large print) as needed to interact with people who receive services]. ▪ People with developmental disabilities are involved in the P&A's community outreach and education activities.

Appendix B3. UCEDDs

- B3-1. 5-Year Planning**
- B3-2. Interdisciplinary Pre-service Teaching and Continuing Education**
- B3-3. Basic and/or Applied Research**
- B3-4. Community Services**
- B3-5. Dissemination**
- B3-6. Governance and Management**

B3-1. 5-Year Planning

Under Section 154 of the Developmental Disabilities Act (DD Act), those applying for or renewing a core center grant must provide a 5-year plan to the Administration on Developmental Disabilities (ADD). Once the grant is awarded, this 5-year plan becomes the template for University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs) activity over the next 5 years. Plans can be modified, if necessary, in annual reports submitted to ADD.

The 5-year plan must include a projected goal related to one or more areas of emphasis for each of the core functions required by UCEDDs (provision of interdisciplinary pre-service preparation and continuing education of students and fellows; provision of community services; conduct of research; and dissemination of information). Section 154 of the DD Act also requires data driven strategic planning, the establishment of a consumer advisory committee (CAC),¹⁸ the development of goals in collaboration with the CAC, and use of UCEDD grant funds to obtain additional public and private funds to successfully achieve the projected goals developed in the 5-year plan.

Benchmarks and Indicators

1.1 UCEDD 5-year plans represent key issues, priorities, and needs of people with developmental disabilities and their families.

1.1.1 The UCEDD process for developing the 5-year plan:

- Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families;
- Enables those in both urban and rural communities to participate;
- Provides opportunities for those who have never participated before to participate, including those who are typically unserved or underserved;¹⁹
- Enables people with developmental disabilities to participate;

¹⁸ According to the DD Act, the majority of CAC members must be people with developmental disabilities and family members. The CAC is also composed of a representative of the Protection and Advocacy (P&A) System, the State Council on Developmental Disabilities, and a self-advocacy organization.

¹⁹“The term ‘unserved and underserved’ includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life” [Section 102(32) of the DD Act].

- Includes the use of feedback from current programs and activities (e.g., intake information, caseload statistics, staff feedback);
 - Includes the use of reliably collected, timely, and valid data; and
 - Includes an assessment of the achievement of long-term state outcomes.
- 1.1.2 UCEDD 5-year plans reflect the stakeholder input and data provided on the needs, priorities, and interests of people with developmental disabilities and their families.
- 1.2 UCEDD planning drives UCEDD activities.
- 1.2.1 UCEDD interdisciplinary pre-service preparation and continuing education activities are consistent with the goals and priorities in the 5-year plan or adjustments to the plan.
- 1.2.2 UCEDD basic and/or applied research activities (including policy analysis and program evaluation) are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.
- 1.2.3 UCEDD community services (including direct services, technical assistance, and training) are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.
- 1.2.4 UCEDD dissemination activities are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.
- 1.2.5 UCEDDs address new and emerging issues not covered in the 5-year plan or adjustments to the plan or drop obsolete topics.

Indicators and Performance Standards

1.1 UCEDD 5-year plans represent key issues, priorities, and needs of people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
<p>1.1.1 The UCEDD process for developing the 5-year plan:</p> <ul style="list-style-type: none"> ▪ Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families; ▪ Enables those in both urban and rural communities and communities across the state to participate; ▪ Provides opportunities for those who have never participated before to participate, including those who are typically unserved or underserved; ▪ Enables people with developmental disabilities to participate. ▪ Includes the use of feedback from current programs and activities (e.g., intake information of direct services programs, staff feedback); and ▪ Includes the use of reliably collected, timely, and valid data; 	<p>The UCEDD can give examples from the last planning cycle in which it:</p> <ul style="list-style-type: none"> ▪ Sought input on the needs of people with developmental disabilities and their families from a variety of stakeholders (e.g., people with developmental disabilities, family members, self-advocacy groups, advocates for people with developmental disabilities and family members, professionals, service providers, DD Councils, P&As); ▪ Sought input from both urban and rural communities in the state; ▪ Sought input from communities across the state; ▪ Sought input from individuals and groups from unserved or underserved populations or communities, such as people: <ul style="list-style-type: none"> - From racial/ethnic minorities; - With limited ability to understand English; and - Others who would fall within the definition of typically unserved or underserved populations or communities. ▪ Provided accommodation to those who needed it in order to participate; ▪ Made requests for input in ways that were meaningful to people with developmental disabilities; ▪ Examined feedback from program activities (e.g., information on recipients' satisfaction with UCEDD-supported programs; staff feedback; and ▪ Used reliably collected, timely, and valid data and reports to identify the needs of people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
1.1.2 UCEDD 5-year plans reflect the stakeholder input and data provided on the needs, priorities, and interests of people with developmental disabilities and their families.	<ul style="list-style-type: none"> ▪ In the last planning cycle, the UCEDD analyzed and synthesized reliable and valid data (e.g., input from stakeholders, reliably collected data from surveys; state statistics; reports from the P&A and other sources; state agency reports). ▪ The goals and objectives in the 5-year plan reflect the findings from the planning process.

1.2 UCEDD planning drives UCEDD activities.

Indicators	Examples of Performance Standards
1.2.1 UCEDD interdisciplinary pre-service preparation and undergraduate teaching and continuing education activities are consistent with the goals and priorities in the 5-year plan or adjustments to the plan.	Undergraduate and graduate teaching and continuing education activities in the past year reflected the goals and objectives in the 5-year plan or adjustments made to the plan.
1.2.2 UCEDD basic and/or applied research activities (including policy analysis and program evaluation) are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.	Basic and/or applied research activities in the past year reflected the goals and objectives in the 5-year plan or adjustments made to the plan.
1.2.3 UCEDD community services (including direct services, technical assistance, and training) are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.	Community services (including direct services, technical assistance, and training) activities in the past year reflected the goals and objectives in the 5-year plan or adjustments made to the plan.
UCEDD dissemination activities are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.	Dissemination activities in the past year reflected the goals and objectives in the 5-year plan or adjustments made to the plan.
1.2.5 UCEDDs address new and emerging issues not covered in the 5-year plan or adjustments to the plan.	The UCEDD is able to provide a rationale for taking on new or emerging issues not covered in the 5-year plan or adjustments.

B3-2. Interdisciplinary Pre-Service Preparation and Continuing Education

Section 153(2)(A) of the DD Act authorizes the network of UCEDDs to engage in interdisciplinary pre-service preparation and continuing education of students and fellows. The goal of this key function is to develop a cadre of individuals with the necessary knowledge, skills, attitudes and

values to increase the capacity of States to provide and/or influence services and supports for people with developmental disabilities and their families.

UCEDDs teach or develop materials for four types of students: (1) Preservice interdisciplinary students – usually graduate students or students pursuing a professional degree – who already have shown an inclination toward participating in a disability-related field; (2) students from a variety of departments who participate in disability studies; (3) students throughout the university who may never have thought about disability as an interest or career but have been exposed to disability content in one of their classes or courses; and (4) continuing education students who may already be practicing in a disability-related field and take a UCEDD-sponsored course that allows them to upgrade their knowledge and skills.

UCEDDs develop and redesign (as needed) a core interdisciplinary curriculum for students who concentrate on disability as part of their studies; infuse disability-related material into curricula in university departments, including offering specialized disability-related courses to students in various university departments; and/or provide continuing education programs (some of which provide credit bearing continuing education units [CEUs]). Continuing education consists of courses, workshops, seminars, and other educational vehicles.

Interdisciplinary teaching involves interaction among multiple disciplines on a common problem. The interdisciplinary nature of UCEDD teaching is expected to provide students with a broad perspective on and an appreciation of a variety of disciplines and how different disciplines approach a common problem. It also is expected to prepare them for leadership and other types of roles on interdisciplinary teams. Interdisciplinary teaching also can include people with developmental disabilities and family members in the design of courses and curricula, as well as in contact with students.

The target audiences for graduate and undergraduate teaching and continuing education consist of undergraduate and graduate students, professionals, and the general public. Professionals may include direct healthcare providers such as physicians, dentists, nurses, social workers, and public health workers; administrators; and individuals who participate in continuing education programs to maintain their professional licenses, obtain state-of-the-art knowledge, remain up-to-date, or want to learn more about working with people with developmental disabilities.

The expected outcomes of this key function include informed, educated, and skilled graduates or people who complete UCEDD continuing education. Graduate students and students pursuing a

professional degree who are already committed to the field of disability are expected to work in positions that benefit the quality of life of people with developmental disabilities and to become leaders in their field. It is also anticipated that many of the students in disability studies programs will consider disability an important component of further education and/or their career. Professionals who took UCEDD-sponsored continuing education courses are expected to apply the knowledge and skills they obtained in their current or future positions.

Benchmarks and Indicators

- 2.1 UCEDD curricula, training materials, and teaching are interdisciplinary.²⁰
 - 2.1.1 UCEDD-developed curricula and syllabi incorporate the perspectives and interactions among a variety of disciplines.
 - 2.1.2 UCEDD teaching is inter-disciplinary.
 - 2.1.3 UCEDD faculty²¹ is comprised of a variety of disciplines.
 - 2.1.4 UCEDD-developed courses use instructors from a variety of disciplines.
 - 2.1.5 UCEDD faculty and staff train students from multiple disciplines.
 - 2.1.6 UCEDDs conduct continuing education programs for a variety of professionals.
 - 2.1.7 People with developmental disabilities and family members are an integral part of the interdisciplinary pre-service preparation and continuing education program.
- 2.2 UCEDD faculty and teaching staff are knowledgeable and up-to-date in their field, skilled in teaching, and student-focused.
 - 2.2.1 Courses taught or developed by UCEDD faculty and staff covers current practices and issues and contain up-to-date content.
 - 2.2.2 UCEDD faculty and teaching staff are considered to be effective teachers by their students and peers.
- 2.3 UCEDD faculty and staff have an influence throughout the university.

²⁰ Interdisciplinary means interaction among multiple disciplines on a common problem.

²¹ UCEDD faculty and teaching staff are individuals with a university or faculty appointment (tenure, non-tenure or adjunct) and who have a designated official role with the UCEDD (e.g., at least some proportion of their salary is funded under the UCEDD's budget or a UCEDD grant or contract; works for a university academic department and is released from some of their departmental academic responsibilities in order to work with the UCEDD; is funded by the university fully or partially to be a UCEDD faculty member; works for an academic department but does some work for the UCEDD in addition to their departmental academic responsibilities).

- 2.3.1 UCEDDs sponsor, co-sponsor, or participate in disability-related seminars, presentations, or other disability-related activities within the University.
- 2.3.2 UCEDDs assist in incorporating disability content into university courses and curricula.
- 2.3.3 UCEDD faculty and staff provide their disability-related expertise to the university.
- 2.4 Former students use what they learned from their experience with UCEDDs in their professional and daily lives.
 - 2.4.1 UCEDD-developed curricula, courses, and course content prepare students to work with and for typically unserved or underserved populations or communities.
 - 2.4.2 Interdisciplinary pre-service students who completed their course of study work to benefit and affect the quality of life of people with developmental disabilities.
 - 2.4.3 Among those students who participated in a disability studies program, disability is an important component of further education, career or their daily lives.
 - 2.4.4 Continuing education students apply what they learned in UCEDD continuing education courses to their work.

Indicators and Performance Standards

2.1 UCEDD curricula, training materials, and teaching are interdisciplinary.

Indicators	Examples of Performance Standards
2.1.1 UCEDD-developed curricula and syllabi incorporate the perspectives and interactions among a variety of disciplines.	The UCEDD can provide examples of curricula and syllabi in the past year that contain the perspectives and interactions among more than one discipline.
2.1.2 UCEDD teaching is inter-disciplinary.	The UCEDD can provide examples of inter-disciplinary teaching.
2.1.3 UCEDD faculty is comprised of a variety of disciplines.	UCEDD faculty represents more than one discipline.
2.1.4 UCEDD-developed courses use instructors from a variety of disciplines.	The UCEDD can provide examples of UCEDD-developed courses taught in the past 2 years that have instructors from more than one discipline (i.e., in one course).

Indicators	Examples of Performance Standards
<p>2.1.5 UCEDD faculty and staff train students from multiple disciplines.</p>	<p>In the last year the UCEDD trained interdisciplinary pre-service students from more than one discipline (e.g., medicine, occupational therapy, nutrition, epidemiology, or nursing).</p> <ul style="list-style-type: none"> ▪ Students in a disability studies program come from a variety of major fields from more than one department (e.g., law, education, physiotherapy). ▪ Students from departments throughout the university (e.g., mathematics, history, political science, journalism, English literature) take courses infused with disability content.
<p>2.1.5 UCEDDs conduct continuing education programs for a variety of professionals.</p>	<p>In the past year, the UCEDD provided continuing education to different types of professionals (e.g., teachers, occupational therapists, physiotherapists, audiologists, family physicians).</p>
<p>2.1.6 People with developmental disabilities and family members are an integral part of the interdisciplinary pre-service preparation and continuing education program.</p>	<p>In the past year, people with developmental disabilities and family members:</p> <ul style="list-style-type: none"> ▪ Contributed to the development of UCEDD curricula and syllabi; ▪ Contributed to classroom instruction; and ▪ Were actively recruited for positions in the UCEDD.

2.2 UCEDD faculty and teaching staff are knowledgeable and up-to-date in their field, skilled in teaching, and student-focused.

Indicators	Examples of Performance Standards
<p>2.2.1 Courses taught or developed by UCEDD faculty and staff cover current practices and issues and contain up-to-date content.</p>	<ul style="list-style-type: none"> ▪ UCEDD faculty and staff can provide examples of course syllabi to which they contributed that cover current practices and issues. ▪ UCEDD faculty and staff can provide examples of course syllabi to which they contributed that contain up-to-date content. ▪ Peers of UCEDD faculty and staff report that courses developed by UCEDD faculty and staff in the past 2 years cover current practices and issues and contain up-to-date content.
<p>2.2.2 UCEDD faculty and teaching staff are considered to be effective teachers by their students and peers.</p>	<ul style="list-style-type: none"> ▪ UCEDD faculty or staff rated by students for effective teaching were rated very good or excellent (i.e., 4 or 5 on a scale of 1 - 5). ▪ UCEDD faculty and staff are reported to be very good or excellent teachers by peers at the University.

2.3 UCEDD faculty and staff have an influence throughout the university.

Indicators	Examples of Performance Standards
<p>2.3.1 UCEDDs sponsor, co-sponsor, or participate in disability-related seminars, presentations, or other disability-related activities within the University.</p>	<p>The UCEDD sponsored, co-sponsored, or participated in disability-related seminar(s), presentation(s), or other activities (e.g., films, art shows) within the University in the past year.</p>
<p>2.3.2 UCEDDs assist in incorporating disability content into university courses and curricula.</p>	<p>The UCEDD can provide examples of courses taught in the past year in which UCEDD faculty assisted in incorporating disability content.</p>
<p>2.3.3 UCEDD faculty and staff provide their disability-related expertise to the university.</p>	<p>The UCEDD can provide examples from the past year in which:</p> <ul style="list-style-type: none"> ▪ UCEDD faculty and staff served on university committees and task forces; ▪ UCEDD faculty and staff were consulted for their expertise by university administrators or faculty and staff in departments throughout the university; ▪ UCEDD faculty chaired or was a member of a Ph.D. committee; or ▪ Other.

Indicators	Examples of Performance Standards
<p>2.4.2 Interdisciplinary pre-service students who completed their course of study work to benefit and affect the quality of life of people with developmental disabilities.</p>	<ul style="list-style-type: none"> ▪ The method the UCEDD uses to follow up former interdisciplinary pre-service students has a response rate of at least 80% at the end of the program and at least 60% 5 years after graduation. ▪ Interdisciplinary pre-service students who graduated in the past year obtained positions that benefit people with disabilities. ▪ Interdisciplinary pre-service students who graduated at least 5 years ago use the interdisciplinary and other skills they acquired from the UCEDD program. ▪ Interdisciplinary pre-service students who graduated at least 5 years ago are working in positions that benefit people with disabilities. ▪ Interdisciplinary pre-service students who graduated from the university at least 5 years ago can give examples of: <ul style="list-style-type: none"> - How they use an interdisciplinary perspective in their work; - How they provide family-centered supports and/or services (if relevant); and/or - How they use evidence-based approaches to care.
<p>2.4.3 Among those students who participated in a disability studies program, disability is an important component of further education, career or their daily lives.</p>	<ul style="list-style-type: none"> ▪ Students who participated in a disability studies program and graduated from the university in the past year were accepted into a disability-related graduate program or obtained a position that benefits people with disabilities. ▪ Students who participated in a disability studies program and graduated from the university in the past year can give examples of how the program was an important component of their daily lives.

Indicators	Examples of Performance Standards
<p>2.4.4 Continuing education students apply what they learned in UCEDD continuing education courses to their work and/or daily lives.</p>	<p>UCEDD continuing education students who took courses from the UCEDD or attended a UCEDD continuing education program in the past year can provide examples in which:</p> <ul style="list-style-type: none"> ▪ They transferred the knowledge and skills they obtained to their work ▪ They improved their effectiveness in providing services to people with developmental disabilities ▪ They improved the effectiveness of the community in including people with developmental disabilities in all aspects of life ▪ They provided accommodations for employees with developmental disabilities ▪ They made use of tax incentives for assistive technology for employees ▪ They made public buildings more accessible ▪ They provided family-centered supports and services; ▪ They used evidence-based approaches to care; and/or ▪ They applied what they learned to their work or personal lives in other ways.

B3-3. Basic and/or Applied Research

Section 153(2)(C) of the DD Act authorizes the network of UCEDDs to engage in four core functions, including the conduct of research. Research may include basic or applied research, evaluation, and the analysis of public policy.

We define research as a systematic investigation designed to contribute to generalizable knowledge. UCEDD research is expected to meet high professional standards, as evidenced by publication in peer-reviewed journals and other types of publications and recognition of UCEDD-affiliated researchers by the research community. In many cases, it is appropriate to involve people with developmental disabilities and family members in the conception, planning, implementation, revision, and outcomes of the research.

The target audience for basic and/or applied research includes policy makers (local, state, and national), state and local agencies, and researchers in universities and other research organizations in the United States and abroad. The conduct of UCEDD research is expected to advance general knowledge in the field of developmental disabilities, provide opportunities for junior faculty and students to develop their research capabilities, and can lead to the development and later formalization of evidence-based practices from demonstration programs and other research efforts. Research findings supported by evidence from UCEDD research can also result in changes to public policies and programs, such as enhancements to service delivery systems.

The translation of research findings into lay language is a critical factor in implementing evidence-based practices in the community and is covered under dissemination.

Benchmarks and Indicators

- 3.1 UCEDD research, evaluation, and/or public policy analysis are of high quality.
 - 3.1.1 UCEDD faculty and staff publish on their disability research.
 - 3.1.2 UCEDD faculty and staff are selected to make presentations on their disability-related research (including public policy analysis and evaluation) at conferences and meetings.
- 3.2 UCEDD faculty and staff are well-recognized in their field of disability research.
 - 3.2.1 UCEDD faculty and staff provide advice on disability related issues to local, state, federal, and international organizations.
 - 3.2.2 UCEDD faculty and staff review grants, manuscripts, books, articles, and other types of publications.
 - 3.2.3 Disability-related publications authored or co-authored by UCEDD faculty and staff are cited by other researchers.
- 3.3 UCEDD research, evaluation, and public policy analysis support action that has an impact on people with developmental disabilities and their families.
 - 3.3.1 Research, public policy analysis, and evaluation conducted by UCEDD faculty and staff support changes to legislation or public policy.
 - 3.3.2 Research, public policy analysis, and evaluation conducted by UCEDD faculty and staff support changes to services and practice provided by service providers and professionals in the community.
 - 3.3.3 People with developmental disabilities participate in UCEDD research.

Indicators and Performance Standards

3.1 UCEDD research, evaluation, and/or public policy analysis are of high quality.

Indicators	Examples of Performance Standards
3.1.1 UCEDD faculty and staff publish on their disability research.	<ul style="list-style-type: none"> ▪ UCEDD faculty or staff published disability-related articles (i.e., on topics that can be of benefit to people with disabilities and their families) in peer-reviewed journals in the past year. ▪ UCEDD faculty or staff authored or co-authored disability-related technical reports or articles (i.e., on topics that can be of benefit to people with disabilities and their families) in the past year. ▪ UCEDD faculty or staff published disability-related chapters and books (i.e., on topics that can be of benefit to people with disabilities and their families) in the past year.
3.1.3 UCEDD faculty and staff make presentations on their disability-related research (including public policy analysis and evaluation) at conferences and meetings.	UCEDD faculty or staff presented on their disability-related research (including public policy analysis and evaluation) at conferences or meetings held in the past year.

3.2 UCEDD faculty and staff are well-recognized in their field of disability research.

Indicators	Examples of Performance Standards
3.2.1 UCEDD faculty and staff provide advice on disability related issues to local, state, federal, and international organizations.	<p>In the past year:</p> <ul style="list-style-type: none"> ▪ UCEDD faculty or staff served on disability-related advisory groups, boards of directors, commissions, Governor’s Councils, legislative committees, school boards, or other groups to study or advise on disability-related issues; ▪ UCEDD faculty or staff gave public testimony, made presentations, or provided consultation to legislators and other public officials; and/or ▪ UCEDD faculty or staff participated in national or international task forces or other committees related to disability.
3.2.2 UCEDD faculty and staff review grants, manuscripts, books, articles, and other types of publications.	<ul style="list-style-type: none"> ▪ UCEDD faculty or staff reviewed articles for a peer review journal, books or book chapters, and other publications in the past year. ▪ UCEDD faculty or staff participated in a funding agency’s grant review committee within the past 5 years.

Indicators	Examples of Performance Standards
3.1.2 Disability-related publications authored or co-authored by UCEDD faculty and staff are cited by other researchers.	Peer-reviewed journal articles, books, and chapters in books published by UCEDD faculty or staff in the past 5 years achieved a minimum average citation ratio. ²²

3.3 UCEDD research, evaluation, and public policy analysis supports action that has an impact on people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
3.3.1 Research, public policy analysis, and evaluation conducted by UCEDD faculty and staff support changes to legislation or public policy.	The UCEDD can provide examples of changes made in the past 5 years to legislation or public policy that have implications for people with developmental disabilities supported by UCEDD research, public policy analysis, or evaluation.
3.3.2 Research, public policy analysis, and evaluation conducted by UCEDD faculty and staff support changes to services and practice provided by service providers and professionals in the community.	The UCEDD can provide examples of changes made in the past 5 years to community practice, or services supported by UCEDD research, public policy analysis, or program evaluations
3.3.3 People with developmental disabilities participate in UCEDD research.	<p>The UCEDD can provide examples from the past year in which people with developmental disabilities and/or family members:</p> <ul style="list-style-type: none"> ▪ Provided input into the identification of research issues; ▪ Participated in the design of data collection instruments; ▪ Helped to interpret findings from the perspective of people with developmental disabilities or family members; and/or ▪ Other.

B3-4. Community Services

Section 153(2)(B) of the DD Act authorizes UCEDDs to engage in the provision of community services. Community services consist of training or technical assistance for people with developmental disabilities, their families, professionals, paraprofessionals, policy makers, students, and other members of the community. UCEDDs also have the option of providing services, supports, and assistance through demonstration and model activities.

²² The citation ratio is one type of indicator that examines the importance of a research paper to the field. Typically, the citation ratio is calculated by subtracting self-citations.

Community services are expected to be performed in a culturally competent manner. Community services can be provided through seminars, forums, workshops, technical assistance, outreach, and public awareness programs. UCEDDS have the option of designing and managing model programs (e.g., diagnosis and followup; provision of daycare to children with developmental disabilities). Under the category of community services, UCEDDs also provide information and technical assistance to state governing bodies and national and international organizations and systems.

The target audience of this key function includes direct service workers, providers not necessarily considered to be part of the developmental disabilities community (e.g., employers, teachers, dentists, physicians, other health care practitioners), policy makers, and people with developmental disabilities and their families.

The expectation is that those receiving community services in the form of technical assistance or training will be able to transfer the knowledge and skills they obtained from the UCEDD to their work and will have more effective contact with people with developmental disabilities. Other outcomes might include people with developmental disabilities advocating for themselves or others and receiving the supports and services they require, and UCEDD model demonstration programs (if provided) serving as the basis for the design of other programs in the state and elsewhere.

Benchmarks and Indicators

- 4.1 UCEDD community services address the needs of people with developmental disabilities and family members.
 - 4.1.1 UCEDDs provide or support community services (i.e., training, technical assistance, and direct services/model programs) to people with developmental disabilities and their families, those who provide supports and services to people with developmental disabilities and their families, and those who potentially have an influence on the inclusion of people with developmental disabilities into the community.
 - 4.1.2 UCEDDs provide or support community services (i.e., training, technical assistance, and direct services/model programs) to typically unserved and underserved populations or communities, including those from racial, ethnic, or linguistic minorities.
 - 4.1.3 UCEDD community services are effective (i.e., met objectives), person-centered, and family-centered accessible, culturally competent.

- 4.2 UCEDD community services have a positive impact on people with developmental disabilities and their families, those who provide services and supports to people with developmental disabilities and their families, policy makers, and on the community at large.
- 4.2.1 UCEDD community services (training, technical assistance, and direct services/model programs, if offered) for people with developmental disabilities and their families strengthen their capacity to meet their self-identified goals.
- 4.2.2 Recipients of UCEDD supported community services (who provide supports and services to people with developmental disabilities and family members and other community professionals):
- Transfer the knowledge and skills they obtained to their work;
 - Have more contact with people with developmental disabilities; and
 - Have more effective (e.g., relevant, meaningful, accessible) contact with people with developmental disabilities.
- 4.2.3 Expert information provided by UCEDD faculty and staff to legislative and other decision making bodies results in:
- new or revised legislation or policy (or maintenance of legislation or policy);
 - changes in (or maintenance of) access to supports and services; and
 - changes in (or maintenance of) services and supports provided in the community.

Indicators and Performance Standards

4.1 UCEDD community services address the needs of people with developmental disabilities and family members, as indicated in the 5-year plan and amendments.

Indicators	Examples of Performance Standards
<p>4.1.1 UCEDDs provide or support community services (i.e., training, technical assistance, and direct services/model programs) to people with developmental disabilities and their families, those who provide supports and services to people with developmental disabilities and their families, and those who potentially have an influence on the inclusion of people with developmental disabilities into the community.</p>	<p>In the past year, the UCEDD provided or supported community services for:</p> <ul style="list-style-type: none"> ▪ People with developmental disabilities; ▪ Families of people with developmental disabilities; ▪ People who provide supports or services to people with developmental disabilities or their families; ▪ Those who potentially have an influence on the inclusion of people with developmental disabilities into the community (e.g., employers, teachers, dentists, physician specialists); ▪ Policy makers; and/or ▪ Others.
<p>4.1.2 UCEDDs provide or support community services (i.e., training, technical assistance, and direct services/model programs) to typically unserved and underserved populations or communities, including those from racial, ethnic, or linguistic minorities.</p>	<p>In the past year, the UCEDD reached out to typically unserved and underserved populations or communities, including people from:</p> <ul style="list-style-type: none"> ▪ Racial or ethnic minorities; ▪ Linguistic minorities; ▪ Both urban and rural areas of the state; ▪ Tribal communities; or ▪ Other populations or communities considered to be unserved or underserved in the state.

Indicators	Examples of Performance Standards
<p>4.1.3 UCEDD community services are effective (i.e., met objectives), person-centered, and family-centered accessible, culturally competent.</p>	<ul style="list-style-type: none"> ▪ In the past year, the UCEDD measured the effectiveness of UCEDD community services. ▪ In the past year, the UCEDD assessed community services recipients' perception of the services they received with regard to being accessible, culturally competent, person-centered, and/or family-centered. ▪ Recipients of community services provided or supported by the UCEDD in the past year reported community services to be: <ul style="list-style-type: none"> - Effective (met their objectives); - Person-centered; - Family-centered; - Culturally competent; and/or - Accessible. ▪ The UCEDD can provide examples in which community services provided or supported by the UCEDD in the past year were: <ul style="list-style-type: none"> - Effective (met their objectives); - Person-centered; - Family-centered; - Culturally competent; and/or - Accessible. ▪ Recipients of community services can provide examples in which community services they received were effective, person-centered, family centered, culturally competent and/or accessible.

4.2 UCEDD community services have a positive impact on people with developmental disabilities and their families, those who provide services and supports to people with developmental disabilities and their families, policy makers, and on the community at large.

Indicators	Examples of Performance Standards
<p>4.2.1 UCEDD community services (training, technical assistance, and direct services/model programs, if offered) for people with developmental disabilities and their families strengthen their capacity to meet their self-identified goals.</p>	<p>People with developmental disabilities and their families who received UCEDD community services in the past year are able to provide examples in which they:</p> <ul style="list-style-type: none"> ▪ Advocated for themselves; ▪ Advocated for others; ▪ Helped a peer or mentored another person with a disability; ▪ Became leaders in the community (e.g., became the chair or a member of the DDC or members or leader in other organizations that advocate on behalf of people with disabilities; became a member or leader in other community organizations; participated in DD Network or other advocacy efforts; used the knowledge and skills they obtained in their personal lives); and/or ▪ Other.
<p>4.2.2 Recipients of UCEDD supported community services (who provide supports and services to people with developmental disabilities and family members and other community professionals):</p> <ul style="list-style-type: none"> ▪ Transfer the knowledge and skills they obtained to their work; ▪ Have more contact with people with developmental disabilities; and ▪ Have more effective (e.g., relevant, meaningful, accessible) contact with people with developmental disabilities. 	<ul style="list-style-type: none"> ▪ Professionals and other service providers who received UCEDD community services in the past 2 years can provide examples of how they: <ul style="list-style-type: none"> - Transferred the knowledge and skills they obtained to their work; - Have more contact with people with developmental disabilities; and/or - Improved their effectiveness in providing services to people with developmental disabilities. ▪ The UCEDD can provide examples of evidence-based practices that were adopted in the community in the past 5 years as a result of UCEDD model programs, if provided.

Indicators	Examples of Performance Standards
<p>4.2.3 Expert information provided by UCEDD faculty and staff to legislative and other decision making bodies results in:</p> <ul style="list-style-type: none"> ▪ New or revised legislation or policy (or maintenance of legislation or policy); ▪ Changes in (or maintenance of) access to supports and services; and ▪ Changes in (or maintenance of) services and supports provided in the community. 	<p>As a result of expert information provided by UCEDD faculty and staff to legislative and other decision making bodies, the UCEDD can provide examples from the past year of:</p> <ul style="list-style-type: none"> ▪ New or revised legislation or policy (or maintenance of legislation or policy); ▪ Changes in (or maintenance of) access to supports and services; and/or ▪ Changes in (or maintenance of) services and supports provided in the community.

B3-5. Dissemination

Section 153(2)(D) of the DD Act authorizes the network of UCEDDs to engage in the core function of dissemination of information.

The goal of dissemination of information is to increase knowledge and awareness of developmental disabilities and issues surrounding developmental disabilities by educating and informing various target audiences. Dissemination of products may include information on developmental disabilities, research findings translated into terms suitable for a lay audience, information on services available to the developmental disabilities community, and education activities conducted by the UCEDDs. Products are tailored to a variety of target audiences and are (should be?) available in alternative, accessible formats and media using language that is culturally competent and appropriate to the target audience.

Target audiences include people with developmental disabilities (including cognitive disabilities) and their families, researchers, policy makers, professional and consumer groups, paraprofessionals, students, employers, other DD Network programs, and the general public.

The expected outcomes of this key function include increased awareness of people with developmental disabilities and issues surrounding people with developmental disabilities and their families and use of information contained in dissemination products by target audiences.

Benchmarks and Indicators

- 5.1 UCEDDs disseminate products that are accessible and appropriate to a variety of audiences.
 - 5.1.1 The network of UCEDDs uses a variety of dissemination strategies to inform target audiences (e.g., people with developmental disabilities, researchers, families, policy makers, professional and consumer groups, paraprofessionals, students, employers, other DD Network programs, and the general public) about developmental disabilities and issues affecting people with developmental disabilities and their families.
 - 5.1.2 UCEDD products are disseminated in accessible and understandable formats, using universal design principles.
- 5.2 Recipients of UCEDD products learn about and become aware of people with developmental disabilities and the issues surrounding people with developmental disabilities and their families.
 - 5.2.1 UCEDDs gauges target audience satisfaction with the products it disseminates.
 - 5.2.2 UCEDDs are responsive to the feedback they receive on UCEDD products that are disseminated.

Indicators and Performance Standards

5.1 UCEDDs disseminate products that are accessible and relevant to a variety of audiences.

Indicators	Examples of Performance Standards
<p>5.1.1 The network of UCEDDs uses a variety of dissemination strategies to inform target audiences (e.g., people with developmental disabilities, researchers, families, policy makers, professional and consumer groups, paraprofessionals, students, employers, other DD Network programs, and the general public) in the state, nationally, and internationally about developmental disabilities and issues affecting people with developmental disabilities and their families.</p>	<p>The UCEDD uses a variety of dissemination strategies to inform target audiences about developmental disabilities and issues affecting people with developmental disabilities and their families, such as:</p> <ul style="list-style-type: none"> ▪ mass media; ▪ public information forums; ▪ presentations to community groups; ▪ mailings; ▪ pamphlets, brochures and other materials distributed to social service agencies and made available to the general public and special interest groups; ▪ maintenance of a resource center; ▪ newsletters; ▪ research briefs; ▪ videos and films; ▪ websites; and/or ▪ other strategies.
<p>5.1.2 UCEDD products are disseminated in accessible and understandable formats, using universal design principles.</p>	<ul style="list-style-type: none"> ▪ The UCEDD can provide examples from the past year in which research findings or other technical types of information were translated into terms that could be understood by lay audiences. ▪ The UCEDD can provide examples in which it used accessible formats (e.g., large print, Braille, symbols, people first language, and other means that address universal design principles) in the past year. ▪ The UCEDD can provide examples from the past year in which people with developmental disabilities and other target audiences gave input on the extent to which UCEDD products were understandable and usable.

5.2 Recipients of UCEDD products learn about and become aware of people with developmental disabilities and the issues surrounding people with developmental disabilities and their families.

Indicators	Examples of Performance Standards
<p>5.2.1 UCEDDs gauge target audience satisfaction with the products it disseminates.</p>	<ul style="list-style-type: none"> ▪ The UCEDD can provide examples of how it assessed satisfaction with disseminated products in the past year. ▪ Among those assessed for satisfaction, a large proportion of people were satisfied or very satisfied with the UCEDD products they received (e.g., 4 or 5 on a scale of 1 – 5).
<p>5.2.2 UCEDDs are responsive to the feedback they receive on UCEDD products that are disseminated.</p>	<ul style="list-style-type: none"> ▪ The UCEDD can provide example(s) of UCEDD responsiveness to feedback on disseminated products.

B3-6. Governance and Management

The goals of governance and management are to ensure that the four functional areas for which the network of UCEDDs are responsible – interdisciplinary pre-service preparation and continuing education; basic and/or applied research; community services, and dissemination of information -- are carried out efficiently and effectively. To be effective, UCEDDs plan, organize, maintain and improve their programs, ensure that key organizations and individuals are appropriately involved in their activities (e.g., people with developmental disabilities and family members), foster and maintain ties within the university, and obtain additional funding.

The direct target audience of governance and management is the funding agency (ADD) whose role is to administer efficient and effective programs that have an impact on people with developmental disabilities, family members, service providers, and State programs. The UCEDD network itself (including faculty, staff, people with developmental disabilities, and family members) also benefits from well-run UCEDD programs, as well as members of the university community and Consumer Advisory Committees.

The expected outcome for this key function is a smoothly functioning, well-funded UCEDD, with strong ties to people with developmental disabilities and their families, the university, and local and state organizations that provide supports and services to people with developmental disabilities and family members.

Benchmarks and Indicators

- 6.1 UCEDDs leverage funding to support and maintain UCEDD programs and activities, as indicated in the 5-year plan and amendments.
 - 6.1.1 UCEDDs apply for and receive external funding from a variety of sources.
 - 6.1.2 UCEDD external funding is consistent with identifiable needs indicated in the 5-year plan or amendments.
- 6.2 UCEDDs maintain and support involvement from Consumer Advisory Committees (CACs).
 - 6.2.1 UCEDDs obtain the perspectives of members of their CAC to guide UCEDD activities.
 - 6.2.2 UCEDDs support CAC members with the tools they need to be meaningfully involved as a CAC member.
 - 6.2.3 CACs provide meaningful input.
- 6.3 UCEDDs receive support from the university.
 - 6.3.1 Universities support UCEDDs in a variety of ways.

Indicators and Performance Standards

- 6.1 UCEDDs leverage funding to support and maintain UCEDD programs and activities, as indicated in the 5-year plan or amendments.

Indicators	Examples of Performance Standards
6.1.1 UCEDDs apply for and receive external funding from a variety of sources.	<ul style="list-style-type: none"> ▪ The UCEDD can provide examples of funding applied for within the past 5 years from local, state, and/or federal sources. ▪ The amount the UCEDD received in grants in the past 5 years in addition to the grant from ADD was at least the same amount or more than the ADD grant.
6.1.2 UCEDD external funding is consistent with identifiable needs indicated in the 5-year plan or amendments.	The UCEDD can demonstrate the association between external funding and goals and objectives in the 5-year plan or amendments.

6.2 UCEDDs maintain and support involvement from Consumer Advisory Committees (CACs).

Indicators	Examples of Performance Standards
<p>6.2.1 UCEDDs obtain the perspectives of their CAC to guide UCEDD activities.</p>	<p>The UCEDD can provide examples of CAC involvement in:</p> <ul style="list-style-type: none"> ▪ Development of the 5-year plan; and ▪ Other UCEDD activities.
<p>6.2.2 UCEDDs support CAC members with the tools they need to be meaningfully involved as a CAC member.</p>	<ul style="list-style-type: none"> ▪ The UCEDD provides the following supports to CAC members: <ul style="list-style-type: none"> - Reimbursements for travel - Child care - Respite - Personal assistance services, if required - Assistance for people with specific impairments (e.g., hearing, visual, cognitive, other) - Assistance for people whose second language is English - Provision of materials in advance of meetings - Assistance with preparation and understanding of materials prior to and during meetings if needed - Other. ▪ CAC members are satisfied or very satisfied with the support they receive from the UCEDD (e.g., 4 or 5 on a scale of 1 – 5).
<p>6.2.3 CACs provide meaningful input.</p>	<ul style="list-style-type: none"> ▪ CAC members can provide examples of input provided by the CAC and used by the UCEDD in the past year. ▪ The UCEDD can provide examples of input provided by the CAC and used in the past year.

6.3 UCEDDs receive support from the university.

Indicators	Examples of Performance Standards
<p>6.3.1 Universities support UCEDDs in a variety of ways.</p>	<p>The UCEDD can provide examples of the support received from the university in the past year.</p>

Appendix B4. Collaboration Among DD Network Programs

In addition to evaluation of the three Developmental Disabilities (DD) Network programs [Protection and Advocacy (P&A) Systems, State Councils on Developmental Disabilities (DD Councils), and the national network of University Centers for Excellence in Developmental Disabilities Education, Research, and Service National Network (UCEDDs)], the Administration on Developmental Disabilities (ADD) independent evaluation will also evaluate collaboration among the three DD Network programs.

The Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) does not define collaboration or specify how it should be achieved. However, it requires that program accountability measures include measurement of the extent to which the DD Network collaborates, and also requires reports to the Secretary of Health and Human Services that provide examples of coordinated activities among the Network. Section 104(a)(3)(D) and 105(1), respectively, state:

- Program Accountability/indicators of progress: At a minimum, the indicators of progress shall be used to describe and measure... (iii) the extent to which the members of the DD Network collaborate with each other to achieve the purpose of this title and the policy described in section 101(c).
- Reports of the Secretary: In preparing the report, the Secretary shall provide meaningful examples of how the councils, protection and advocacy systems, centers, and entities funded under subtitles B, C, D, and E, respectively...--have undertaken coordinated activities with each other ...

Since the DD Act does not provide a definition of collaboration, the following is considered the working definition of collaboration for this evaluation:

Collaboration is a well-defined relationship entered into by two or more individuals, groups, and/or organizations to achieve common goals of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) [adapted from T. E. Backer (Editor). *Evaluating Community Collaborations*. NY: Springer Publishing, 2003].

For the purpose of the ADD Independent Evaluation, the primary focus of collaboration will be on all three DD Network programs (DD Councils, P&As, and UCEDDs). In states in which there are more than one UCEDD, the evaluation will also examine collaboration among the UCEDDs and the other DD Network programs.

Although the DD Act focuses on collaboration among the three DD Network programs, programs also recognize the importance and effectiveness of collaboration among groups that are outside the DD Network. Thus, the ADD independent evaluation will ascertain collaboration among the three DD Network programs as well as with other individuals, groups, organizations and agencies. The benchmarks and indicators in this document relate only to collaboration among the three DD Network programs.

There are three basic components of collaboration among the three DD Network programs. The first component consists of the underlying infrastructure and resources available so collaboration can take place (e.g., contribution of staff time, dollars, meeting room, etc.). The second component emphasizes the working relationship among the entities (the process of collaboration), and the third component relates to the outcomes of collaboration. Therefore, the evaluation of collaboration will address the resources, processes, and results or outcomes of collaboration among the three DD Network programs.

The DD Act does not specify the expected outcomes of collaboration, only that it must be done and reported on. For this evaluation, we consider the expected outcome of collaboration to be the achievement of short-term outcomes that result from achieving common goals set by the DD Network programs (e.g., changes in community practice, improved access to services, leaders in disability). Short-term outcomes are expected to have an impact on people with developmental disabilities and family members of people and improve their quality of life.

Benchmarks and Indicators

1. DD Network programs have a process for identifying, planning, and implementing collaborative efforts.
 - 1.1 DD Network programs identify and document common goals on which to collaborate.
 - 1.2 DD Network programs support and encourage collaborative efforts.
2. DDN programs collaborate to achieve common goals.
 - 2.1 DD Network programs communicate regularly.
 - 2.2 DD Network programs show a united front to the community.
 - 2.3 DD Network programs monitor progress and barriers of collaborative efforts.

- 2.4 DD Network programs revise goals and objectives, as appropriate, to overcome barriers identified.
- 3. Collaboration achieves outcomes that have an impact on people with developmental disabilities and their families.
- 3.1 DD Network programs collaboratively achieve common goals set by the DD Network programs (e.g., changes in community practice, improved access to services, increase in disability leaders in the community).

Indicators and Performance Standards

- 1. DDN programs have a process for identifying, planning, and implementing collaborative efforts.

Indicators		Examples of Performance Standards	
1.1	DD Network programs identify and document goals on which to collaborate.	<ul style="list-style-type: none"> ▪ DD Network programs have a means of identifying goals (formal or informal). ▪ DD Network program goals are recorded (e.g., in each program's plan). 	
1.2	DD Network programs support and encourage collaborative efforts.	In the past year, each DD Network program contributed to ongoing collaborative efforts in some way (e.g., with funding, staff time, space, or in kind contributions).	

- 2. DDN programs collaborate to achieve common goals.

Indicators		Examples of Performance Standards	
2.1	DD Network programs communicate regularly.	<p>In the past year, DD Network communication on collaborative efforts included the following:</p> <ul style="list-style-type: none"> ▪ Sharing information and progress on ongoing efforts; ▪ Regular updates to participants in the collaborative effort; ▪ Reports on milestones achieved (if appropriate); ▪ Discussion of issues that arose (if appropriate); and ▪ Debriefing at the end of a collaborative effort (if appropriate). 	
2.2	DD Network programs show a united front to the community.	DD Network programs can provide examples in which they worked and reported together on a community issue in the past year.	

Indicators		Examples of Performance Standards
2.3	DD Network programs monitor progress and barriers of collaborative efforts.	<ul style="list-style-type: none"> ▪ DD Network programs identified leadership of each collaborative effort in the past 2 years. ▪ DD Network programs can provide examples in which collaborative efforts in the past year have been monitored. ▪ DD Network programs report yearly on progress and barriers
2.4	DD Network programs revise goals and objectives, as appropriate, to overcome barriers identified.	<ul style="list-style-type: none"> ▪ DD Network programs can give examples of revised goals and objectives in response to overcoming identified barriers.

3. Collaboration achieves outcomes that have an impact on people with developmental disabilities and their families.

Indicators		Examples of Performance Standards
3.1	DD Network programs collaboratively achieve common goals set by the DD Network programs (e.g., changes in community practice, improved access to services, increase in disability leaders in the community).	DD Network programs can provide examples in which their collaborative efforts within the past 5 years achieved the common goals that were set.

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Appendix C. Data Collection Instruments

- C1. QUESTIONNAIRES FOR THE STATE COUNCILS ON DEVELOPMENTAL DISABILITIES**
- C2. PROTECTION AND ADVOCACY SYSTEMS**
- C3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE**

Appendix C1. Questionnaires for the State Councils On Developmental Disabilities

- C1-1. Executive Director and Management Staff**
- C1-2. DD Council Chair and Members**
- C1-3. Group Interview: Policymakers, Collaborators, and Contractors**
- C1-4. Recipients of Advocacy and Leadership Education and Training**
- C1-5. Recipients of Education and Training to Improve Community Capacity**

C1-1. Executive Director and Management Staff

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

EXECUTIVE DIRECTOR AND COUNCIL STAFF INTERVIEW

[Interviewer]: Thank you for taking the time to meet with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Rockville, Maryland.

As we've already discussed, the Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This evaluation is intended to provide feedback to the ADD to help improve the effectiveness of its programs and policies, to serve as a decision-making tool for ADD, and to promote accountability to the public.

Nineteen states and one territory were randomly selected to participate in the full-scale evaluation. We will be visiting all three DD Network programs in your state/territory. If your state/territory has more than one UCEDD, we will be visiting the UCEDD randomly selected from those within your state. The evaluation will consist of interviews with key stakeholders (e.g., Executive Directors and staff, DD Council members, policy makers and DD Council collaborators, recipients of DD Council self-advocacy and leadership development training, and recipients of DD Council community capacity development training). We will also be conducting the evaluation at UCEDDs and P&As. We will summarize the information provided by interviewees (yourself included) in all programs to help us to examine the impact of DD Councils at the national level. (INCLUDE ONLY IN THOSE STATES/TERRITORIES WITH MORE THAN ONE UCEDD--There is more than one UCEDD in your state/territory. We will include those UCEDDs in your state/territory that were not selected for the full-scale evaluating in our discussion of collaboration among the DD Network programs within your state/territory.

As the DD Council executive director, you are an important source of information regarding the operations and achievements of this program. We have some specific questions to ask you about the different key functions of your Council. The interview should last approximately 3-4 hours.

Before we start, we would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. The recording will be used by Westat only; it will not be provided to ADD or anyone else.

Do you have any questions before we start?

PART A. STATE PLAN DEVELOPMENT

As you know, DD Councils are required by law to develop and have an approved 5-year State Plan.

Process for Developing Goals and Priorities

Let's start with the process your DD Council uses for developing the State Plan, thinking about what happened during the last planning cycle.

1. What methods did you use to obtain input on the needs and priorities of people with developmental disabilities and their families? Please describe.

Probe:

- Public meetings
- Focus groups
- Surveys
- Analysis of telephone calls to the DD Council
- Input from staff and contractors
- Other _____

2. Whom did you contact to participate in providing input?

Groups/individuals	Contacted (✓)	Provided input (✓)
People with developmental disabilities		
Family members		
Advocates		
Service providers		
Policy makers		
P&A		
P&A Board of Directors/Advisory Council		
UCEDD(s)		
UCEDD Consumer Advisory Committee (CAC)		
Other, please specify		

3. What groups/organizations/individuals provided your DD Council with input for the last planning cycle?

4. What did you do to accommodate people with developmental disabilities so they were able to participate in the planning and priority setting process? Please describe.

Probe:

- Methods of contact
- Materials used
- Accessibility at meetings
- Assistance with materials
- Other, please specify _____

5. How did you make sure you provided opportunities to participate to those who had never participated before in the process? For example, please describe how you sought input from:

Probe:

- People from both urban and rural communities;
- People throughout all parts of the state;
- People from ethnic/minority groups in your state;
- People who have difficulty understanding English;
- Others, please specify _____

6. What did you do to provide accommodation to those who needed it in order to participate? Please give examples.

7. What type of existing data or reports did you use to identify the needs and interests of people with developmental disabilities? Please give examples.

Probe:

- Census data
- Findings from UCEDD reports [Obtain copy or references.]
- Findings from published literature [Obtain references.]
- Findings from P&A reports [Obtain copy.]
- Findings from DD Council-supported demonstration projects [Obtain copy.]
- State agency reports [Obtain copy.]
- Other _____
[Obtain copy or references.]

8. In the last planning cycle, how did you use feedback about current activities to inform the planning and priority setting process? Please describe.

- a. What kind of information did you collect about current activities (e.g., information on recipients' satisfaction with DD Council-supported programs)?
- b. How did you collect it?
- c. From whom (e.g., staff and contractor feedback)?
- d. How did you use it? Give examples.

Results of Planning Process

9. What is the process you use to move from stakeholder input to statements of goals and priorities in your SGP? Please describe.
- a. What do you do?
 - b. Who is involved?
Probe:
 - Staff
 - DD Council members
 - State officials
 - People with developmental disabilities
 - Family members
 - Representatives from other DD Network programs
 - Other _____
 - c. How do you make sure the end result is consistent with both stakeholder input and existing data regarding the needs and priorities of people with developmental disabilities? Please explain.
 - d. How do you make sure the end result is truly reflective of the findings from the planning process? Please describe.

I see the goals and objectives in the State Plan are _____ **(Refer to State Plan)**.

10. How do these relate to the feedback you received from stakeholders? Please give examples.

Use of State Plan to Shape DD Council Activities

We've been told that the State Plan and amendments are used to shape the activities of the DD Council.

- 11. How does your DD Council use the State Plan? Please describe.
- 12. How did your DD Council deal with new and emerging issues that arose in the past year? Please give examples.
- 13. What was the rationale for taking on these new and emerging issues not covered in the State Plan? Please explain.

PART B. SELF-ADVOCACY AND LEADERSHIP DEVELOPMENT

According to the DD Act [Sec. 125(c)(5)(C)], DD Councils “may support and conduct training for persons who are individuals with developmental 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.”

We’d like to talk a little bit about self-advocacy and leadership development activities supported by your Council. The kinds of activities we mean are those that are targeted toward people with developmental disabilities (and sometimes their families) and that provide them with knowledge and skills to obtain supports and services for themselves and advocate for systems change so that their choices can meet their desired lifestyle goals and will be included in the community.

Self-Advocacy and Leadership Training Programs and Supports

14. What self-advocacy and leadership activities did the DD Council support or conduct last year? Please describe.
Probe:
 - Types
 - Content
 - Skills taught
 - Target audience

15. In the past year, did you identify the unserved and underserved populations and communities in your state? Please describe.
Probe:
 - Process for identification
 - Groups/populations identified

16. How did you or your grantees go about recruiting these populations and communities for participation in self-advocacy and leadership activities? Please describe.

17. Did you keep track of the number that participated in DD Council-supported education, training, and technical assistance in the past year?

Council Supports to State Self-Advocacy Organizations Led by People With Developmental Disabilities

Apart from helping people with developmental disabilities to develop their advocacy and leadership skills, DD Councils, according to the DD Act, are also called upon to “establish or strengthen a program for the direct funding of a State self-advocacy organization led by people with developmental disabilities” [Sec. 124(c)(4)(A)(ii)(I)].

18. Would you please talk about what your Council does to comply with this section of the Act?

a. To which organization(s) did you provide support in the past year? Please describe organization(s).

Probe:

- Name of organization(s)
- Mission
- Participants

b. What type of support did you provide?

Probe:

- Provided funding
- Provided training or technical assistance on grant writing
- Identified public or private funding opportunities
- Provided opportunities for members to participate in Council activities
- Identified opportunities for members to participate in other advocacy activities of other organizations
- Other _____

c. How did these organizations use the support you provided? What were the results in the past year? Please give examples.

Probe:

- Submission of grant applications
- Receipt of grant and contract awards
- Increase in the number of organizations throughout the state
- Increase in size of the organization
- Achievement of financial independence
- Other

Results of Self-Advocacy and Leadership Training Programs

We would like to get an idea of the impact of your Council-supported advocacy and leadership training programs on people with developmental disabilities and their families.

19. How does the DD Council (or contractors) evaluate the effectiveness of advocacy and leadership activities? Please describe.

Probe:

- Satisfaction surveys
- Followup surveys
- Other _____

20. How do participants in Council-supported advocacy and leadership activities use the information and skills they obtained?

- a. Among your current Council members, how many are former recipients of Council-supported self-advocacy and leadership training?

- b. Among those who participated in DD Council-supported advocacy and leadership training within the past 5 years, did any become members or leaders of community organizations that advocate on behalf of people with disabilities? Please give examples.

- c. Among those who participated in DD Council-supported education and training within the past 5 years, did any participate in Council-supported advocacy activities? Please give examples.

Probe:

- Approximate number
- Types of activities
 1. Attendance at meetings with policymakers
 2. Letter writing or sending emails to policymakers
 3. Provision of personal testimony to legislators
 4. Speaking at Council-sponsored conferences
 5. Other (please specify)

- d. Among those who participated in Council-supported self-advocacy and leadership training in the past 5 years, did any take part in other advocacy activities organized by the DD Council or another organization? Please give examples.

Probe:

- Approximate number
- Types of activities
 1. Attendance at meetings with policymakers
 2. Letter writing or sending emails to policymakers
 3. Provision of personal testimony to legislators
 4. Speaking at Council-sponsored conferences
 5. Other (please specify)

- e. How do participants in Council-supported advocacy and leadership training use the information and skills they obtained in their personal lives? Please give examples.

Probe:

- Became an employee or volunteer of a disability advocacy organization
- Used the knowledge and skills they obtained to enhance their lives and become self-sufficient
- Obtained supports and services for oneself
- Obtained supports and services for others
- Obtained or retained a job
- Mentored others
- Other

PART C. COMMUNITY CAPACITY DEVELOPMENT

Now we would like to talk about Council-supported activities that educate the public in order to build community capacity to better serve people with developmental disabilities, provide them with choice and help them to be independent and included in the community.

We'll start with the ways you support educational activities, the target audiences of these activities, and how you make sure that these activities are accessible, culturally competent, and appropriate to the target audiences for which they are intended.

Educational Activities (Training, Demonstration Projects, Technical Assistance)

21. Within the past year, what educational activities (including training, demonstration projects, and technical assistance) did you conduct or support?

Probe:

- Purpose
- Types of activities
- Format
- Content

22. Who implemented these activities? Please describe.

Probe:

- DD Council
- Grantees
- Other _____

23. What audiences were targeted? Please give examples.

Probe:

- The media
- Policy makers
- Service providers
- Disability-related organizations
- Non-disability related organizations that interact with the public
- Employers
- Health care providers
- Teachers
- Others _____

24. Did you (or your grantees) keep track of the number that participated in DD Council-supported educational activities (including training, demonstration projects, and technical assistance)?

Results of Educational Activities

Now we'd like to ask you some questions on the results of the educational activities you supported and how you evaluated them.

25. How did the DD Council (your contractor) evaluate the effectiveness of its educational activities?

a. What was done? Please describe.

Probe:

- Satisfaction surveys
- Followup surveys
- Other _____

b. How did participants in DD Council-supported capacity-building efforts use what they learned? Please give examples.

Probe:

- Transferred the knowledge and skills they obtained to their work
- Improved their effectiveness in providing services to people with developmental disabilities
- Improved the effectiveness of the community in including people with developmental disabilities in all aspects of life
- Provided accommodations for employees with developmental disabilities
- Made use of tax incentives for assistive technology for employees
- Made public buildings more accessible
- Other _____

PART D. IDENTIFICATION OF PROMISING AND EFFECTIVE PRACTICES

We would like to learn about your Council’s activities with regard to the identification of promising and effective practices for providing services to people with developmental disabilities and their families and including people with developmental disabilities in the community. We define promising practices as new approaches to serving people with developmental disabilities and their families and including people with developmental disabilities in the community. Promising practices are practices that have not yet been tested (evaluated) for effectiveness.

Identifying Promising Practices

26. Did your DD Council identify or test²³ any promising practices in the past 5 years?
- a. What promising practices did your Council identify or test within the past 5 years?
Please give examples.
Probe:
 - Description of practice
 - Intended target audience
 - b. Why are these considered promising practices?
 - c. What did you find/conclude?

[See table.]

27. How did your DD Council go about identifying and/or testing promising practices in the past 5 years? Please describe.
Probe:
- Issued requests for proposals to identify promising practices
 - Issued requests for proposals to test promising practices using DD Council funds
 - Secured external funding to identify or test promising practices
 - Assisted community organizations in obtaining funding to identify or test promising practices
 - Partnered with other agencies or organizations to identify or test promising practices
 - Other _____

²³ “Testing” refers to evaluation with both rigorous methodology and less rigorous methodology (e.g., observation of trying out a promising practice).

Results of Identifying and Testing Promising Practices

Now let's talk about how your Council uses the results from these efforts.

28. For each of the promising practices identified and/or tested in the past 5 years, how were findings disseminated? Please describe.

Probe:

- Placed on DD Council web site
- Mailouts (or email blasts) to specific target audiences
- Presentations of findings at conferences and meetings
- Descriptions in newsletters
- Other _____

29. For each of these, to which organizations/individuals were these findings disseminated? Please be specific.

Probe:

- Council members
- DD Network sister agencies
- Disability-related organizations in the community
- Other _____

30. How were the results used? Please give examples.

Probe:

- For future Council planning
- In development of new requests for proposals
- Used by service providers and others in the community
- Used to increase inclusion and choice in the community
- Other _____

31. Are any of your DD Council's current activities the result of findings/conclusions that were found from the process of identifying or testing promising practices in the past? Please give examples.

Identifying and Testing Promising Practices

Description of Practice (Q26a)	Target Audience (Q26a)	Results/Conclusions (Q26c)	Method of Identifying/Testing (Q27)	Followup of Results/ Conclusions (Dissemination and Use) Q28-31)

PART E. SYSTEMS CHANGE THROUGH ADVOCACY

According to the DD Act, DD Councils are called upon to support and conduct activities related to barrier elimination, systems design and systems redesign [Sec. 125(c)(5)(H)] – that is, system change activities. The next section of this interview has to do with systems change through advocacy.²⁴

Questions in this section will address the types of systems design projects you implemented in the past few years, collaboration with other organizations and individuals as part of the advocacy process, participation of people with developmental disabilities and their families in these activities, and the specific outcomes of DD Council advocacy efforts.

32. First, let's start with a systems change project in which you used advocacy strategies in the past 3 years. Please describe.

[See table.]

Probe:

- Issue
- Strategies used
 - Wrote position papers
 - Obtained press coverage
 - Informed policy makers
 - Gave public testimony
 - Drafted legislation
 - Gave funding to support systems change (or maintenance) efforts
 - Other _____
- DD Council role (e.g., lead, supportive)

Collaboration to Support Advocacy Efforts

In order to achieve advocacy goals, it is often beneficial to collaborate with other groups who have similar goals. Thinking about the issues you've described, let's talk about the groups and individuals with whom your DD Council collaborated to achieve your goals and the nature and extent of the collaboration.

33. What groups/individuals were involved?
- People with developmental disabilities
 - Family members
 - Legislators
 - Other policy makers
 - Advocacy groups
 - Coalition (disability network) members
 - Others

²⁴ Advocacy is an umbrella term for organized activism related to a particular set of issues. It is the act or process of defending or maintaining a cause or proposal. In the context of the key function of advocacy and leadership development, advocacy includes advocacy for self and others.

34. What was each group's/individual's contribution? Please describe.
35. What role did the DD Council play? Please describe.

Outcomes of Systems Change (Advocacy) Activities

We realize that a large part of systems design and improvement is educating policymakers, so we'd like to talk about your efforts to educate policymakers.

We realize that it may take a long time to see the impact of DD Council-supported systems design and improvement efforts on the lives of people with developmental disabilities and their families. However, we'd like to know if any changes were made (or not made) as a result of your Council's system design and improvement activities.

36. Can you think of any examples in which system changes were made (or not made) as a result of Council-supported advocacy efforts in the past year 5 years? Please describe.
 - a. How were legislation and policy changed (or maintained) to address gaps in and barriers to supports and services for people with developmental disabilities and their families as a result of Council activities that took place in the past 5 years? Please give examples.
 - b. How did DD Council efforts in the past 5 years support changes to community practice? Please give examples.
 - c. How did DD Council efforts in the past 5 years lead to inclusion in the community, independence and increased choice? Please give examples.
 - d. How do you know these changes were a result of Council efforts? Would they not have occurred but for Council efforts? Please explain.

Examples of DD Council System Design and Improvement Activities

Systems Change/Project Issue (Q32)	Strategies Used (Q32)	Collaborators (Q33)	Contributions of Collaborators (Q34)	DD Council Role (Q35)

[INTERVIEWER: REPEAT QUESTION 32-35 FOR OTHER ISSUES.]

Systems Change/Project Issue (Q32)	Strategies Used (Q32)	Collaborators (Q33)	Contributions of Collaborators (Q34)	DD Council Role (Q35)

PART F. GOVERNANCE AND MANAGEMENT

Capacity of the DD Council to Fulfill Its Roles and Responsibilities

Let's start by looking at the composition of the Council.

[Use list of Council members from PPR or web site.]

37. As a whole, what areas of expertise does the Council represent? Please describe.

Probe:

- Knowledge of the needs of people with developmental disabilities and family members
- Legal expertise
- Financial and business expertise
- Leadership qualities
- Policy expertise
- Knowledge of community supports and services available for people with developmental disabilities and family members
- Knowledge and understanding of the state population
- Other _____

38. How do Council members become familiar with the principles and goals in the DD Act and the DD Council? Please describe.

Probe:

1. Orientation of new members
2. Attendance at national meetings
3. Participation in or chair of a DD Council sub-committee
4. Attendance at a community meeting on behalf of the DD Council
5. Participation in or observation of Council activities
6. Other _____

39. How does the DD Council assess its own efficiency and effectiveness in meetings its goals and objectives? In the past 5 years, did the Council:

- a. Review itself;
- b. Review the Designated State Agency;
- c. Review the Executive Director; and
- d. Other? _____

Please describe.

Supports Provided to DD Council Members

40. What kinds of supports do DD Council members receive so that they can meaningfully participate in meetings and fulfill their responsibilities?

Probe:

- Reimbursements for travel expenses
- Stipend
- Receipt of relevant meeting materials in advance
- Assistance from a support person to aid in preparation and understanding of materials before and during meetings
- Other _____

Procedures for Selecting Grantees

41. Does your Council have a policy or practice to identify and select competent and experienced grantees? Please describe.

Probe:

- Requirement for review committee
- Stated review criteria
- Methods for handling unsolicited proposals²⁵
- Other _____

[Obtain a copy of policy or practice.]

42. Is there a requirement for a review committee or sub-committee? Please describe.

Probe:

- Method of selection
- Composition
 - Council membership
 - Knowledge of issues affecting people with developmental disabilities and their families
 - At least one person with a developmental disability
 - Evaluation/research expertise
 - Understanding of subject matter being discussed
- Other _____

43. How does your Council handle unsolicited proposals? Please describe.

- a. In the past year, were any unsolicited proposals funded?
- b. What process was used to review and make decisions on unsolicited proposals?

²⁵ An unsolicited proposal is one that is independently developed and submitted rather than in response to a solicitation or request for proposal (RFP) of State Councils on Developmental Disabilities.

PART G. COLLABORATION

According to the DD Act, DD Network programs are required to report the extent to which they collaborate with one another. We've talked a little bit about collaboration as part of your systems change/advocacy activities. Now we would like to focus on your collaborative efforts with the DD Network programs on all types of activities besides systemic advocacy.

For this evaluation, we define collaboration as a well-defined relationship entered into by two or more individuals, groups, and/or organizations to achieve common goals of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (the DD Act).

Let's start first with how the DD Network programs identify issues and common goals on which to collaborate.

44. What process do the programs use for identifying, planning, and implementing collaborative efforts? Please describe.

Probe:

- Nature of process
- Participants
- Meeting frequency
- Formal vs. informal
- Other _____

45. What are the issues and goals on which the DD Network programs are currently collaborating? Please describe.

[See following table.]

[Obtain written goals/objectives.]

- a. What project or issues are you collaborating on with DD Network programs? Would you please explain each issue?
 - b. What are the goals you and your collaborators were trying to achieve?
46. Which organizations or groups (including other DD Network programs) are you collaborating with on these issues?
47. What is the role of each collaborator, including the P&A and other DD Network programs?
48. How would you characterize the type of leadership for each project?
- Probe:
- Single
 - Joint
 - Other _____

Resources for Collaboration

49. Collaboration suggests shared resources being available and used. What resources did each group or organization contribute? Please describe.

Probe:

- Funding
- Staff time
- Meeting place
- In kind contributions
- Other _____

Collaborations

No.	Project/Issue (Q45a)	Goals/Objectives (Q45b)	Collaborators (including P&A) (Q46)	Collaborators' role (including role of DD Council) (Q47)	Leadership (Single/joint) (Q48)	Resources Contributed (Q49)
a.						
b.						
c.						

[INTERVIEWER: REPEAT QUESTIONS 45 THROUGH 49 FOR TWO MORE EXAMPLES.]

Process of Collaboration – Regular Communication

Let's talk about the process of communication by using the same examples.

50. What were some of the ways you achieved regular communication during your collaborative efforts? Please describe.

- a. Sharing information and progress on ongoing efforts
Probe:
 - Examples
 - Frequency
 - Recipients
 - Other
- b. Regular updates to participants in the collaborative effort
Probe:
 - Examples
 - Frequency
 - Recipients
 - Other
- c. Reports on milestones achieved
Probe:
 - Examples
 - Frequency
 - Recipients
 - Other
- d. Discussion of issues that arose
Probe:
 - Examples
 - Frequency
 - Recipients
 - Other
- e. Debriefing at the end of a collaborative effort (if appropriate)
Probe:
 - Examples
 - Frequency
 - Recipients
 - Other

51. In the past year, were there any issues that arose in the community on which the DD Network programs responded together? Please give examples.
52. What was the joint response of the DD Network programs?
53. What is the process the DD Network programs use to monitor progress and barriers of collaborative efforts? Please describe.
 - a. Please give examples of ways in which the programs monitor and identify barriers.
 - b. For collaborative efforts implemented in the past 2 years, what process was used to identify leadership? What decisions were made on leadership of each effort?
 - c. What barriers have been identified?
 - d. Have goals and objectives been changed as a result of monitoring and identifying barriers? Please give examples.

Results of Collaboration

Finally, let's talk about achieving your goals and objectives -- the results of your collaborative efforts.

54. Were there any products derived from your collaborative efforts? Please give examples and describe?

Probe:

- White papers
- Wording for legislation
- Brochure on joint program
- Program enrollment form
- Other _____

[Obtain examples of products developed in past year, if applicable.]

55. What has been the result of your collaboration with DD Network programs and other organizations? Please give examples from the past 5 years.

Probe:

- Changes to (or maintenance of) State and local systems (e.g., changes or maintenance in practices and legislation)
- System changes (or maintenance) that affected people with developmental disabilities and their families, including people who are traditionally unserved and underserved (e.g., racial or ethnic minorities, people with little or no use of English, or people who live in remote or rural areas or live in poverty)
- Increases in the capacity of the community to provide supports and services to people with developmental disabilities and their families (e.g., accommodations are provided in public services such as transportation, education, and employment)
- Ways participants in DDN collaborative efforts have improved their knowledge or skills in ways that benefit people with developmental disabilities and their families
- Other _____

PART H: DEBRIEFING [AT END OF PROGRAM VISIT]

56. Before we leave, we would like to give you the opportunity to ask any questions you might have, raise any issues you might want to raise, or talk about anything related to your program that you would like to expand upon.
- a. First, do you have any general comments to make?
 - b. Issues?
 - c. Further explanation of your DD Council?
57. There are also a few things I want to make sure we don't forget.
- Obtain materials requested, if easily available.
 - Confirm products to be sent. Leave FedEx form.
 - Obtain contact information for additional individuals who need to be contacted.
 - Confirm process for telephone interviews and availability of interviewees.
 - Leave business card.

We'd like to thank you again for taking the time to meet with us these past 2 days. We also appreciate you making your staff available and arranging for us to meet with many of your stakeholders.

C1-2. DD Council Chair/Council Members

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

DD COUNCIL CHAIR/COUNCIL MEMBERS INTERVIEW

[Interviewer]: Thank you for taking the time to talk with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Maryland.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This DD Council 20 DD Councils in 19 states and one territory that have been randomly selected to participate in the evaluation.

As a DD Council member (Chair), you are an important source of information regarding this DD Council. We would like to learn about your experiences with the DD Council, how you learn about your roles and responsibilities, what DD Council staff does to help you meet your roles and responsibilities and your satisfaction with the amount of help that is given.

Before we begin, I would like to read this consent form to you or ask you to read it yourself.

**READ CONSENT FORM OR ALLOW TIME FOR CLIENT TO READ THE
CONSENT FORM. ANSWER ANY QUESTIONS THE CLIENT MAY HAVE. OBTAIN
SIGNATURE ON CONSENT FORM.**

Now that we're ready to begin, we would like to ask your permission to record the interview so that we do not miss any of your responses to our questions. The recording is for Westat's use only and will not be provided to ADD or anyone else.

Do you have any questions before we start?

Let's start first by talking about your background and how you became interested in the DD Council and what it does.

1. Please tell us how long you have been a member of the DD Council (Chair) and how you first became involved.
 - a. How did you become interested in developmental disabilities? Please explain.
Probe:
 - Is a person with a developmental disability
 - Is a family member of a person with a developmental disability
 - Has a friend or other acquaintance with a developmental disability (e.g., work colleague)
 - Other _____
 - b. How did you first learn about the DD Council?
 - c. When did you become a DD Council member? Chair?

Composition of DD Council

We'd like to understand the composition of the DD Council and what each person contributes.

2. Please tell us a little bit about your own background and relevant experience and other aspects of your background or experience help you in your role as Chair (member) of the DD Council? Please explain.
Probe:
 - Personal experience with developmental disabilities
 - Education
 - Training
 - Job experience
 - Volunteer experience
 - Race/ethnicity
 - Languages spoken
 - Understanding of the needs and rights of people with developmental disabilities
 - Understanding of State system that provides supports and services to people with developmental disabilities and their families
 - Knowledge of availability of supports and services
 - Research expertise
 - Policy or legal expertise
 - Financial or business expertise
 - Other _____

In order to participate meaningfully in the roles and responsibilities of the DD Council, Council members must learn about legislation and the policies and procedures that influence Council activities. The next few questions are about how Council members gain the knowledge they need to fulfill their roles and responsibilities.

Council Capacity to Fulfill Its Role

3. How did you as a DD Council member (Chair) become familiar with the DD Act, the DD Council, and your roles and responsibilities?
- a. Did you attend an orientation provided by the DD Council? Please describe.
Probe:
 - Content
 - Format
 - Duration
 - Timing
 - b. Did you or any other Council member attend a national technical assistance meeting in the past year? Please describe.
 - c. Did you or any other Council member observe or participate in any DD Council activities that helped you to understand the DD Act or the work of the DD Council? Please describe.
 - Development of State Plan
 - Self-advocacy and leadership activities
 - Community capacity development activities
 - Identification of promising and effective practices
 - Selection of grantees to implement DD Council projects
 - Attendance at a community meeting on behalf of the DD Council
 - Other _____
4. Overall, how familiar do you consider yourself to be with regard to:
- a. The DD Act? Please explain.
 Very familiar Familiar Not very familiar
 - b. The DD Council mission? Please explain.
 Very familiar Familiar Not very familiar
 - c. Goals and objectives in the State Plan? Please explain.
 Very familiar Familiar Not very familiar

Supports Provided to DD Council Members (Chair)

5. What kinds of supports do you and other DD Council members receive so that you can meaningfully participate in meetings and fulfill your responsibilities?

Probe:

- Reimbursements for Council-related travel expenses
- Stipend
- Receipt of relevant meeting materials in advance
- Assistance from a support person to aid in preparation and understanding of materials before and during meetings
- Other _____

6. How satisfied are you with the supports you receive? Please explain.

Very satisfied Somewhat satisfied Not very satisfied

Explain: _____

That ends all of our questions. Do you have any questions yourself?

Again, we would like to thank you for taking the time to meet with us today and answer our questions.

C1-3. Group Interview: Policy Makers, Collaborators, and Grantees

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

POLICY MAKERS, COLLABORATORS, AND GRANTEE INTERVIEW

[Interviewer]: Thank you for taking the time to talk with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Rockville, Maryland.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This DD Council is one of 20 DD Councils in 19 states and one territory that has been randomly selected to participate in the evaluation. You were invited to participate in this group discussion because of your involvement with the DD Council on systems change and advocacy issues related to people with developmental disabilities (and family members).

Purpose: The purpose of today's group discussion is to learn about your experiences with the [NAME OF DD COUNCIL] systems change/advocacy activities on a specific issue and your thoughts about the impact of these activities. This discussion will last about 1 ½ to 2 hours.

Logistics: Before we begin, let me explain a few practical things. You have two forms in front of you—an expense reimbursement form, and a consent form. After this meeting, please complete the reimbursement form and mail it to Westat so we can reimburse you to cover your expenses in coming here today.

Consent: The second form is a consent form. Before we begin this session, please read and sign the consent form, which indicates your willingness to participate in our discussion. Please remember that you do not have to answer any questions you don't want to answer, and you may also leave this meeting at any time.

[COLLECT CONSENT FORMS.]

Finally, we would like – with your consent – to record this discussion. This will allow us to focus our full attention on what everyone is saying, and it eases the burden of note-taking. The recording is for Westat's use only. We will not be giving it to anyone else. Is there anyone who objects to us recording this discussion? [WAIT TO HEAR IF THERE ARE OBJECTIONS.]

All of you were assembled today because you worked on a particular systems change/advocacy issue or had an interest in this issue. The issue we will be talking about is

Do you have any questions at this point?

Let's start by everyone stating their first name and saying something about how you interact with people with developmental disabilities.

1. Would you please tell us how that issue first became important to you or your organization?
2. What initiated your relationship with the DD Council and your organization (you) becoming involved in this issue with the DD Council?
3. Please describe some of the activities that took place in the past year (3 years, 5 years) related to this issue and your organization's particular involvement.

Probe:

- Research and analysis of background information
- Drafting white papers, reports, other documents
- Drafting policy or legislation
- Attending meetings with policymakers
- Obtaining input from the developmental disabilities community
- Making appearances at legislative and other meetings
- Making presentations
- Receiving input on the issue
- Responding to input
- Other _____

4. What were some of the outcomes of these activities? Provide examples.

Probe for:

- Barriers to services eliminated
- New barriers to services prevented
- New laws/policies/procedures/practices established
- Existing laws/policies/procedures/practices enforced or implemented
- Corrections made by agencies, providers, or facilities
- Complaints of abuse, neglect, or discrimination remedied
- Services to traditionally unserved or underserved populations increased
- Knowledge and skills among DD Network program participants increased

5. Based on your experiences with these systemic advocacy activities, what role you think the DD Council played in
 - a. Building and maintaining a collaborative relationship with your organization to achieve common goals and objectives? Please explain.
 - b. Helping you to understand issues affecting people with developmental disabilities and their families? Please explain.
 - c. Meeting the goals and objectives of this issue? Please explain.
 - d. Other _____

That ends all of our questions. Do any of you have any questions of your own?

Again, we would like to thank you for taking the time to answer our questions.

C1-4. Recipients of Advocacy and Leadership Education and Training

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

RECIPIENTS OF SELF-ADVOCACY AND LEADERSHIP EDUCATION AND TRAINING

[Interviewer]: Thank you for taking the time to talk with me today. My name is [interviewer's name], and I work for Westat, a private research company in Rockville, MD.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. The DD Council that contacted you to participate in this evaluation is one of 20 DD Councils in 19 states and one territory that has been randomly selected to participate in the evaluation. As someone who is a recipient of DD Council-supported self-advocacy and leadership education or training, you are an important source of information.

We have some questions we would like to ask you about your experiences with DD Council self-advocacy and leadership activities and the ways in which you used or hope to use the information you obtained. The interview should last approximately ½ hour – 45 minutes.

Before we begin, I would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. This recording is for Westat use only. It will not be made available to anyone else. Do we have your permission to record?

Do you have any questions before we start?

Let's start with some information about you.

Self-Advocacy and Leadership Training

Let's begin by you telling us about the self-advocacy and leadership training activities you took part in.

1. Which program was it (e.g., name)?
2. When was it held?
3. How did you find out about the program?

4. What did the program teach? Please describe.

Probe:

- Rights and responsibilities of people with developmental disabilities under the law
- Available supports and services in the community
- How to obtain supports and services in the community
- Gaps in and barriers to supports and services
- Impact of public policies on the lives of people with developmental disabilities and their families
- How public policy is developed
- Skills to advocate
- Other (please specify) _____

5. How easy was it for you to get in and out of the building in which the training program was held? Please explain.

- Very easy Somewhat easy Not very easy

6. What did the program do to make it easier for you to attend and take part? What type of support or accommodation was provided? Please give examples.

Probe:

- Arranged for transportation
- Arranged for accommodation (e.g., personal assistance)
- Provided materials in an appropriate format
- Other _____

Results of Council-Supported Training Program

Now let's talk about what you learned and how you used what you learned.

7. What particular skills did you learn from the training program? Please describe.

Probe:

- Effective letter-writing
- Providing legislative testimony
- Presenting opinions to decision makers
- Other

8. Did you have opportunities to use what you learned? If yes, please describe your experiences. If no, why not?

Probe:

- Obtained supports and services for yourself
- Obtained supports and services for others
- Participated in self-advocacy activities (give examples)
- Took on a leadership position (e.g., Council Chair, Chair of another disability-related organization or committee)
- Became a member of a community organization
- Was nominated to become a member of the DD Council
- Became the Chair of the DD council or of a DD Council sub-committee
- Became a leader or sub-committee member of the DD council
- Became a member or leader in other organizations that advocate on behalf of people with disabilities
- Became a member or leader in other community organizations
- Participated in DD Council or other advocacy efforts on behalf of people with developmental disabilities
- Helped a peer or mentored another person with a disability
- Became an employee or volunteer of a disability advocacy organization
- Used the knowledge or skills you obtained to enhance your life and become self-sufficient
- Other (please specify) _____

9. How satisfied were you with ...? Please explain.

	Very satisfied	Somewhat satisfied	Not satisfied at all
a. Location of program			
b. Materials provided			
c. Support and accommodation provided by the DD Council			
d. Usefulness of information you obtained from the training program			

10. Overall, how satisfied were you with the [NAME OF PROGRAM]? Please explain.

- Very useful
 Somewhat useful
 Not very useful

Those are all the questions we have for you. Do you have any questions you would like to ask us? We'd like to thank you again for taking the time to answer our questions.

C1-5. Recipients of Education and Training to Improve Community Capacity

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION STATE COUNCILS ON DEVELOPMENTAL DISABILITIES

RECIPIENTS OF EDUCATION AND TRAINING TO IMPROVE COMMUNITY CAPACITY

[Interviewer]: Thank you for taking the time to talk with me today. My name is [interviewer's name], and I work for Westat, a private research company in Rockville, MD.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. The DD Council that contacted you to participate in this evaluation is one of 20 DD Councils in 19 states and one territory that has been randomly selected to participate in the evaluation. As someone who participated in a DD Council-supported program to build community capacity, you are an important source of information. We have some questions we would like to ask you about your experiences with the DD Council program you attended and the ways in which you used or hope to use the information you obtained. The interview should last approximately ½ hour – 45 minutes.

Before we begin, I would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. This recording is for Westat's use only. It will not be made available to anyone else. Do we have your permission to record?

Do you have any questions before we start?

Background Information

Let's start with some information about you.

1. Prior to participating in the DD Council-supported program, what kinds of experiences or background did you have with people with developmental disabilities? Please describe.
Probe:
 - Personal disability
 - Family member with a disability
 - Worked with people with disabilities
 - Other
2. How did you first learn about the DD Council?
3. How did you learn about the program?

Council-Supported Education and Training Program

4. Please describe the program you participated in.

- a. What was the name?
- b. When did you attend?
- c. Where was it held?
- d. What type of format was used (e.g., discussion group, lecture, other)?
- e. What did the presenter talk about?

Probe:

- Legislation (e.g., Americans with Disabilities Act, Workforce Investment Act)
- Services and resources available to people with developmental disabilities
- Gaps in supports and services
- Accommodations
- Ways to obtain accommodations
- Other _____

5. Were accommodations made available for you or others who might have needed them? Please describe.

Probe:

- Use of accessible locations
- Training materials
- Distance learning
- Facilitation in obtaining assistive technology for participants
- Other _____

6. What was done to make sure these education activities were culturally competent and appropriate for you?

- Please describe the process.
- Please describe the materials that were used.

Probe:

- Format
- Language
- Readable for people with minimum English-language skills
- Language geared to your background and training
- Other

[Obtain 3 examples.]

Results of Council-Supported Training Program

Now let’s talk about what you learned, your overall impressions of the training program, and your experiences in using what you learned to help people with developmental disabilities and their families.

7. What were the most important things you learned from this program?

Probe:

- Legislative requirements
- Services and resources available to people with developmental disabilities
- Gaps in supports and services
- Accommodations
- Ways to obtain accommodations
- Other

8. How did this program help you to become familiar with issues affecting people with developmental disabilities? Please describe.

9. Have you had the opportunity to use what you learned from the training program ? If yes, please describe your experiences. If no, please explain the reasons.

Probe:

- Transferred the knowledge and skills they obtained to their work
- Improved their effectiveness in providing services or supports to people with developmental disabilities
- Improved the effectiveness of the community in including people with developmental disabilities in all aspects of life (e.g., improved the accessibility of the workplace; obtained assistive technology for an employee)
- Served more people with developmental disabilities
- Other _____

10. What did you think of the training program you attended? How satisfied were you with ...? Please explain.

	Very satisfied	Somewhat satisfied	Not satisfied at all
a. Accessibility of setting/location?			
b. Accommodations that were provided?			
c. Type of information covered?			
d. Usefulness of training materials?			
e. Clarity of training materials?			
f. Appropriateness of training materials?			
g. Relevancy of the training materials?			
h. The program overall?			

Is there anything else you would like to tell us about the training program you participated in? Do you have any questions before we end this discussion?

We’d like to thank you again for taking the time to answer our questions.

Appendix C2. Questionnaires for the Protection and Advocacy (P&A) System

- C2-1. Executive Director (and Legal Director/Management Staff, at Executive Director's discretion) [in-person, individual interview(s)]**
- C2-2. P&A staff [in-person, individual interviews]**
- C2-3. Board of Directors (Commissioners) – Chair and Members [telephone, individual interviews]**
- C2-4. Policy makers and Collaborators [in-person, group interview]**
- C2-5. Recipients of Community Education [telephone, individual interviews]**
- C2-6. P&A Clients [in-person, individual interviews]**

C2-1. Executive Director Interview (With Selected Staff, as Appropriate)

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION PROTECTION AND ADVOCACY (P&A) SYSTEM

EXECUTIVE DIRECTOR INTERVIEW (WITH SELECTED STAFF, AS APPROPRIATE)

[Interviewer]: Thank you for taking the time to meet with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Rockville, MD.

As we've already discussed, the Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This evaluation is intended to provide feedback to the ADD to help improve the effectiveness of its programs and policies, to serve as a decision-making tool for ADD, and to promote accountability to the public.

Your program is one of 20 P&A programs in 19 states and one territory that have been randomly selected to participate in the evaluation. The evaluation will consist of interviews with key stakeholders (e.g., Executive Directors, P&A staff, P&A Board of Directors members, policymakers and P&A collaborators, recipients of P&A public education, and P&A clients). We will also be conducting the evaluation at UCEDDs and State Councils on Developmental Disabilities. We will summarize the information provided by interviewees (yourself included) in all programs to help us to examine the impact of the P&A system at the national level.

As the P&A executive director, you are an important source of information regarding the operations and achievements of this program. We have some specific questions to ask you about the different key functions of your P&A. The interview should last approximately 3-4 hours.

Before we start, we would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. The recording will be used by Westat only; it will not be provided to ADD or anyone else.

Do you have any questions before we start?

PART A. PLANNING AND PRIORITY SETTING

We would like to begin by discussing the planning and priority setting process at your P&A and your Statement of Goals and Priorities (SGP). Specifically, we would like to talk about how you obtain input, the different kinds of input you use to develop the SGP, and how you use the SGP.

Process for Developing Goals and Priorities

Let's start with the process your P&A uses for developing the SGP each year, thinking about what happened during the last planning cycle.

1. What methods did you use to obtain input on gaps in and barriers to supports and services? Please describe.

Probe:

- Public meetings
- Focus groups
- Surveys
- Analysis of telephone calls to the P&A
- Input from staff
- Input from the P&A Advisory Council
- Other _____

2. Whom did you contact to participate in providing input?

Groups/individuals	Contacted (✓)	Provided input (✓)
People with developmental disabilities		
Family members		
Advocates		
Service providers		
Policy makers		
P&A Advisory Council		
DD Council		
UCEDD(s)		
Other, please specify		

3. What groups/organizations/individuals provided your P&A with input for the last planning cycle?

4. What did you do to accommodate people with developmental disabilities so they were able to participate in the planning and priority setting process? Please describe.

Probe:

- Methods of contact
- Materials used
- Accessibility at meetings
- Assistance with materials
- Other, please specify _____

5. How did you make sure you provided opportunities to participate to those who never participated before in the process? For example, please describe input sought from:

- People from both urban and rural communities;
- People throughout all parts of the state;
- People from ethnic/minority groups in your state;
- People who have difficulty understanding English;
- Others, please specify _____

6. What do you do to provide accommodation to those who need it in order to participate? Please give examples.

7. What type of existing data or reports did you use to identify the needs and interests of people with developmental disabilities? Please give examples.

Probe:

- Census data
- Findings from UCEDD reports [Obtain copy or references.]
- Findings from published literature [Obtain references.]
- Findings from DD Council Comprehensive Review and Analysis of the State Plan
_____ [Obtain copy.]
- Findings from DD Council-supported demonstration projects [Obtain copy.]
- State agency reports [Obtain copy.]
- Other _____ [Obtain copy or references.]

8. In the last planning cycle, how did you use feedback about current activities to inform the planning and priority setting process? Please describe.

- a. What kind of information did you collect about current activities (e.g., information on recipients' satisfaction with P&A supported programs)?
- b. How did you collect it?
- c. From whom (e.g., staff and contractor feedback)?
- d. How did you use it? Give examples.

Results of Planning Process

9. What is the process you use to move from stakeholder input to statements of goals and priorities in your SGP? Please describe.
- a. What do you do?
 - b. Who is involved?
Probe:
 - Staff
 - Members of the board of directors (commissioners)
 - State officials
 - People with developmental disabilities
 - Family members
 - Representatives from other DD Network programs
 - Other _____
 - c. How do you make sure the end result is consistent with both stakeholder input and existing data regarding the needs of people with developmental disabilities? Please explain.
 - d. How do you make sure the end result is truly reflective of the findings from the planning process? Please describe.

I see the goals and priorities for this year are _____ **(Refer to SGP).**

10. How do these relate to the feedback you received from stakeholders? Please give examples.

Use of SGP to Shape P&A Activities

We've been told that the SGP is used to shape the activities of the P&A for the year.

11. How does your P&A use the SGP? Please describe.
Probe:
- To determine which individual advocacy cases to take
 - To determine which systemic advocacy activities to support or sponsor
 - To determine which community outreach activities to support or sponsor
 - To determine which community education activities to support or sponsor
 - Other

12. How do P&A forms and materials reflect the goals and priorities in the SGP? Please give examples.

Probe:

- Intake form
- Intake training materials
- Board of Directors/Commission orientation materials
- Outreach materials made publicly available
- Website
- Other _____

13. How did your P&A deal with emerging and/or emergency issues that arose in the past year? Please give examples.

14. What was the rationale for taking on these emerging or emergency issues not covered in the SGP? Please explain.

PART B. INTAKE AND ASSISTANCE

The next section of our interview has to do with the intake process and decisions made about the best way to meet the needs of people who contact the P&A. Questions in this section involve procedures of your intake process and how you make sure they are being followed, the P&A's ability to meet the needs of people who contact the P&A, and client satisfaction. Let's start with the intake process.

Procedures of the Intake Process

15. Please describe the procedures that regulate the intake process at your P&A. Are the procedures written?

[Obtain copies of procedures and intake form.]

Probe:

- Requirements on the collection of basic intake information
- Criteria for determining the amount of information to collect on each type of caller (e.g., those for whom a file is opened; those who require information and/or referral only)
- Maximum response times
- Circumstances under which a person is referred to a P&A lawyer/advocate to receive individual advocacy
- Other _____

16. Do P&A staff members receive training on P&A intake procedures? Please describe.
Probe:
- Arranged training on the intake procedures for all new intake staff
 - Included people with developmental disabilities and family members in training
 - Included training on cultural competency²⁶
 - Arranged for existing intake staff to receive review training periodically
 - Other _____
17. How does P&A management monitor the extent to which intake staff appropriately follows the intake procedures?
Probe:
- Nature of monitoring process (e.g., data review; performance review)
 - Frequency of monitoring
 - Other
18. How well do intake staff members adhere to the P&A policy and/or procedures? Please explain.
Probe:
- Completion of forms
 - Maximum response times to requests for information
 - Statistics kept

Satisfaction of P&A Clients

We understand that some P&As collect information on satisfaction of their clients, so we'd like to understand what this P&A does with regard to assessing the satisfaction of those who are served by the P&A.

19. How do you measure client satisfaction? Please describe.
- a. How does the P&A collect satisfaction data?
Probe:
- Survey (mail out or telephone)
 - Form given to every client who exits? Given randomly?
 - Unsolicited letters
 - Other _____
- b. What kind of satisfaction is ascertained (i.e., satisfaction with what)?
[Obtain forms, questionnaires, or other documentation.]
-

²⁶ According to the DD Act, cultural competency means “services, supports, or other assistance are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance. These services, supports, or other assistance are conducted or provided in a manner that has the greatest likelihood of ensuring the maximum participation of people with developmental disabilities and their families in the program involved” [sec. 102(7) of the DD Act].

20. How and when do you inform callers and clients about the grievance procedure?

Probe:

- Provision of information on the grievance process to those who are denied P&A services beyond information and referral.
- Provision of information on the grievance process to those who are taken on as clients.

PART C. INDIVIDUAL ADVOCACY

We would like to turn now to the topic of individual advocacy. Let's start by talking about client objectives and needs, how they are determined and monitored, and the extent to which they are achieved.

Client Objectives and Needs

21. What are some of the things P&A staff, attorneys, advocates, or contractors did in the past year to adhere to clients' preferred mode of communication? Please give examples.

Probe:

- Used interpreters (including sign language interpreters)
- Provided personal assistance for those with a cognitive disability
- Communicated in person
- Communicated both in person and in writing
- Spoke/wrote in a language other than English
- Used large print
- Other _____

P&A representatives need to make sure their clients understand the issues that need to be resolved and what the P&A is going to do to resolve them.

22. In the past year, how did the P&A make sure the client understood the process and results throughout the representation process? Please give examples.

23. What does the P&A do to make sure it is meeting the objectives of its clients?

a. Does the P&A use a client representation agreement to identify and document client objectives? Please describe. Does the agreement follow a written, standard format? Please describe.

Probe:

- Lists issues P&A will address for the client
- Lists client's objectives
- Describes process by which P&A will attempt to meet client's objectives
- Provides an estimated timeframe
- Other

[Obtain 3 examples.]

b. Is a closing letter included in clients' file to document the processes and outcomes of the assistance clients received? Please describe.

Probe:

- Under what circumstances is a closing letter prepared?
- What information is included?
 1. documented objectives
 2. agreements made by P&A
 3. what the P&A did
 4. estimated timeframe

[Obtain 3 examples.]

c. In the past year, did staff members discuss cases and issues during staff meetings? Please describe.

Probe:

- Frequency of discussions
- Format (formal or informal)
- Other _____

Confidentiality

24. How does the P&A maintain the confidentiality of individual advocacy clients? Please describe.

Probe:

- Use of private offices or rooms
 - Password protection of electronic files
 - Secure storage of files that contain personal/confidential information
 - Other _____
- a. a. How does the P&A ensure that staff members are adequately familiar with confidentiality policies and procedures? Please describe.
- b. b. How does the P&A ensure that staff members are complying with confidentiality policies and procedures? Please describe.

PART D. SYSTEMATIC ADVOCACY

The next section of the interview has to do with systemic advocacy. Questions in this section will address systemic advocacy strategies, collaboration to meet systemic advocacy goals, and the outcomes of P&A systemic advocacy efforts. Let's start by talking about systemic advocacy strategies used by the P&A.

Systemic Advocacy Strategies

25. First, please give us 3 examples of a systemic advocacy project or activity you took part in over the past year.

[Use table. Interviewer: Work through one project or activity at a time.]

- a. Please explain what the systemic advocacy issue was.
- b. Please describe the type of projects or activities (strategies) that were involved.
- c. Who were the collaborators on each issue?
- d. What did each collaborator contribute?
- e. What role did the P&A play (i.e., lead role or participant)?

Probe:

- Issue
- Activity
- Collaborators (groups, individuals)
- Contributions of each collaborator
- Whether P&A took a lead or supportive role

Examples of Systemic Advocacy Issues

Ex.	Issue (Q. 25a)	Systemic Advocacy Project/Activity (Q. 25b)	Collaborators (Q. 25c)	Contributions of Collaborators (Q. 25d)	P&A Lead (L) or Participant (P) (Q. 25e)
1.					
2.					
3.					

26. Thinking about your systemic advocacy activities in the past year, what different strategies did your P&A use to meet systemic advocacy goals in addition to ones mentioned as examples? Please describe.

Probe:

- Individual litigation
- Writing position papers
- Obtaining press coverage
- Informing policy makers
- Including people with developmental disabilities/family members in the process
- Providing testimony
- Securing pro bono law firms to assist
- Drafting legislation
- Other _____

27. In supporting the systemic activities of other organizations in the past year, what did the P&A contribute? Please give examples.

Probe:

- Staff time
- Funding
- Location for meetings
- Other _____

Outcomes of Systemic Advocacy Efforts

We would now like to talk about some of the outcomes of P&A systemic advocacy activities.

28. In what ways have systemic advocacy activities facilitated system changes or prevented system changes from occurring over the past 3-5 years; 5-10 years? Please describe.

Probe:

- Supported, enhanced, or prevented changes to legislation or statewide or local public policy
- Supported, enhanced or maintained changes to statewide or local community practice or services
- Other _____

PART E. COMMUNITY OUTREACH AND EDUCATION

This section of the interview is about P&A community outreach²⁷ and community education.²⁸

Community Outreach

We'll start with questions on community outreach first – what your outreach activities look like, the audiences these activities target, and your success in reaching the audiences you intended to reach.

Community outreach consists of efforts made to connect or bring awareness of the P&A and P&A services to organizations, groups, or the general public. One goal of community outreach is to identify typically unserved and underserved populations who might benefit from P&A services and programs.

29. In the past year, how did your P&A reach out to the public or potential clients to increase access to P&A services for traditionally unserved or underserved populations? Please describe.
Probe:

- Use of media
- Use of P&A web site
- Presentations at meetings/conferences
- Distribution of brochures **[Obtain a copy of brochures/announcements used in the past year.]**
- Other _____

30. What audiences did the P&A target last year for outreach?
Probe:

- African-American communities or other minority populations
- Specific ethnic populations
- Native American Indian populations
- People with specific types of disabilities and their families
- Specific communities (e.g., low income, rural)
- Other _____

31. How were these targets selected? Please explain.

²⁷ Community outreach consists of efforts made to connect or bring awareness of the P&A and P&A services to organizations, groups, or the general public. One goal of community outreach is to identify typically unserved and underserved populations who might benefit from P&A services and programs.

²⁸ Community education consists of informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.

32. What does your P&A do to make sure your outreach reaches traditionally unserved or underserved populations or communities?

- Collaborates with other individuals or groups in order to reach unserved and underserved populations (e.g., disability-related organizations/agencies, local tribal leaders, local political or community leaders, etc.)?

Probe:

- Which organizations/individuals?
- What do these organizations/individuals do?
- Other _____

Community Education

Let's move on to your community education activities. We think of community education as informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.

We'll ask you what your community education activities consisted of, the target audiences of these activities, how you determined which organizations or individuals to target for community education, and how you made sure that your community education activities were culturally competent and appropriate to each target audience.

33. Last year, what training and education did you provide or support for people with developmental disabilities and family members? Please give examples.

Probe:

- Provided training and education for people with developmental disabilities and family members to advocate for themselves
- Referred people with developmental disabilities to local or state self-advocacy organizations
- Identified potential participants in training and education for people with developmental disabilities and family members (e.g., Partners in Policymaking)
- Other _____

34. What activities does your P&A provide or support to the community at large to improve access, inclusion, and choice? Please give examples.

Probe:

- Presentations to employers on hiring people with developmental disabilities or reasonable accommodation
- Awareness training to service providers on client or patient rights
- Technical assistance to attorneys on disability-related legislation
- Other _____

35. In the past year, what audiences were addressed?

Probe:

- People with developmental disabilities
- Family members of people with developmental disabilities
- Media
- Policy makers
- Service providers
- Disability-related organizations
- Non-disability related organizations that interact with people with disabilities and their families
- Employers
- Health care providers
- Teachers
- Others _____

- a. What does your P&A do to make sure community education activities are conducted or provided in a culturally competent and appropriate manner? Please give examples.

[Obtain examples of materials.]

36. How do you make sure public education materials are appropriate to the target audience? Please describe.

Now we'd like to ask you some questions on the results of your community education activities.

37. How does the P&A learn about the effectiveness of its community education activities? Please describe.

38. How do recipients of P&A community education use the information provided? Please give examples.

Probe:

- People with developmental disabilities obtain services for themselves.
- Recipients provide accommodations for employees with developmental disabilities.
- Recipients make use of tax incentives for assistive technology for employees.
- Recipients make public buildings more accessible.
- Recipients improve the quality of their interactions with people with developmental disabilities and their families (e.g., classroom instruction and policies, accessibility of their workplace; accessibility of community events).
- Recipients seek and make changes to policies that benefit people with developmental disabilities.
- Recipients increase the number of people with developmental people they serve or hire.
- Other _____

PART F. GOVERNANCE AND MANAGEMENT

Now we would like to talk about how your P&A is governed and managed.

Board of Governors (Commissions)

First, we have questions about your board of directors (commissions) and its role in your P&A. Even if you do not have a board of directors, we are interested in learning about how your P&A is governed and how certain functions are covered without a board.

As we understand it, your P&A does (does not) have a board of directors.

39. Please describe the form of governance under which your P&A operates (e.g., part of a state agency, a non-profit organization, no board of directors/commission).

If no board of directors:

40. Is there another type of group that fills some of the roles of a board of directors (e.g., commissioners)? Please describe.

[Interviewer: if no board of directors or commissioners, go to question 42.]

For P&As that have a board of directors or commissioners:

41. Does the P&A provide any supports to the members of the board of directors (commissioners) to help them fulfill their roles and responsibilities? Please describe.
Probe for:
- Regular reporting to the Board of Directors or Commission
 - Orientation
 - Accommodations for people with developmental disabilities
 - Reimbursement for P&A-related travel when requested
 - Provision of written background materials in advance of meetings
 - Provision of a support person to help with preparation and understanding before and during meetings for those who required it
 - Provided other accommodations
 - Provided an orientation to new Board members on their responsibilities, the DD Act, and other governing Federal requirements
 - Other _____

If no board of directors or commissioners:

42. We recognize that there is no board of directors or commissioners at your P&A. How does your P&A cover some of the functions typically fulfilled by a board of directors or commissioners?

Probe:

- Oversight
- Policy advice
- Business advice
- Understanding of needs of people with developmental disabilities and family members

P&A Infrastructures for Efficiency and Effectiveness

43. How does the P&A make sure it has qualified staff to effectively provide services, including services to typically unserved or underserved populations and communities?

Probe:

- Conducts staff performance review each year
 - Uses experienced staff to assist or mentor less experienced staff
 - Hires people with personal experience with people or communities that are typically unserved or underserved (e.g., racial and ethnic minorities; people whose first language is not English; people with a developmental disability, including a cognitive disability)
 - Other
-

44. How does the P&A facilitate responsiveness to emerging issues and emergency issues that arise suddenly?

a. What structures and procedures do you have in place? Please describe.

b. In the past year, how did the P&A deal with emerging and emergency issues that arose suddenly? Please give examples.

45. In the past year, how did the P&A ensure sound fiscal management? Please describe.

46. What evidence do you have to demonstrate that the P&A is financially sound?

[Obtain results of fiscal audit from the past calendar year.]

P&A Adherence to the Principles and Goals of the DD Act

47. What are some of the things you do to maintain the P&A's independence from the governor and other senior state officials? Please give examples.

Probe:

- No restrictions on P&As ability or authority to litigate;
- P&A is not financially encumbered by office of the Governor or state developmental disabilities service system;
- Other _____

48. To what extent are P&A facilities (in main and satellite offices) physically accessible? Please describe the ways in which P&A facilities are physically accessible.

Probe:

- Ramps at front entrance
- Wide doorways to accommodate wheelchairs
- Proximity to public transportation
- Other _____

49. In what ways is the P&A programmatically accessible? Please give examples.

Probe:

- Provision of technology and translators to communicate with clients
- Forms in Braille as needed
- Use of interpreters (including sign language interpreters) to communicate with clients
- Bilingual staff/volunteers
- Other _____

PART G. COLLABORATION

According to the DD Act, DD Network programs are required to report the extent to which they collaborate with one another. We've talked a little bit about collaboration as part of your systemic advocacy activities. Now we would like to focus on your collaborative efforts with the DD Network programs, as well as collaboration on other types of activities besides systemic advocacy.

For this evaluation, we define collaboration as a well-defined relationship entered into by two or more individuals, groups, and/or organizations to achieve common goals of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (the DD Act).

Let's start first with how the DD Network programs identify issues and common goals on which to collaborate.

50. What process do the programs use for identifying, planning, and implementing collaborative efforts? Please describe.

Probe:

- Nature of process
- Participants
- Meeting frequency
- Formal vs. informal
- Other _____

51. What are the issues and goals on which the DD Network programs are currently collaborating? Please describe.

[See following table.]

[Obtain written goals/objectives.]

- a. What project or issues are you collaborating on with DD Network programs? Would you please explain each issue?
- b. What are the goals you and your collaborators were trying to achieve?

52. Which organizations or groups (including other DD Network programs) are you collaborating with on these issues?

53. What is the role of each collaborator, including the P&A and other DD Network programs?

54. How would you characterize the type of leadership for each project?

Probe:

- Single
- Joint
- Other _____

Resources for Collaboration

55. Collaboration suggests shared resources being available and used. What resources did each group or organization contribute? Please describe.

Probe:

- Funding
- Staff time
- Meeting place
- In kind contributions
- Other _____

Collaborations

No.	Project/Issue (Q. 51a)	Goals/Objectives (Q. 51b)	Collaborators (including P&A) (Q. 52)	Collaborators' role (including role of P&A) (Q. 53)	Leadership (Single/joint) (Q. 54)	Resources Contributed (Q. 55)
1.						
2.						
3.						

[INTERVIEWER: REPEAT QUESTIONS 51 THROUGH 55 FOR TWO MORE EXAMPLES.]

No.	Project/Issue (Q. 51a)	Goals/Objectives (Q. 51b)	Collaborators (including P&A) (Q. 52)	Collaborators' role (including role of P&A) (Q. 53)	Leadership (Single/joint) (Q. 54)	Resources Contributed (Q. 55)
4.						
5.						

Process of Collaboration – Regular Communication

Let's talk about the process of communication by using the same examples.

56. What were some of the ways you achieved regular communication during your collaborative efforts? Please describe.

a. Sharing information and progress on ongoing efforts

Probe:

- Examples
- Frequency
- Recipients
- Other

b. Regular updates to participants in the collaborative effort

Probe:

- Examples
- Frequency
- Recipients
- Other

c. Reports on milestones achieved

Probe:

- Examples
- Frequency
- Recipients
- Other

d. Discussion of issues that arose

Probe:

- Examples
- Frequency
- Participants
- Other

e. Debriefing at the end of a collaborative effort (if appropriate)

Probe:

- Examples
- Frequency
- Recipients
- Other

57. In the past year, were there any issues that arose in the community on which the DD Network programs responded together? Please give examples.
58. What was the joint response of the DD Network programs?
59. What is the process the DD Network programs use to monitor progress and barriers of collaborative efforts? Please describe.
 - a. Please give examples of ways in which the programs monitor and identify barriers.
 - b. For collaborative efforts implemented in the past 2 years, what process was used to identify leadership? What decisions were made on leadership of each effort?
 - c. What barriers have been identified?
 - d. Have goals and objectives been changed as a result of monitoring and identifying barriers? Please give examples.

Results of Collaboration

Finally, let's talk about achieving your goals and objectives -- the results of your collaborative efforts.

60. Were there any products derived from your collaborative efforts? Please give examples and describe?
Probe:

- White papers
- Wording for legislation
- Brochure on joint program
- Program enrollment form
- Other _____

[Obtain examples of products developed in past year, if applicable.]

61. What has been the result of your collaboration with DD Network programs and other organizations? Please give examples from the past 5 years.
Probe:

- Changes to (or maintenance of) State and local systems (e.g., changes or maintenance in practices and legislation)
- System changes (or maintenance) that affected people with developmental disabilities and their families, including people who are traditionally unserved and underserved (e.g., racial or ethnic minorities, people with little or no use of English, or people who live in remote or rural areas or live in poverty)
- Increases in the capacity of the community to provide supports and services to people with developmental disabilities and their families (e.g., accommodations are provided in public services such as transportation, education, and employment)
- Ways participants in DDN collaborative efforts have improved their knowledge or skills in ways that benefit people with developmental disabilities and their families
- Other _____

PART H: DEBRIEFING [AT END OF PROGRAM VISIT]

62. Before we leave, we would like to give you the opportunity to ask any questions you might have, raise any issues you might want to raise, or talk about anything related to your program that you would like to expand upon.
- a. First, do you have any general comments to make?
 - b. Issues?
 - c. Further explanation of your P&A?
63. There are also a few things I want to make sure we don't forget.
- Obtain materials requested, if easily available.
 - Confirm products to be sent. Leave FedEx form.
 - Obtain contact information for additional individuals who need to be contacted.
 - Confirm process for telephone interviews and availability of interviewees.
 - Leave business card.

We'd like to thank you again for taking the time to meet with us these past 2 days. We also appreciate you making your staff available and arranging for us to meet with many of your stakeholders.

C2-2. P&A staff [in-person, individual interviews]

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION PROTECTION AND ADVOCACY (P&A) SYSTEM

INTERVIEW WITH P&A STAFF

[Interviewer]: Thank you for taking the time to meet with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Rockville, MD.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This evaluation is intended to provide feedback to ADD to help improve the effectiveness of its programs and policies, to serve as a decision-making tool for ADD, and promote accountability to the public.

Your program is one of 20 P&A programs in 19 states and one territory that have been randomly selected to participate in the evaluation. As a P&A staff member, you are an important source of information regarding some of the operations of this program. In particular, we would like to ask you some questions on the intake process [individual advocacy, community education] at the P&A. The interview should last approximately ½ hour to 45 minutes.

Before we begin, we would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. The recording is for _____ use only and will not be given to anyone else. Do we have your permission to record?

Do you have any questions before we start?

PART I. P&A STAFF BACKGROUND

We would like to begin this interview by asking you some questions about yourself. Specifically, we would like to know about your formal background and training, and the experiences that have prepared you for your work at the P&A.

Staff Qualifications, Background, Experience

1. First, we'd like to understand what you do at the P&A. Please describe.
 - a. What is your current position?
 - b. What do you do? Please describe.
Probe:
 - Intake
 - Individual advocacy
 - Community education
 - Other _____
 - c. How long have you been working in your current position? At the P&A?
2. Next, please talk about your background and experience.
Probe:
 - Formal education and training
 - Relevant work or volunteer experience
 - Personal experience with a disability
3. Please describe your background with regard to addressing issues and providing services to people from diverse backgrounds.
Probe:
 - Race/ethnicity
 - Languages spoken
 - Personal relationship with disability
 - Previous jobs
 - Volunteer experience
 - Other _____

PART II. INTAKE*

The next section of this interview has to do with the intake process. We will ask questions about the P&A's intake process, training required to facilitate the intake process, and the effectiveness of the intake process in meeting the needs of people who contact the P&A.

Intake Policy and Procedures

4. Does the P&A have written intake procedures? Please describe.
 - a. What is included?
Probe:
 - Requirements on the collection of basic intake information
 - Criteria for determining how much of the intake form must be completed for each client
 - Maximum response times
 - Other requirements _____
 - b. Are you able to meet the requirements that are in the policy and procedures? Please explain.
Probe:
 - Extent to which you meet the requirements
 - Reasons for not meeting the requirements
5. Please describe the process your P&A uses for intake.
 - a. How is intake conducted? Please give examples (e.g., information and referral, further assistance).
 - b. Besides you, how many staff conduct intake? Which staff?
 - c. How do you determine the appropriate needs of the person contacting the P&A?
 - d. How do you handle a caller who speaks little or no English?
 - e. How do you handle a caller who has difficulty explaining to you why s/he is calling?
6. Describe the process and system for keeping track of information on people who contact the P&A. Do you use special forms? Please describe.
Probe:
 - Information collected
 - Circumstances under which data are collected

* Questions pertain only to staff involved in intake

Training

7. Please describe the training you went through in order to be able to conduct intake.
Probe:

- Content of training
- Process
- Duration of training
- Training on cultural competence
- Frequency of training, including supplemental or refresher training

8. When was the last time you received intake training?

Effectiveness of Intake Process

9. How would you describe an effective intake process?

10. Is anything done at the P&A to determine whether the P&A intake process is effective? Please describe.

Probe:

- Monitoring individual performance
- Looking at statistics
- Other _____

PART III. INDIVIDUAL ADVOCACY*

Next we would like to talk about Individual Advocacy.

Examples of cases

11. How do you determine which cases to take on? Please describe the process.

* Questions pertain only to staff involved in individual advocacy activities.

12. Let's take two examples from two cases you handled that closed within the past year. We would like you to walk us through the individual advocacy process with these examples. Please have the case file in front of you as you answer these questions.

[Interviewer: Work through one example at a time.]

[See following table.]

- a. What was the major issue?
- b. What objectives did the client want to achieve?
- c. What did P&A staff do to achieve those objectives?
- d. For how long did the case go on?
- e. What was the outcome?

Let's talk about some of your other cases.

13. How many open cases do you now have?
14. I'd like to go through each of them briefly and ask you to describe them.²⁹ Please tell me about:
- Objectives of each client
 - Steps expected to meet the objectives
 - Status of each case

[Interviewer: Staff member can have case files in front of him/her.]

²⁹ If caseload contains more than 10 open cases, sample. Total number of cases should be 10.

WORKING DRAFT – JANUARY 24, 2008

Individual advocacy cases

Issue (Q. 12a)	Client's Objective (Q. 12b)	Activities to Meet Objectives (Q. 12c)	Dates (From Opening to Closing) (Q. 12d)	Outcome (Q. 12e)

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[INTERVIEWER: REPEAT QUESTION 12 FOR ONE MORE INDIVIDUAL ADVOCACY EXAMPLE.]

Issue (Q. 12a)	Client's Objective (Q. 12b)	Activities to Meet Objectives (Q. 12c)	Dates (From Opening to Closing) (Q. 12d)	Outcome (Q. 12e)

High Quality, Professional Representation

15. What do you do to ensure that you are providing your clients with high quality, professional representation?

a. In the past year, did you meet with other individual advocacy staff to share case experiences? Please describe.

Probe:

- Frequency
- Participants
- Examples of cases that were shared
- Outcome
- Other

b. Are your cases typically reviewed by a more senior legal staff member? Please describe.

Probe:

- Process
- Who reviews
- Frequency
- Outcomes
- Example of most recent review
- Other _____

c. How do you maintain confidentiality for your individual advocacy clients? Please describe.

Probe:

- Policy
- Procedures (use of private offices or rooms, password protection of electronic files, secure storage of files that contain personal/confidential information)
- Penalty for infringement of policy
- Other _____

d. How often do you typically talk to your clients regarding their case to provide them with information on progress? Please explain.

[Ask staff member to walk through one of the case files.]

e. How often do you typically update case files? Please explain.

[Ask staff member to walk through one of the case files.]

Meeting Client Objectives

16. What do you do to facilitate meeting clients' objectives?

a. Do you use a client representation agreement or a similar document so you can keep track of the client's objective(s) determined at intake? Please describe.

Probe:

- Content
 - Issues the P&A will address for the client
 - Client's objectives
 - Description of process by which P&A will attempt to meet the client's objectives
 - Provision of an estimated timeframe for the process
- Circumstances of use
- Format

[Ask staff member to walk through the client representation agreement in two of the case files to identify content.]

b. Please give some examples of ways in which you have accommodated or made arrangements for clients so your legal advice would be accessible and understandable.

Probe:

- Arranged for an interpreter (including a sign language interpreter) for in-person meetings
- Arranged for personal assistance for those with a cognitive disability
- Had written communications translated into Braille
- Talked in person about the closing letter
- Other _____

c. How do you go about making sure that you are using the client's chosen mode of communication? Please give examples.

d. Do you provide a closing letter in client files that describes the process and outcomes of the assistance provided? Please describe.

Probe:

- Content
- Timing
- Circumstances under which closing letter is written
- Accommodation

e. Have you ever been grieved against? Please describe.

Probe:

- Issue
- Resolution
- Management/Board (Commissioners) involvement
- Other _____

PART IV. COMMUNITY EDUCATION*

This next section covers P&A-sponsored community education activities and your role in these activities.

We consider community education to be informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.

Community Education Activities

17. Were you involved in community education activities in the past year?

[See following table.]

- a. Please describe.
- b. How were these activities initiated? Please describe.
- c. Who were the target audiences?
Probe:
 - People with developmental disabilities
 - Family members of people with developmental disabilities
 - Media
 - Policy makers
 - Service providers
 - Disability-related organizations
 - Employers
 - Clinical groups or individuals
 - Others _____
- d. What type of format did you use? What was the setting like? Please describe.
- e. What did you talk about?
Probe:
 - Legal rights of people with developmental disabilities (e.g., under the Americans with Disabilities Act or Workforce Investment Act)
 - Services and resources available
 - Gaps in supports and services
 - Accommodations and ways to obtain them
 - Other _____

* Questions pertain only to staff involved in community education activities.

Community Education Activities

Activity (Q. 17a)	Initiation (Q. 17b)	Target Audience (Q. 17c)	Format/Setting (Q. 17d)	Content (Q. 17e)

[INTERVIEWER: REPEAT QUESTION 17a-e FOR ONE MORE COMMUNITY EDUCATION ACTIVITIES]

Activity (Q. 17a)	Initiation (Q. 17b)	Target Audience (Q. 17c)	Format/Setting (Q. 17d)	Content (Q. 17e)

Use of Information

18. Did you get any sense of how the recipients of the information you provided might be able to use the information? Provide examples.

Probe:

- Will advocate for themselves to obtain needed supports and services
- Will become a client of the P&A
- Will provide accommodations for employees
- Will apply for tax incentives for assistive technology for employees
- Will hire more people with developmental disabilities
- Will institute company hiring policies that ensure there is no discrimination against a person with a developmental disability
- Will interact more often or more effectively with people with developmental disabilities to whom they provide services
- Will contact service providers
- Other _____

19. Do you or the P&A do any followup to find out? Please describe.

That ends all of our questions. Do you have any questions yourself?

Again, we would like to thank you for taking the time to answer our questions.

C2-3. Board of Directors (Commissioners) – Chair and Members [telephone, individual interviews]

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION PROTECTION AND ADVOCACY (P&A) SYSTEM

BOARD OF DIRECTORS (COMMISSIONERS) – CHAIR AND MEMBERS

[Interviewer]: Thank you for taking the time to talk with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Rockville, MD.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This evaluation is intended to provide feedback to the ADD to help improve the effectiveness of its programs and policies, to serve as a decision-making tool for ADD, and to promote accountability to the public.

This P&A program is one of 20 P&A programs in 19 states and one territory that has been randomly selected to participate in the evaluation. As a P&A Board [Commission] member [Chair], you are an important source of information regarding governance of this program. In particular, we have some questions to ask you about the P&A and your role as a board (commission) member. The interview should last approximately ½ hour to 45 minutes.

Before we begin, we would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. The recording is for Westat use only and will not be given to anyone else. Do we have your permission to record?

Do you have any questions before we start?

1. To start the interview off, please tell us how long you have been a member of the P&A board of directors (commission) and how you first became involved.

Composition and Role of Board (Commission)

We would like to understand the composition of the board of directors (commissioners) and what each person contributes.

2. Please tell us about your own relevant background and experience.

Probe:

- Education
- Training
- Experience
- Personal experience with developmental disabilities

3. What other aspects of your background help you in your role as Chair (member) of the P&A board of directors (commission)? Please describe.

Probe:

- Race/ethnicity
- Languages spoken
- Other _____

4. What is it about your own background and experience that you specifically bring to this board (commission)?

Probe:

- Legal expertise
- Business or financial expertise
- Understanding of the needs of people with developmental disabilities
- Understanding of the rights of people with developmental disabilities
- Advocacy
- State systems
- Other _____

5. What do you see as the most important role(s) of the board of directors (commissioners)? Please explain.

Probe:

- Policy approval
- Approval of the Statement of Goals and Priorities (SGP)
- Performance review of the Executive Director
- Oversight to ensure sound fiscal management
- Oversight to ensure efficient and effective management
- Provision of advice (e.g., financial, governance)
- Provision of advice on needs of developmental disabilities community
- Fundraising
- Other _____

The next few questions are about how Board (Commission) members gain the knowledge they need to fulfill their roles and responsibilities.

Board (Commissioners) Members' Familiarity With P&A Mission, SGP, and DD Act

6. How did you as a board (commission) member learn about the P&A and its mission?
- a. Did you attend an orientation provided by the P&A? Please describe.
Probe:
- Content
 - Format
 - Instructor(s)
 - Duration
- b. Did you attend or participate in any P&A activities that might have prepared you?
Please describe.
7. Overall, how familiar do you consider yourself to be with regard to:
- a. The P&A mission? Please explain.
 Very familiar Familiar Not very familiar
- b. Goals and priorities of the P&A? Please explain.
 Very familiar Familiar Not very familiar
- c. Populations/communities of interest to the P&A? Please explain.
 Very familiar Familiar Not very familiar
- d. The DD Act? Please explain.
 Very familiar Familiar Not very familiar

Supports Provided to Board (Commission) Members

8. What kinds of supports do board (commission) members receive so that they can meaningfully participate in meetings and fulfill their responsibilities?
Probe:
- Reimbursements for travel expenses
 - Stipend
 - Receipt of relevant meeting materials in advance
 - Assistance from a support person to aid in preparation and understanding of materials before and during meetings
 - Receipt of other accommodations as required
 - Other _____

Involvement in P&A Activities

For the last part of this interview, we'd like to learn about any P&A activities you have been involved in or provided input for.

9. In the past year, were you involved in any P&A activities? Please describe.

Probe:

- Development of Statement of Goals and Priorities (SGP)
 - Monitoring the budget
 - Developing policies that affect P&A operations
 - Outreach activities
 - Community education activities
 - Other _____
-

That ends all of our questions. Do you have any questions yourself?

Again, we would like to thank you for taking the time to answer our questions.

C2-4. Policy makers and Collaborators [in-person, group interview]

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION PROTECTION AND ADVOCACY (P&A) SYSTEM

GROUP INTERVIEW: POLICY MAKERS AND COLLABORATORS

Introduction: Welcome and thank you for participating in this group discussion. Before we begin, let us briefly introduce ourselves. My name is [first facilitator's name] and this is [second facilitator's name]. We both work for Westat, a private research company in Rockville, MD. Let's go around the room and have each of you give your name and affiliation (if you represent a specific organization).

Let me tell you why you're here. The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This P&A program is one of 20 P&A programs in 19 states and one territory that has been randomly selected to participate in the evaluation. As a collaborator with the P&A on a systemic advocacy issue, you all are important sources of information regarding how the P&A approaches systemic advocacy and the role community organizations and individuals play.

Purpose: The purpose of today's group discussion is to learn about your experiences with the [NAME OF P&A] systemic advocacy activities and your thoughts about the impact of these activities. This discussion will last about 1 ½ to 2 hours.

Logistics: Before we begin, let me explain a few practical things. You have two forms in front of you—an expense reimbursement form, and a consent form. After this meeting, please complete the reimbursement form and mail it to Westat so we can reimburse you to cover your expenses in coming here today.

Consent: The second form is a consent form. Before we begin this session, please read and sign the consent form, which indicates your willingness to participate in our discussion. Please remember that you do not have to answer any questions you don't want to answer, and you may also leave this meeting at any time.

[COLLECT CONSENT FORMS.]

Finally, we would like – with your consent – to record this discussion. This will allow us to focus our full attention on what everyone is saying, and it eases the burden of note-taking. The recording is for Westat use only. We will not be giving it to anyone else. Is there anyone who objects to us recording this discussion? [WAIT TO HEAR IF THERE ARE OBJECTIONS.]

Do you have any questions at this point?

All of you were assembled today because you worked on a particular systemic advocacy issue or had an interest in this issue. The systemic advocacy issue we will be talking about is

1. Would you please tell us how that issue first became important to you or your organization?
2. What initiated your relationship with the P&A and your organization (you) becoming involved in this issue with the P&A?
3. Please describe some of the activities that took place in the past year (3 years, 5 years) related to this issue and your organization's particular involvement.

Probe:

- Research and analysis of background information
- Drafting white papers, reports, other documents
- Drafting policy or legislation
- Attending meetings with policymakers
- Obtaining input from the developmental disabilities community
- Making appearances at legislative and other meetings
- Making presentations
- Receiving input on the issue
- Responding to input
- Other _____

4. Where did the P&A fit in?

- a. What did it do?

Probe:

- Researched and analyzed background information
- Drafted white papers, reports, other documents
- Attended meetings with policymakers
- Obtained input from the developmental disabilities community
- Made appearances at legislative and other meetings
- Made presentations
- Other _____

- b. Was its main role to lead the activities or participate in them?

5. What were some of the outcomes of these activities? Provide examples.

Probe for:

- Barriers to services eliminated
- New barriers to services prevented
- New laws/policies/procedures/practices established
- Existing laws/policies/procedures/practices enforced or implemented
- Corrections made by agencies, providers, or facilities
- Complaints of abuse, neglect, or discrimination remedied
- Services to traditionally unserved or underserved populations increased
- Knowledge and skills among DD Network program participants increased

6. Based on your experiences with these systemic advocacy activities, what role you think the P&A played in ...

- a. Building and maintaining a collaborative relationship with your organization to achieve common goals and objectives? Please explain.
- b. Helping you to understand issues affecting people with developmental disabilities and their families? Please explain.
- c. Meeting the goals and objectives of this issue? Please explain.
- d. Other _____

Those are all the questions we have for you today. Do you have any questions before we end this discussion?

We'd like to thank you again for taking the time to answer our questions. Please don't forget to take your expense form and return envelope so you will be reimbursed for your expenses in coming here today.

C2-5. Recipients of Community Education [telephone, individual interviews]

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION PROTECTION AND ADVOCACY (P&A) SYSTEM

RECIPIENTS OF COMMUNITY EDUCATION

[Interviewer]: Thank you for taking the time to talk with me today. My name is [interviewer's name], and I work for Westat, a private research company in Rockville, MD.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. The P&A program that contacted you to participate in this evaluation is one of 20 P&A programs in 19 states and one territory that has been randomly selected to participate in the evaluation. As someone who participated in a P&A community education program, you are an important source of information. We consider community education to consist of informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.

We have some questions we would like to ask you about your experiences with P&A community education program you attended and the ways in which you used or hope to use the information you obtained. The interview should last approximately ½ hour – 45 minutes.

Before we begin, I would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. This recording is for Westat use only. It will not be made available to anyone else. Do we have your permission to record?

Do you have any questions before we start?

Let's start with some information about you.

1. Prior to participating in a P&A community education program, what kinds of experiences or background did you have with people with developmental disabilities? Please describe.

Probe:

- Personal disability
- Family member with a disability
- Worked with people with disabilities
- Other _____

2. How did you first learn about the P&A?

3. How did you first come across the P&A community education program?

4. Please describe the community education program you participated in.
- a. What was the topic (i.e., What did the presenter talk about)?
Probe:
 - Legislation (e.g., Americans with Disabilities Act, Workforce Investment Act)
 - Services and resources available to people with developmental disabilities
 - Gaps in supports and services
 - Accommodations and ways to obtain them
 - Other _____
 - b. Where was it held?
 - c. What type of format was used (e.g., discussion group, lecture, other)?
 - d. Were accommodations made available for you or others who might have needed them?
Please describe.
5. Have you had the opportunity to use what you learned? Please describe.
- a. How have you used this information?
Probe:
 - Advocated for oneself to obtain needed supports and services
 - Became a client of the P&A
 - Provided accommodations for employees with a disability
 - Applied for tax incentives for assistive technology for employees
 - Instituted company hiring policies so discrimination against a person with a developmental disability would not take place
 - Interacted more often or more effectively with people with developmental disabilities to whom they provide services
 - Contacted a service provider on behalf of a person with a developmental disability
 - Other _____
 - b. How do you think you might use this information in the future?
Probe:
 - Will advocate for needed supports and services
 - Will contact the P&A again
 - Will provide accommodations for employees with a disability
 - Will apply for tax incentives for assistive technology for employees
 - Will institute company hiring policies so discrimination against a person with a developmental disability will not take place
 - Will interact more often or more effectively with people with developmental disabilities to whom they provide services
 - Will contact a service provider
 - Other _____

6. Did the information you received meet your expectations? Please explain.
- What were your expectations?
 - Were they met?
 - What could have been done to better meet your expectations?
7. Were you asked to provide feedback on the education and training you received? Please describe.
Probe:
- Satisfaction survey to complete on same day
 - Satisfaction survey sent to work/home
 - Followup telephone survey
 - Other _____
8. Overall, how useful was the information you received from [NAME OF P&A]? Please explain.
- Very useful Somewhat useful Not very useful
9. How likely would you be to recommend the P&A to someone you know for educational programs or other services? Please explain.
- Very likely Somewhat likely Not very likely

Those are all the questions we have for you today. Do you have any questions before we end this interview?

We'd like to thank you again for taking the time to answer our questions.

C2-6. P&A Clients [in-person, individual interviews]

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION PROTECTION AND ADVOCACY (P&A) SYSTEM

P&A CLIENTS

[Interviewer]: Thank you for taking the time to talk with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Maryland.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This P&A program is one of 20 P&A programs in 19 states and one territory that has been randomly selected to participate in the evaluation.

As a P&A client, you are an important source of information regarding this P&A program. We would like to learn about your experiences with the P&A, what P&A staff did to help you, and what happened as a result. We would also like to know about your satisfaction with your experience with the P&A.

Before we begin, I would like to read this consent form to you or ask you to read it yourself.

READ CONSENT FORM OR ALLOW TIME FOR CLIENT TO READ THE CONSENT FORM. ANSWER ANY QUESTIONS THE CLIENT MAY HAVE. OBTAIN SIGNATURE ON CONSENT FORM.

Now that we're ready to begin, we would like to ask your permission to record the interview so that we do not miss any of your responses to our questions. The recording is for Westat's use only and will not be provided to anyone else.

Do you have any questions before we start?

1. How did you hear about the [NAME OF P&A]?

Probe:

- P&A outreach materials
- Word-of-mouth
- Internet
- Telephone book
- Another disability-related organization
- Case manager
- Other _____

2. Why did you contact the [NAME OF P&A]? What were the issues you needed help with? Please describe.
3. Who was it that helped you at the [NAME OF P&A]? What was their job?
4. What were your expectations?
5. What did they do? Please describe.
 - a. Did they meet with you to talk about your issue(s)?
 - b. Did they describe the type of help they would give you?
 - c. What did they tell you they were going to do to resolve your issue(s)? Please describe.
 - d. Did they tell you what was happening every so often – keep you posted on progress?
 - e. What did they tell you about what you could do if you did not like something about how your issue was being handled (i.e., the [NAME OF P&A] grievance procedures)?
6. Where did the lawyer/advocate meet with you?
 - a. Did you feel like the meeting place was private? Please describe.
 - b. How easy or difficult was it for you to you meet at the location?
7. What kind of accommodations did the P&A make for you?

Probe:

 - Communicated in your preferred mode of communication and language
 - Used an interpreter, if needed
 - Translated letters and other important documents, if needed
 - Read documents to you, if needed
 - Asked your permission to leave confidential messages with others
 - Other _____
8. What happened? Please describe.
 - a. Were you able to take action based on the advice you received from the [NAME OF P&A]?
 - b. What did you do?
 - c. Was your problem solved? Please explain.
 - d. What did you learn about your legal rights after working with the [NAME OF P&A]?
 - e. Did you improve your understanding of your legal rights after working with the [NAME OF P&A]?
 - f. Do you feel like you now would be able to deal with a similar issue by yourself?

9. What did you think of the help you received from the [NAME OF P&A]?

a. What did you like?

Probe:

- Ability to talk with lawyer/advocate
- Ability to understand what was happening
- Frequency with which lawyer/advocate let you know about the progress of your issue
- Other _____

b. What did you not like?

Probe:

- Inability to talk with lawyer/advocate when you wanted
- Inability to understand what was happening
- Frequency in which lawyer/advocate let you know about the progress of your issue
- Other _____

c. How likely would you be to return to the [NAME OF P&A] if you had another issue that needed to be resolved? Please explain.

Very likely Somewhat likely Not very likely

d. How likely would you be to recommend the [NAME OF P&A] to someone you know with a similar problem? Please explain.

Very likely Somewhat likely Not very likely

Those are all the questions we have for you today. Do you have any questions before we end this discussion?

We'd like to thank you again for taking the time to answer our questions. Here is an expense form and return envelope for you to fill out so we can pay you for your expenses to come here today.

**Appendix C3. University Centers for Excellence in
Developmental Disabilities Education, Research, and Service**

- C3-1. Executive Director (and Staff)**
- C3-2. Consumer Advisory Committee (Chair and Members)**
- C3-3. Peer Researchers and Colleagues**
- C3-4. Recipients of Community Services**
- C3-5. Current and Graduated Students**

C3-1. Executive Director (and Staff)

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES (UCEDDS)

EXECUTIVE DIRECTOR INTERVIEW

[Interviewer]: Thank you for taking the time to meet with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Rockville, MD.

As we've already discussed, the Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. This evaluation is intended to provide feedback to the ADD to help improve the effectiveness of its programs and policies, to serve as a decision-making tool for ADD, and to promote accountability to the public.

Your program is one of 20 UCEDDs in 19 states and one territory that have been randomly selected to participate in the evaluation. The evaluation will consist of interviews with key stakeholders (e.g., Executive Directors and staff, Consumer Advisory Committee members, recipients of UCEDD community services, former and current students, and UCEED peers (e.g., researchers and administrators). We will also be conducting the evaluation at DD Councils and P&As. We will summarize the information provided by interviewees (yourself included) in all programs to help us to examine the impact of DD Councils at the national level.

As the UCEDD executive director, you are an important source of information regarding the operations and achievements of this program. We have some specific questions to ask you about the different key functions of your UCEDD. The interview should last approximately 3-4 hours.

Before we start, we would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. The recording will be used by Westat only; it will not be provided to ADD or anyone else.

Do you have any questions before we start?

PART A. 5-YEAR PLANNING

As you know, those applying for or renewing a core center grant must provide a 5-year plan to ADD. This section contains questions on the process for developing the goals and objectives in the plan, the plan itself, and how the plan is used.

Process for Developing Goals and Priorities

Let's start with the process your center uses for developing the 5-year plan, thinking about what happened during the last planning cycle.

1. What methods did you use to obtain input on the needs and priorities of people with developmental disabilities and their families? Please describe.

Probe:

- Public meetings
- Focus groups
- Surveys
- Analysis of telephone calls to the UCEDD
- Input from staff and grantees
- Other _____

2. Whom did you contact to participate in providing input?

Groups/individuals	Contacted (✓)	Provided input (✓)
People with developmental disabilities		
Family members		
Advocates		
Service providers		
Policy makers		
P&A		
P&A Board of Directors/Advisory Council		
DD Councils		
UCEDD Consumer Advisory Committee (CAC)		
Other, please specify		

3. What groups/organizations/individuals provided your center with input for the last planning cycle?

4. What did you do to accommodate people with developmental disabilities so they were able to participate in the planning and priority setting process? Please describe.

Probe:

- Methods of contact
- Materials used
- Accessibility at meetings
- Assistance with materials
- Other, please specify _____

5. How did you make sure you provided opportunities to participate to those who had never participated before in the process? For example, please describe how you sought input from:

Probe:

- People from both urban and rural communities;
- People throughout all parts of the state;
- People from ethnic/minority groups in your state;
- People who have difficulty understanding English;
- Others, please specify _____

6. What did you do to provide accommodation to those who needed it in order to participate? Please give examples.

7. What type of existing data or reports did you use to identify the needs and interests of people with developmental disabilities? Please give examples.

Probe:

- Census data
- Findings from UCEDD reports [Obtain copy or references.]
- Findings from published literature [Obtain references.]
- Findings from P&A reports [Obtain copy.]
- Findings from DD Council Comprehensive Review and Analysis of the State Plan [Obtain copy.]
- Findings from DD Council-supported demonstration projects [Obtain copy.]
- State agency reports [Obtain copy.]
- Other _____ [Obtain copy or references.]

8. In the last planning cycle, how did you use feedback about current activities to inform the planning and priority setting process? Please describe.

- a. What kind of information did you collect about current activities (e.g., information on recipients' satisfaction with UCEDD-supported programs)?
- b. How did you collect it?
- c. From whom (e.g., staff and grantee feedback)?
- d. How did you use it? Give examples.

Results of Planning Process

9. What was the process you used to move from stakeholder input to statements of goals and priorities in your 5-year plan? Please describe.
- a. What did you do?
 - b. Who was involved?
Probe:
 - Staff
 - DD Council members
 - State officials
 - People with developmental disabilities
 - Family members
 - Representatives from other DD Network programs
 - Other _____
 - c. How did you make sure the end result is consistent with both stakeholder input and existing data regarding the needs and priorities of people with developmental disabilities? Please explain.
 - d. How did you make sure the end result is truly reflective of the findings from the planning process? Please describe.

I see the goals and objectives in the 5-year plan are _____ **(Refer to 5-year plan)**.

10. How do these relate to the feedback you received from stakeholders? Please give examples.

Use of 5-Year Plan to Shape UCEDD Activities

Now let's talk about the relationship between the 5-year plan and UCEDD activities.

- 11. How does your UCEDD use the 5-year plan? Please describe.
- 12. How did your UCEDD deal with new and emerging issues that arose in the past year? Please give examples.
- 13. What was the rationale for taking on these new and emerging issues not covered in the 5-year plan or amendments to the plan? Please explain.

PART B. INTERDISCIPLINARY PRE-SERVICE PREPARATION AND CONTINUING EDUCATION

For this part of the interview, we'd like to talk about the aspects of your program that make it disciplinary, faculty and staff considered to be "UCEDD faculty," the UCEDD's influence throughout the university, and the outcomes achieved as a result of the interdisciplinary pre-service preparation and continuing education program.

Interdisciplinary Aspects of Program

First, we want to ask you about the interdisciplinary nature of the pre-service program. We define "interdisciplinary" as "interaction among multiple disciplines on a common problem."

14. How does the UCEDD promote interdisciplinary education within the interdisciplinary pre-service program?
- a. Please provide some examples of UCEDD-sponsored curricula and syllabi that incorporate the perspectives and interactions among a variety of disciplines.

[Obtain 3 examples of curricula or syllabi.]

- b. What makes these interdisciplinary?
Probe:
- Examines/considers perspective of a variety of disciplines
 - Uses instructors from a variety of disciplines
 - Development of program was based on input from experts in a variety of disciplines
 - Other _____
15. How would you characterize the students the UCEDD faculty and staff teach or prepare disability content for?
Probe:
- Pre-service interdisciplinary students – usually graduate students or students pursuing a professional degree – who already have shown an inclination toward participating in a disability-related field
 - Students from a variety of departments who participate in disability studies
 - Students throughout the university who may never have thought about disability as an interest or career but have been exposed to disability content in one of their classes or courses
 - Continuing education students who may already be practicing in a disability-related field and take a UCEDD-sponsored course that allows them to upgrade their knowledge and skills
 - Other _____

16. In the past year, in what ways did people with developmental disabilities and family members contribute to interdisciplinary pre-service preparation and continuing education programs. Please describe.

Probe:

- Contributed to development of UCEDD curricula and syllabi
- Contributed to classroom instruction
- Were actively recruited for positions in the UCEDD
- Other _____

UCEDD Faculty and Staff

Now we'd like to talk about UCEDD faculty and teaching staff – the extent to which they are knowledgeable and up-to-date in their field, skilled in teaching, and student-focused.

We define faculty UCEDD faculty and teaching staff as individuals with a university or faculty appointment (tenure, non-tenure or adjunct) and who have a designated official role with the UCEDD (e.g., at least some proportion of their salary is funded under the UCEDD's budget or a UCEDD grant or contract; works for a university academic department and is released from some of their departmental academic responsibilities in order to work with the UCEDD; is funded by the university fully or partially to be a UCEDD faculty member; works for an academic department but does some work for the UCEDD in addition to their departmental academic responsibilities).

17. To what extent did the courses taught or developed by UCEDD faculty and staff over the past year cover current practices and issues relating to developmental disabilities and contain up-to-date content? Please describe.
- a. Please describe the practices and/or issues covered in 3 courses taught over the past year.
 - b. Please describe the content of 3 courses taught over the past year that would demonstrate that the courses contain up-to-date content.

[Obtain 3 examples of course syllabi developed by UCEDD faculty and staff and used in the past year that cover current practices and issues.]

[Obtain 3 examples of course syllabi used in the past year that contain up-to-date content (e.g., required readings).]

18. What type of assessment of faculty and teaching staff effectiveness was conducted in the past year at this UCEDD? Please describe.

19. What do UCEDD faculty and teaching staff do to assist students in meeting their disability-related career goals?

Probe:

- Established process for providing career assistance to students (e.g., mentoring program; method for sharing job opportunities with students)
- UCEDD faculty and teaching staff identified employment opportunities for students
- Other _____

Influence of UCEDD Throughout the University

Now we'd like to understand the influence the UCEDD has throughout the university.

20. In the past year, did the UCEDD sponsor, co-sponsor or participate in disability-related seminars, presentation, or other disability-related activities within the university? Please describe.

Probe:

- Nature of activities
- Target audience

21. In the past year, did the UCEDD assist in incorporating disability content into university courses and curricula? Please describe.

Probe:

- Nature of course(s)
- Department(s)
- Approximate number of students taking course(s)

[Obtain 3 examples of syllabi of courses conducted in the past year that incorporate disability content.]

22. In the past year, did UCEDD faculty and staff provide their disability-related expertise to the university? Please describe.

Probe:

- Served on university committees and task forces
- Were consulted for their expertise by university administrators or faculty and staff in departments throughout the university
- Chaired or was a member of a Ph.D. committee
- Other _____

Outcomes Achieved as a Result of the Interdisciplinary Pre-Service Preparation and Continuing Education

23. In the past year, how did the UCEDD prepare students to work with and for typically unserved and/or underserved populations or communities?³⁰ Please give examples.

Probe:

- Provided clinic experiences with specific populations
- Provided community services with specific populations
- Taught students about cultural competency³¹
- Other _____

24. In what ways do UCEDD courses demonstrate cultural competency? Please give examples.

Probe:

- Materials [Obtain 3 examples.]
- Accessible locations
- Other _____

25. How did interdisciplinary pre-service students who completed their course of study use what they learned from their experience with the UCEDD? Please give examples.

- a. How does the UCEDD follow up students to obtain information on how they have benefited from their UCEDD program?
- b. To what extent do former students work in positions that benefit people with developmental disabilities?
- c. How did the UCEDD interdisciplinary pre-service program have an effect on the way in which former students work?

Probe:

- Use of interdisciplinary perspective in their work
- Provision of family-centered supports and/or services (if relevant)
- Use of evidence-based approaches to care
- Other _____

³⁰ “The term ‘unserved and underserved’ includes populations such as individuals from racial and ethnic minority backgrounds, disadvantaged individuals, individuals with limited English proficiency, individuals from underserved geographic areas (rural or urban), and specific groups of individuals within the population of individuals with developmental disabilities, including individuals who require assistive technology in order to participate in and contribute to community life” [Section 102(32) of the DD Act].

³¹ The term “culturally competent” means services, supports, or to other assistance that is conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals who are receiving the services, supports, or other assistance, and in a manner that has the greatest likelihood of ensuring their maximum participation in the program involved [Sec. 102(7) of the DD Act].

26. How did students who participated in a disability studies program use what they learned?
Probe:

- Acceptance into disability-related graduate program
- Obtained position that benefits people with disabilities
- Became an important component of daily lives
- Other _____

27. How did continuing education students apply what they learned in UCEDD continuing education courses to their work and/or daily lives?
Probe:

- Transferred the knowledge and skills they obtained to their work
 - Improved their effectiveness in providing services to people with developmental disabilities
 - Improved the effectiveness of the community in including people with developmental disabilities in all aspects of life
 - Provided accommodations for employees with developmental disabilities
 - Made use of tax incentives for assistive technology for employees
 - Made public buildings more accessible
 - Provided family-centered supports and services
 - Used evidence-based approaches to care
 - Applied what they learned to work or personal lives in other ways
-

ASK FOR EXAMPLES OF WHAT STUDENTS AFTER 5 YEARS

PART C. BASIC AND/OR APPLIED RESEARCH

We'd now like to move into some questions on the basic and/or applied research conducted here. We'd like to understand the type of research this UCEDD conducts, the recognition the UCEDD faculty and staff receive in their field of disability research, and the impact UCEDD research has on people with developmental disabilities and their families.

Type of Research

28. How would you characterize the type of research typically conducted at this UCEDD?
Probe:

- Basic
- Policy analysis
- Evaluation
- Clinical
- Epidemiology
- Other _____

29. Please describe three of the major research projects being conducted by UCEDD research faculty.

[See table.]

Probe:

- Purpose
- Brief description
- Research design
- Methodology
- Variables of interest
- Relationship to developmental disabilities population

UCEDD Research Projects (Q. 29)

Project	Brief description	Research design	Methodology	Variables of Interest	Relationship to developmental disabilities population

Recognition UCEDD Faculty and Staff Receive in Their Field of Disability Research

30. In the past year, how have UCEDD faculty and staff shown themselves to be well-recognized in their field of disability research? Please describe.

Probe:

- Provision of advice on disability-related issues to local, state, federal, and international organizations
 - Review of grants, manuscripts, books, articles, and other types of publications
 - Citations by other authors of their research
 - Other
-

Impact of UCEDD Research Has on People With Developmental Disabilities and Their Families

31. In what ways do UCEDD researchers involve people with developmental disabilities and family members in the research process, including members of the CAC? Please describe.

a. Do people with developmental disabilities and/or family members provide input into the research agenda? Please give examples.

Probe:

- Process used to obtain input on the research agenda
- Frequency/circumstances
- Examples of input in past year

b. Do they help in developing data collection and other study materials? Please describe.
Probe:

- Ways of helping to develop study materials (e.g., focus groups, participation in cognitive interviews, other)
- Types of materials in which they provide input (e.g., recruitment letters, consent forms, interview questionnaires, other).
- Extent to which they review materials prior to use in research studies
- Other _____

c. Do they help to interpret findings? Please give examples.

d. Do they participate in any other ways? Please describe.

32. Thinking about the past 5 years, in what ways has the research, evaluation, and/or public policy analysis conducted by this UCEDD benefited people with developmental disabilities and their families? Please give examples.

Probe:

- Supported changes to legislation or public policy
 - Supported changes to services and practice provided by service providers and professionals in the community
 - Other
-

PART D. COMMUNITY SERVICES

We would like to change gears and focus now on the community services offered by the UCEDD. We are going to ask questions about the community services your UCEDD develops and implements, the recipients of your community service efforts, and the impact these services have on people with developmental disabilities and the community. What does the UCEDD do that might be described as community services?

Community Services Provided

33. First let's start with the type of community services your UCEDD provides. Please describe.
Probe:

- Educational programs on developmental disabilities
 - Technical assistance
 - Diagnostic programs
 - Model demonstration programs
 - Child care programs
 - Employment programs
 - Other _____
-

34. Please describe each one.

[See table.]

Probe:

- Purpose
- Format
- Content
- Followup (if appropriate)

UCEDD Community Services

Name of Program	Type of Services	Description (purpose, format, content, followup)	Target Audience	Recruitment

35. What is the target audience for each program?

Probe:

- Employers at residential facilities
- Personal assistants
- Job coaches
- Employers in the community (non-disability related)
- City officials
- Health care professionals (e.g., physician assistants, dentists)
- Workforce Investment Boards
- One-Stop Career Center staff
- Policy makers
- Individuals who have potential influence on the inclusion and integration of people with developmental disabilities into the community
- General public
- Others _____

Recipients of Community Service Activities

36. How do you make sure your community service programs are geared to reaching unserved and underserved populations or those that are likely to reach those populations? Please describe.

a. How do you recruit participants for community service programs? Please describe.

b. In the past year, what groups/populations did you recruit for community services?
Probe:

- Racial or ethnic minorities
- Linguistic minorities
- Both urban and rural areas of the state
- Tribal communities
- Others considered to be typically unserved or underserved in the state
- _____

37. In the past year, how did the UCEDD make sure that its community services:

- Were effective (met objectives)
- Were accessible
- Were person-centered
- Were family-centered
- Were culturally competent

[Obtain 3 examples of community services materials (e.g., recruitment brochure, forms) that demonstrate community services were person-centered, family-centered, culturally competent).]

Impacts of UCEDD Community Services

38. In the past year, how did UCEDD community services (training, technical assistance, and direct services/model programs, if offered) for people with developmental disabilities and their families strengthen their capacity to meet their self-identified goals?

Probe:

- Advocated for themselves;
- Advocated for others;
- Helped a peer or mentored another person with a disability;
- Became leaders in the community (e.g., became the chair or a member of the DDC or members or leader in other organizations that advocate on behalf of people with disabilities; became a member or leader in other community organizations; participated in DD Network or other advocacy efforts; used the knowledge and skills they obtained in their personal lives)
- Other _____

39. How do UCEDD community services have an impact on recipients who provide supports and services to people with developmental disabilities and family members and other community professionals?

Probe:

- Transferred the knowledge and skills they obtained to their work
- Have more contact with people with developmental disabilities
- Improved their effectiveness in providing services to people with developmental disabilities
- Adopted evidence-based practices
- Other _____

40. How does the expert information provided by UCEDD faculty and staff to legislative and other decision making bodies have an impact on people with developmental disabilities and family members?

Probe:

- New or revised legislation or policy (or maintenance of legislation or policy)
- Changes in (or maintenance of) access to supports and services
- Changes in (or maintenance of) services and supports provided in the community
- Other _____

PART E. DISSEMINATION OF INFORMATION

In addition to community service programs, another way to reach out to the community is through the dissemination of various products developed by the UCEDD. Let's talk about these UCEDD products that are disseminated, those who receive UCEDD products, and the impact these products have.

Products and Target Audiences

41. Thinking about last year, what dissemination strategies did your UCEDD use to inform target audiences about developmental disabilities and issues affecting people with developmental disabilities and their families? Please describe.

Probe:

- Mass media
- Public information forums
- Presentations to community groups
- Mailings\pamphlets, brochures and other materials distributed to social service agencies and made available to the general public and special interest groups
- Maintenance of a resource center
- Newsletters
- Research briefs
- Videos and films
- Websites
- Other _____

42. Who were the target audiences for the dissemination of UCEDD products?

Probe:

- People with developmental disabilities
- Researchers
- Families
- Policy makers
- Professional and consumer groups
- Paraprofessionals, students
- Employers
- _____
- Other DD Network programs
- The general public
- Other _____

43. What does the UCEDD do to make its products accessible and understandable to the target audience for which it is intended? Please give examples.

a. In the past year, how were research findings and other technical types of information translated into terms that can be understood by lay audiences? Please describe.

b. In the past year, what did the UCEDD do to make other materials accessible and understandable? Please describe.

Probe:

- Used lay terminology
- Made products available in Braille or large print
- Produced materials in different languages
- Produced products in language appropriate for professional groups
- Other _____

–

[Obtain 3 examples of products disseminated, including one in which research findings were translated into lay terminology.]

44. How does the UCEDD determine whether materials are appropriate for the target audiences for which they are intended? Please describe.

a. In the past year, who participated in the process?

Probe:

- People with developmental disabilities
- CAC members
- Family members
- Members of the target audience
- Other _____

b. To what extent was the UCEDD responsive to feedback received? Please provide examples from the past year.

Satisfaction With UCEDD Products

45. In the past year, did the [NAME OF UCEDD] do anything to gauge the level of satisfaction with UCEDD products among those who receive (or access) them? Please describe.

Probe:

- Process
- Type of satisfaction sought
- Other

PART F. GOVERNANCE AND MANAGEMENT

This section of the interview pertains to the governance and management of the UCEDD. We will cover outside funding received by the UCEDD, maintenance and support of the CAC, and support received from the university. Let's start by talking about outside funding.

Outside Funding

We have a few questions about the UCEDD's ability to leverage funds.

46. Please describe the UCEDD projects that received external funding in the past 5 years.
[See table.]
47. How are these projects associated with the goals and objectives in the 5-year plan? Please explain.

UCEDD External Funding

Description of project	Association with 5-year plan

Consumer Advisory Committee (CAC)

48. How does the UCEDD obtain the perspectives of the CAC to guide UCEDD activities?
Please describe.

Probe:

- Development of the 5-year plan in the last planning cycle
- Involvement in other UCEDD activities in the past year
- Other _____

49. What input did the CAC provide in the past year to the UCEDD? Please provide examples.

50. What CAC input was used in the past year? Please provide examples.

51. In what ways does the UCEDD provide CAC members with the tools they need to be meaningfully involved as a CAC member? Please describe.

Probe:

- Reimbursements for travel
- Child care
- Respite
- Personal assistance services, if required
- Assistance for people with specific impairments (e.g., hearing, visual, cognitive, other)
- Assistance for people whose second language is English
- Accessible meeting locations
- Provision of materials in advance of meetings
- Assistance with preparation and understanding of materials prior to and during meetings if needed
- Other _____

Support from University

52. Please describe the support that the UCEDD receives from the university.

PART G: COLLABORATION

According to the DD Act, DD Network programs are required to report the extent to which they collaborate with one another. We've talked a little bit about collaboration as part of your systems change/advocacy activities. Now we would like to focus on your collaborative efforts with the DD Network programs on all types of activities besides systemic advocacy.

For this evaluation, we define collaboration as a well-defined relationship entered into by two or more individuals, groups, and/or organizations to achieve common goals of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (the DD Act).

Let's start first with how the DD Network programs identify issues and common goals on which to collaborate.

53. What process do the programs use for identifying, planning, and implementing collaborative efforts? Please describe.

Probe:

- Nature of process
- Participants
- Meeting frequency
- Formal vs. informal
- Other _____

54. What are the issues and goals on which the DD Network programs are currently collaborating? Please describe.

[See following table.]

[Obtain written goals/objectives.]

a. What project or issues are you collaborating on with DD Network programs? Would you please explain each issue?

b. What are the goals you and your collaborators were trying to achieve?

55. Which organizations or groups (including other DD Network programs) are you collaborating with on these issues?

56. What is the role of each collaborator, including the P&A and other DD Network programs?

57. How would you characterize the type of leadership for each project?

Probe:

- Single
- Joint
- Other _____

Resources for Collaboration

58. Collaboration suggests shared resources being available and used. What resources did each group or organization contribute? Please describe.

Probe:

- Funding
- Staff time
- Meeting place
- In kind contributions
- Other _____

Collaborations

No.	Project/Issue (Q. 54a)	Goals/Objectives (Q 54b)	Collaborators (including P&A) (Q. 55)	Collaborators' role (including role of DD Council) (Q. 56)	Leadership (Single/joint) (Q. 57)	Resources Contributed (Q. 58)
1.						
2.						
3.						

[INTERVIEWER: REPEAT QUESTIONS 54 THROUGH 58 FOR TWO MORE EXAMPLES.]

No.	Project/Issue (Q. 54a)	Goals/Objectives (Q 54b)	Collaborators (including P&A) (Q. 55)	Collaborators' role (including role of DD Council) (Q. 56)	Leadership (Single/joint) (Q. 57)	Resources Contributed (Q. 58)
4.						
5.						

Process of Collaboration – Regular Communication

Let's talk about the process of communication by using the same examples.

59. What were some of the ways you achieved regular communication during your collaborative efforts? Please describe.

a. Sharing information and progress on ongoing efforts

Probe:

- Examples
- Frequency
- Recipients
- Other

b. Regular updates to participants in the collaborative effort

Probe:

- Examples
- Frequency
- Recipients
- Other

c. Reports on milestones achieved

Probe:

- Examples
- Frequency
- Recipients
- Other

d. Discussion of issues that arose

Probe:

- Examples
- Frequency
- Participants
- Other

e. Debriefing at the end of a collaborative effort (if appropriate)

Probe:

- Examples
- Frequency
- Recipients
- Other

60. In the past year, were there any issues that arose in the community on which the DD Network programs responded together? Please give examples.
61. What was the joint response of the DD Network programs?
62. What is the process the DD Network programs use to monitor progress and barriers of collaborative efforts? Please describe.
 - a. Please give examples of ways in which the programs monitor and identify barriers.
 - b. For collaborative efforts implemented in the past 2 years, what process was used to identify leadership? What decisions were made on leadership of each effort?
 - c. What barriers have been identified?
 - d. Have goals and objectives been changed as a result of monitoring and identifying barriers? Please give examples.

Results of Collaboration

Finally, let's talk about achieving your goals and objectives -- the results of your collaborative efforts.

63. Were there any products derived from your collaborative efforts? Please give examples and describe?
Probe:

- White papers
- Wording for legislation
- Brochure on joint program
- Program enrollment form
- Other _____

[Obtain examples of products developed in past year, if applicable.]

64. What has been the result of your collaboration with DD Network programs and other organizations? Please give examples from the past 5 years.
Probe:

- Changes to (or maintenance of) State and local systems (e.g., changes or maintenance in practices and legislation)
- System changes (or maintenance) that affected people with developmental disabilities and their families, including people who are traditionally unserved and underserved (e.g., racial or ethnic minorities, people with little or no use of English, or people who live in remote or rural areas or live in poverty)
- Increases in the capacity of the community to provide supports and services to people with developmental disabilities and their families (e.g., accommodations are provided in public services such as transportation, education, and employment)
- Ways participants in DDN collaborative efforts have improved their knowledge or skills in ways that benefit people with developmental disabilities and their families
- Other _____

PART H: DEBRIEFING [AT END OF PROGRAM VISIT]

65. Before we leave, we would like to give you the opportunity to ask any questions you might have, raise any issues you might want to raise, or talk about anything related to your program that you would like to expand upon.
- a. First, do you have any general comments to make?
 - b. Issues?
 - c. Further explanation of your DD Council?
66. There are also a few things I want to make sure we don't forget.
- Obtain materials requested, if easily available.
 - Confirm products to be sent. Leave FedEx form.
 - Obtain contact information for additional individuals who need to be contacted.
 - Confirm process for telephone interviews and availability of interviewees.
 - Leave business card.

We'd like to thank you again for taking the time to meet with us these past 2 days. We also appreciate you making your staff available and arranging for us to meet with many of your stakeholders.

C3-2. Consumer Advisory Committee (Chair and Members)

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION NATIONAL NETWORK OF UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES (UCEDDS)

INTERVIEW WITH THE CHAIR AND MEMBERS OF THE CONSUMER ADVISORY COMMITTEE

[Interviewer]: Thank you for taking the time to talk with us today. My name is [interviewer's name] and this is [second interviewer's name]. We both work for Westat, a private research company in Maryland.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the UCEDD on the lives of people with developmental disabilities and their families. This UCEDD is one of 20 UCEDDs in 19 states and one territory that have been randomly selected to participate in the evaluation.

As a CAC member (Chair), you are an important source of information regarding this UCEDD. We would like to learn about your experiences with the CAC, how you learned about your roles and responsibilities, what the UCEDD staff does to help you meet your roles and responsibilities and your satisfaction with the amount of help that is given.

Before we begin, I would like to read this consent form to you or ask you to read it yourself.

READ CONSENT FORM OR ALLOW TIME FOR CLIENT TO READ THE CONSENT FORM. ANSWER ANY QUESTIONS THE CLIENT MAY HAVE. OBTAIN SIGNATURE ON CONSENT FORM.

Now that we're ready to begin, we would like to ask your permission to record the interview so that we do not miss any of your responses to our questions. The recording is for Westat's use only and will not be provided to ADD or anyone else.

Do you have any questions before we start?

Experience with the UCEDD and the CAC

Let's start by talking about you and the Consumer Advisory Committee.

1. How did you become interested in the Consumer Advisory Committee? Please explain.
Probe:

- Personal relationship with disability – self
- Personal relationship with disability – family member
- Other _____

2. How long have you been a member of the Consumer Advisory Committee?

What the CAC Does

3. In the last planning cycle, how did the CAC contribute to the development of the UCEDD's 5-year plan? Please describe.

Probe:

- Attended public meetings
- Discussed input received by UCEDD
- Other _____

4. In the past year, how did the CAC contribute to the UCEDD's interdisciplinary pre-service preparation and continuing education program? Please describe.

Probe:

- Contributed to development of curricula and syllabi
- Contributed to classroom instruction
- Assisted in recruiting people with developmental disabilities to UCEDD positions
- Other _____

5. In the past year, how did the CAC contribute to UCEDD research? Please describe.

Probe:

- Provided input into the identification of research issues
- Participated in the design of data collection instruments
- Helped to interpret findings
- Other _____

6. In the past year, how did the UCEDD provide support so members could fulfill their role and responsibilities and participate in CAC activities?

Probe:

- Reimbursements for travel
- Child care
- Respite to caregivers
- Personal assistance services
- Assistance for people whose second language is English
- Advance distribution of meeting materials
- Arrangement to have someone help with preparation and understanding of material prior to and during meetings if needed
- Other

7. How satisfied were you with the supports provided by the UCEDD in the past year? Please explain.

Very satisfied

Somewhat satisfied

Not satisfied

Those are all the questions I have for you. Is there anything about your membership on the CAC that you would like to tell us? Do you have any questions before we end this interview?

We'd like to thank you for taking the time to answer these questions.

C3-3. Peer Researchers and Colleagues

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION NATIONAL NETWORK OF UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES (UCEDDS)

INTERVIEW WITH PEER RESEARCHERS AND COLLEAGUES

[Interviewer]: Thank you for taking the time to talk with me today. My name is [interviewer's name], and I work for Westat, a private research company in Rockville, MD.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. [NAME OF EXECUTIVE DIRECTOR] OF [NAME OF UCEDDD] that contacted you to participate in this evaluation is one of 20 UCEDDs in 19 states and one territory that have been randomly selected to participate in the evaluation. As someone who is a peer and colleague of UCEDD faculty members, you are an important source of information. We have some questions we would like to ask you about your interaction with the [NAME OF UCEDDD] and your impressions of the work that is done. The interview should last approximately ½ hour – 45 minutes.

Before we begin, I would like to ask your permission to record this interview so that we do not miss any of your responses to our questions. This recording is for Westat's use only. It will not be made available to anyone else. Do we have your permission to record?

Do you have any questions before we start?

Background

Let's start with a little background.

1. First, would you please tell us what you do?
Probe:
 - Ways s/he spends time (research, teaching, administration, other)
 - Affiliation/name of organization/department
 - Inside/outside university
 - Disability related/not disability related

2. What is your relationship with the [NAME OF UCEDD]? Please describe.
Probe:

- Collaborator on disability-related course(s) [Part A]
- Collaborator on disability-related materials [Part A]
- Research collaborator [Part B]
- Collaborator/participant in UCEDD community services [Part C]
- Other _____

[Interviewer: Only use sections relevant to respondent.]

Now we'll try to get a few details on each of the ways you have interacted with the UCEDD, starting with the [NAME OF UCEDD]'s interdisciplinary pre-service preparation and continuing education program.

PART A. INTERDISCIPLINARY PRE-SERVICE PREPARATION AND CONTINUING EDUCATION

3. You mentioned that you've collaborated [PROVIDE DETAILS FROM QUESTION 2]. Would you please tell us a little about it?
- a. How was the collaboration initiated?
 - b. What kinds of courses/syllabi/course materials were developed as a result of the collaboration? Please give examples.
 - c. For what types of courses (university program; continuing education)?
 - d. What was your role?
 - e. With whom did you collaborate?
 - f. What was the UCEDD's faculty or staff member's role?

4. Have you been involved in any continuing education programs/courses offered by the [NAME OF UCEDD]? Please describe.
Probe:
- Method of initiation
 - Nature of program/courses
 - Nature of involvement (e.g., development of materials; provision of class or seminar)
5. What is your perception of the courses developed by UCEDD faculty and staff? To what extent do you consider them to cover current practices and issues and contain up-to-date content? Please give examples.
6. What is your perception of the effectiveness of UCEDD faculty and teaching? Please explain.
Probe:
- Content
 - Delivery
 - Perceived engagement of students
 - Achievement of teaching objectives
 - Source of perception (e.g., observation, participation in meetings)
 - Other _____
7. What impact do you think the UCEDD teaching program has on its students? Please describe.
Probe:
- Careers
 - Everyday life
 - Other _____

PART B. BASIC AND/OR APPLIED RESEARCH

You mentioned that you collaborated with a member of the research faculty of [NAME OF UCEDD].

8. Would you please describe the nature of that collaboration?
Probe:
- Interviewee provided access to study subjects
 - Jointly developed research questions
 - Jointly developed design and methodology
 - Interviewee was responsible for implementation of study
 - Interviewee was responsible for data collection
 - Interviewee was responsible for data analysis
 - Coauthored article or report
 - Other _____

9. What is your overall impression of the visibility and standing of the [NAME OF UCEDD] among members of your area of research?
- Are any members of the UCEDD research faculty considered to be experts in certain aspects of disability research? Please give examples.
 - Is there a sense that UCEDD research faculty publish in high quality journals? Please explain.
 - Are you seeing the work of UCEDD faculty cited by other researchers? Please give examples.
10. Have you served on any professional committees or advisory panels with a [NAME OF UCEDD] research faculty member? Please describe.
Probe:
- Name and description of committee/program
 - Purpose of committee/program
 - Specific role of interviewee
 - Specific role of [NAME OF UCEDD] committee/program member
 - Size and composition of committee/program

We realize that research findings often take a long time to percolate, become known by researchers and non-researchers, and to be used, but we'd like to get your perception of the impact [NAME OF UCEDD] research has had on people with developmental disabilities, their families, and the developmental disabilities community, including researchers.

10. In what ways has UCEDD research (including evaluation and/or public policy analysis) been able to support, encourage, or provide the underpinning for certain actions that benefit people with developmental disabilities and their families?
- Can you think of any examples in which UCEDD research supported changes in legislation or public policy over the past 10 years? Please describe.
 - How effective would you consider UCEDD research efforts in directly or indirectly altering legislation or public policy? Please explain.
 very effective somewhat effective not effective
 - Can you think of any examples where UCEDD research findings have supported changes in practice or services for people with developmental disabilities? Please describe.
 - How effective would you consider UCEDD efforts to be in directly or indirectly altering practices or services? Please explain.
 very effective somewhat effective not effective
 - Can you think of any other way that UCEDD research has benefited people with developmental disabilities and their families? Please describe.

PART C. COMMUNITY SERVICES

You indicated that you were involved with [NAME OF UCEDD] in some of its community services activities, so we'd like to get some details on that.

11. What was the nature of the community services activity(ies)? Please describe.

Probe:

- Purpose
- Type of activity (e.g., model demonstration program; train the trainer)
- Frequency
- Target audience
- Method of recruitment

12. What was the nature of your involvement?

Probe:

- Assisted in design of a program or service
- Contributed expertise to the UCEDD activity
- Other _____

We'd like to get an idea of your perception of the impact [NAME OF UCEDD] community services has on the developmental disabilities community in this state and beyond.

13. Are any of the UCEDD community services activities known beyond the local community or State? Please give examples.

14. Have any of the UCEDD community service activities been adopted by service and support providers beyond the local community or state? Please give examples

Is there anything else you can tell us about your association with one or more members of the faculty or staff of this UCEDD?

That completes this interview. Do you have any questions before we sign off?

Again, we'd like to thank you for taking the time to talk with us.

C3-4. Recipients of Community Services

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES (UCEDDS)

RECIPIENTS OF COMMUNITY SERVICES OR MEMBERS OF ORGANIZATIONS/AGENCIES THAT ARE TRAINED TO PROVIDE COMMUNITY SERVICES

[Interviewer]: Thank you for taking the time to talk with me today. My name is [interviewer's name], and I work for Westat, a private research company in Rockville, MD.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. [NAME OF EXECUTIVE DIRECTOR] from [NAME OF UCEDDD] that contacted you to participate in this evaluation is one of ____ UCEDDs in ____ states that have been randomly selected to participate in the evaluation.

The purpose of this interview is to learn about your experiences with the [NAME OF UCEDDD] community services and your thoughts about the impact these services have had on people with developmental disabilities, their families, and the community at large.

Before we begin, I would like to read this consent form to you or ask you to read it yourself.

READ CONSENT FORM OR ALLOW TIME FOR FORM TO BE READ. OBTAIN SIGNATURE ON CONSENT FORM.

Now that we're ready to begin, we would also like to ask your permission to record this interview so that we do not miss any of your responses to our questions. This recording is for Westat's use only. It will not be made available to anyone else at the UCEDD or anyone else. Do we have your permission to record?

1. Let's begin by having you describe the community services or training you received from the [NAME OF UCEDD].

Probe:

- What it was (e.g., train the trainer program, model demonstration program, technical assistance)
- What it did
- Who provided the services (physician, nurse, social worker, teacher, visiting speakers, UCEDD faculty member)
- How you heard about it (e.g., UCEDD Web site, word of mouth from a friend; community newsletter; disability-related organization)
- How the services were provided (lecture, seminar speakers, physical examination)
- Frequency of sessions
- Followup (if appropriate)

2. Were there materials that went along with the community services you received (e.g., PowerPoint presentations, handouts, brochures)? Please describe.

Probe:

- Types and nature of materials
- Format – accessibility
- Appropriateness

3. What other features did the community services program in which you participated have? Please describe.

Probe:

- Person-centered
- Family-centered
- Culturally competent

4. What were your objectives in participating in the community services program? Please describe.

5. Were your objectives met? Please explain.

6. What did you think of the community services you received? How satisfied were you with:

a. The content

Very satisfied Somewhat satisfied Not very satisfied

b. Expertise of presenters (instructors/service providers)

Very satisfied Somewhat satisfied Not very satisfied

c. Materials

Very satisfied Somewhat satisfied Not very satisfied

Please explain.

Finally, let's talk about how you think you benefited from the community services provided by the [NAME OF UCEDD].

7. How have you benefited from the services provided by the [NAME OF UCEDD]? Please describe.

8. Did these services help you to obtain supports or services for yourself, a family member or another person with a developmental disability? Provide examples.

Probe:

- Advocated for themselves
- Advocated for others
- Helped a peer or mentored another person with a disability
- Other _____

9. Did these services help you to become a leader in the community? Please give examples.
Probe:

- Became chair or member of the CAC or DD Council
 - Became member or leader in other organizations that advocate on behalf of people with disabilities
 - Became a member or leader in other community organizations
 - Participated in DD Network advocacy efforts
 - Other _____
- a. In what ways have the community services provided by the [NAME OF UCEDD] strengthened your ability to help people with developmental disabilities? Provide examples.
- b. In what ways have you had an impact on people with developmental disabilities and/or their families as a result of the community services you received from the [NAME OF UCEDD]? Provide examples.
- c. What kinds of improvements have you seen or been responsible for within the community as a result of the community services sponsored by the [NAME OF UCEDD]? Provide examples.

Is there anything else you would like to say about your experiences with the community services provided by the UCEDD?

Those are all the questions we have for you today. Do you have any other questions before we end this discussion?

We'd like to thank you for taking the time to participate in this interview.

C3-5. Current and Graduated Students

DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION (DDPIE) PROJECT NATIONAL NETWORK OF UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES (UCEDDS)

TELEPHONE INTERVIEW WITH CURRENT AND GRADUATED STUDENTS

[Interviewer]: Thank you for taking the time to talk with me today. My name is [interviewer's name], and I work for Westat, a private research company in Rockville, MD.

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of Developmental Disabilities Network programs and collaboration among them. The purpose of this evaluation is to examine the impact of the Developmental Disabilities (DD) Network programs on the lives of people with developmental disabilities and their families. The UCEDD that contacted you to participate in this evaluation 20 UCEDDs in 19 states and one territory that have been randomly selected to participate in the evaluation.

The purpose of this interview is to learn about your experiences at the University of _____ with regard to your disability-related education and training. We are talking with current and former students and people who attended continuing education classes. We would like to learn about your experiences and how these experiences affected your job or personal life after you graduated or completed the course(s) you took. We expect the interview to take between half an hour and 45 minutes.

Before we begin, we would like to ask your permission to record this interview so that we do not miss any of your comments. This is for Westat's use only. It will not be made available to anyone else. Do we have your permission to record?

Program of Study

1. Let's begin by having you talk about the type of disability-related training or education you received through the University of _____. How did disability factor into your studies at the [NAME OF UNIVERSITY]?

Probe:

- Graduate or student in a professional program (e.g., medicine, nutrition, physiotherapy), focusing on disability
- Undergraduate in a disabilities studies program
- Undergraduate taking a non-disability-related program; at least one course had disability-related content
- Continuing education student
- Other _____

2. What [disability-related] program/courses were you involved in at the [NAME OF UNIVERSITY]?

Probe:

- Name/type of program
- Program/course objectives
- Nature of content from some of the classes
- Relationship to disability

University Centers of Excellence on Developmental Disabilities often talk about the interdisciplinary education their students receive. Interdisciplinary is defined as “interaction among multiple disciplines on a common problem.”

3. In what ways was your disability-related education and training at the University of _____ interdisciplinary?

- a. Did the classes you took incorporate material from more than one discipline? Provide examples.
- b. Was the approach geared toward discussing issues or problems from the perspective of more than one discipline? Provide examples.
- c. Please describe the way material from multiple disciplines was integrated into your classes. Provide examples.

4. In what ways did the UCEDD expose you to traditionally unserved and underserved populations or communities (e.g., racial/ethnic minorities, people who understand little or no English, people who live in remote or rural communities, or low income communities)?

- a. What types of opportunities were offered to work with or interact with traditionally unserved or underserved populations or communities? Please describe.
- b. What kinds of practical experiences did you participate in? Please describe.

Satisfaction

5. Does (did) the UCEDD program have system in which students could rate their courses or the teaching faculty? Please describe.

Probe:

- a. What elements of the course are (were) rated (e.g., usefulness of materials, availability of professors, effectiveness of lectures)?
- b. Overall, how satisfied were you with the course(s) or program that taught you disability-related material? Please explain.

Highly satisfied

Satisfied

Somewhat satisfied

6. Overall, how useful do you think the contents of the disability-related program (classes, courses) were? Please explain.

Very useful

Useful

Not very useful

Now we'd like to get an idea of how you've been able to use your experiences gained through your involvement with disability-related courses developed through the UCEDD.

7. Does (did) the UCEDD provide offer any assistance in meeting your disability-related career goals? Please describe.

Probe:

- Mentoring program
- Method for sharing job opportunities with students
- Other _____

Impact of Experience With the UCEDD

8. In what ways have you applied your experience with the [UCEED NAME] in your professional life?

- a. Did you obtain a position that benefits people with developmental disabilities? Please describe.
- b. If yes, how does this position improve the quality of life for people with developmental disabilities or family members? Please describe.
- c. Have you been able to apply skills from different disciplines in order to solve problems at work? Please give examples.
- d. Did you gain a greater understanding of research and research methodology? Please explain.
- e. Did you alter your practices or services based on your experiences with the UCEDD? Please explain.
- f. Did you gain a greater understanding of disability-related concepts as a result of your experiences with the UCEDD? Please explain.

Other _____

Is there anything else about your experiences in the UCEDD teaching program that you would like to tell us about? Do you have any questions yourself?

We'd like to thank you for taking the time to participate in this discussion.

Appendix D. Notification of Sample Selection by ADD



DEPARTMENT OF HEALTH & HUMAN SERVICES

ADMINISTRATION FOR CHILDREN AND FAMILIES

370 L'Enfant Promenade, S.W.
Washington, D.C. 20447

Name
Program
Address

Dear _____:

The Administration on Developmental Disabilities (ADD) is conducting an independent evaluation of the Developmental Disabilities Network (DD Network) programs and collaboration among the programs. As a result of a random sampling process within the four U.S. Census regions, your state/territory has been selected as one of 20 to participate in this full-scale independent evaluation. ADD is conducting this evaluation to address accountability requirements set forth in Section 104(a) (Program Accountability) of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act), the Government Performance and Results Act (GPRA) of 1993, and the November 13, 2007 Executive Order on Improving Government Program Performance. In addition to accountability responsibilities, we are also confident that the results of the evaluation will help to promote the positive achievements of DD Network programs and improve the effectiveness of programs and policies. ADD has received clearance to conduct the evaluation from the Office of Management and Budget (OMB No. ____).

The evaluation is known as the Developmental Disabilities Independent Program Evaluation (DDPIE). The purpose of the evaluation is to demonstrate the effectiveness of the DD Network programs at the national level and to assess the impact these programs have on the lives of people with developmental disabilities and their families. ADD has engaged Westat, a private research firm in Rockville, Maryland, to conduct the evaluation. Westat staff will visit all three DD Network programs in your state/territory during the week of _____.

Data collection for the evaluation will consist of in-person individual and group interviews, individual telephone interviews, completion of a self-administered questionnaire asking primarily for statistical information on your program, and review of background materials (e.g., forms, letter templates, policy handbooks, additional data you have collected) that you will be asked to provide to

Westat. The attached chart provides more information about the data collection interviews, including the categories of interviewees and the approximate length of time for the interviews.

Within the next week, an evaluator from Westat will contact you by email to provide additional information on the evaluation and begin the process of setting up your program visit. We want to assure you that the data collected for this evaluation will be kept confidential, that the information provided will not be used to evaluate your specific program, and that all data will be reported at the national level.

If you have questions about the project in general or its implementation, please contact Lynn Elinson, the Westat project director for the independent evaluation, (412-421-8610 or lynnelinson@westat.com) or Linda Lynch, Westat deputy project director for the evaluation, (301-251-4280 or lindalynch@westat.com).

ADD is looking forward to reporting information from an independent evaluation on the important work that the DD Network programs perform for the nation's population of people with developmental disabilities and their families.

Thank you in advance for your cooperation in this important effort.

Yours sincerely,

Commissioner
Administration on Developmental Disabilities

Attachment

Appendix E. Westat Email to Sampled Programs

- E1. COUNCILS**
- E2. P&A Programs**
- E3. UCEDDs**

E1. Councils

COUNCILS

Name
Executive Director
Program
Address

Dear _____:

As you know, the Administration on Developmental Disabilities (ADD) has engaged Westat, a research firm located in Rockville, MD to conduct an independent evaluation of Developmental Disabilities (DD) Network programs and collaboration among them. As _____, Commissioner of ADD, indicated in her/his letter to you recently, your State has been selected to participate in the evaluation during the week of _____.

The evaluation will consist of visits to DD Network programs, interviews (both in person and over the telephone), and consolidation of data and background information on your program. During our visit to your program, we would like to interview you (and any senior staff you would like to have present), to learn about the functioning of your DD Council and the impact of your programs and activities on people with developmental disabilities and family members. We would also like to meet individually with the Chair and members of the DD Council to talk about their role and responsibilities, as well as with individuals who received self-advocacy and leadership training sponsored by the DD Council. We also hope to meet as a group with individuals who collaborated with your DD Council or were affected by systems change and advocacy activities. Finally, we would like to conduct telephone interviews with recipients of education and training for the purpose of improving the capacity of the community to include people with developmental disabilities in all aspects of community life. In addition to the interviews, Westat has developed a self-administered questionnaire for completion by you or a member of your program staff. The form collects quantitative data about your program.

We will be providing you with additional information about the program visit and self-administered questionnaire in future correspondence and telephone calls. My immediate goal is to begin the process of arranging a visit to your program and developing a 2-day agenda. _____ from Westat will be contacting you to provide you with more details about the evaluation and to make final program visit arrangements.

If you have any questions, please feel free to email me at lynnelinson@westat.com or call me at 412.421.8610. I am looking forward to learning about your program and the important work you have been doing.

Sincerely,

Lynn Elinson
DDPIE Project Director

E2. P&A Programs

PROTECTION AND ADVOCACY

Name
Executive Director
Program
Address

Dear _____:

As you know, the Administration on Developmental Disabilities (ADD) has engaged Westat, a research firm located in Rockville, MD to conduct an independent evaluation of Developmental Disabilities (DD) Network programs and collaboration among them. As _____, Commissioner of ADD, indicated in her/his letter to you recently, your State has been selected to participate in the evaluation during the week of _____.

The evaluation will consist of visits to DD Network programs, interviews (both in person and over the telephone), and consolidation of data and background information on your program. During our visit to your program, we would like to interview you (and any senior staff you would like to have present), to learn about the functioning of your P&A program and the impact of your programs and activities on people with developmental disabilities and family members. We would also like to talk by telephone with the Chair and members of the Board of Directors to talk about their role and responsibilities, as well as with individuals who received public education sponsored by the DD Council. We also hope to meet as a group with individuals who collaborated with your P&A or were affected by systemic advocacy activities. Finally, we would like to meet in person with P&A clients to obtain information on their experiences. In addition to the interviews, Westat has developed a self-administered questionnaire for completion by you or a designated program staff member. The form collects quantitative data about your program.

We will be providing you with additional information about the program visit and self-administered questionnaire in future correspondence and telephone calls. My immediate goal is to begin the process of arranging a visit to your program and developing a 2-day agenda. _____ from Westat will be contacting you to provide you with more details about the evaluation and to make final program visit arrangements.

If you have any questions, please feel free to email me at lynnelinson@westat.com or call me at 412.421.8610. I am looking forward to learning about your program and the important work you have been doing.

Sincerely,

Lynn Elinson
DDPIE Project Director

E3. UCEDDs

UCEDDs

Name
Executive Director
Program
Address

Dear _____:

As you know, the Administration on Developmental Disabilities (ADD) has engaged Westat, a research firm located in Rockville, MD to conduct an independent evaluation of Developmental Disabilities (DD) Network programs and collaboration among them. As _____, Commissioner of ADD, indicated in her/his letter to you recently, your State has been selected to participate in the evaluation during the week of _____.

The evaluation will consist of visits to DD Network programs, interviews (both in person and over the telephone), and consolidation of data and background information on your program. During our visit to your center, we would like to interview you (and any senior staff you would like to have present), to learn about the functioning of your UCEDD and the impact of your programs and activities on people with developmental disabilities and family members. We would also like to talk by telephone with the Chair and members of the Board of Directors to talk about their role and responsibilities, as well as with researchers/colleagues of UCEDD faculty and staff and current and former students. We also hope to meet in person with Consumer Advisory Committee members and recipients of community services (or those trained to provide community services). In addition to the interviews, Westat has developed a self-administered questionnaire for completion by you or a designated program staff member. The form collects quantitative data about your program.

We will be providing you with additional information about the program visit and self-administered questionnaire in future correspondence and telephone calls. My immediate goal is to begin the process of arranging a visit to your program and developing a 2-day agenda. _____ from Westat will be contacting you to provide you with more details about the evaluation and to make final program visit arrangements.

If you have any questions, please feel free to email me at lynnelinson@westat.com or call me at 412.421.8610. I am looking forward to learning about your program and the important work you have been doing.

Sincerely,

Lynn Elinson
DDPIE Project Director

Appendix F. Followup Letter From Westat to Confirm Program Visit Dates

Dear [Executive Director]:

Thank you for your cooperation in setting up a date for Westat staff to conduct a 2-day program visit at (INSERT NAME OF SITE). The purpose of this letter is to confirm the date of the program visit and describe what will happen during the visit.

As agreed, the dates of the visit will be _____. During this time, two Westat staff will be meeting with you [and members of your staff], as well as P&A collaborators on a systemic advocacy issue, and individual advocacy clients. The purpose of the program visit is to implement data collection instruments developed for the Administration on Developmental Disabilities (ADD) of the U.S. Department of Health and Human Services for an independent evaluation of Developmental Disabilities Network Programs.

We would like to begin the program visit by meeting with you [and additional staff, as appropriate], for approximately 3-4 hours over the 2-day period (not necessarily all at once). The scheduling of the remaining interviews during the 2-day program visit is flexible. During the remainder of the program visit, we would like to meet individually with staff who are responsible for intake, individual advocacy, and public education, and the Chair and two members of the board of directors for approximately ½ hour to 45 minutes each. In addition, we would like to conduct individual in-person interviews with at least three individual advocacy clients (and a family member or personal assistant if requested by the client). These interviews are also expected to last approximately ½ hour to 45 minutes each. We will also conduct a group interview consisting of six to eight individuals who collaborated with or had experiences with the P&A on a systemic advocacy issue.

We would appreciate it if you would provide a private room for all interviews in order to ensure the confidentiality and privacy of all participants.

Once the program visit is completed, we would like to conduct individual telephone interviews with the chair and board of director members [if appropriate] and three individuals who received P&A public education for the purpose of improving the capacity of the community to include people with developmental disabilities in all aspects of community life. These telephone interviews will last approximately ½ hour to 45 minutes each. Any participants who were unavailable to attend interviews during the program visit may also be interviewed by telephone at a later date. Westat staff will work with you to develop the agenda to ensure that the appropriate people are interviewed. For your information, I am enclosing the data collection protocols that will be used as a guide for each interview.

In addition to assisting us in arranging interviews, we would appreciate it if you would provide some materials that Westat's interviewers will review in preparation for the program visit (e.g., amendments to your Statement of Goals and Priorities, policies, procedures). _____ will be in touch with you shortly to work with you to develop a list of materials for your P&A program and discuss further arrangements for the program visit.

The independent evaluation is being conducted because of ADD's commitment to having an independent evaluation of the outcomes, impacts, and benefits of the DD Network programs it has funded. In addition, the results of the final evaluation will be used to inform ADD's annual performance reporting and in the Program Assessment and Results Tool (PART) process, required by and consistent with the Office of Management and Budget emphasis on program evaluations for all federal agencies

Again, we would like to thank you for your cooperation in organizing this program visit. If you have any questions about the program visit or the evaluation, please feel free to contact me (lynnelinson@westat.com or 412 421-8610).

Westat staff are looking forward to meeting you and learning more about your P&A program.

Sincerely,

Lynn Elinson, Ph.D.
DDPIE Project Director

Enclosures

Appendix G. Consent Forms

- G1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES**
- G2. PROTECTION AND ADVOCACY SYSTEMS**
- G3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL
DISABILITIES EDUCATION, RESEARCH, AND SERVICE**

G1. State Councils On Developmental Disabilities

Developmental Disabilities Program Independent Evaluation (DDPIE) Full-Scale Evaluation DD Council Chair and Members

I, _____, consent to participate in the Developmental Disabilities Program Independent Evaluation (DDPIE), which is funded by the Administration on Developmental Disabilities (ADD) in the U.S. Department of Health and Human Services. The purpose of the DDPIE is to conduct an independent evaluation of the Developmental Disabilities Network Programs and collaboration among them. The (DD COUNCIL NAME) is one of 20 State Councils on Developmental Disabilities selected for the evaluation. By consenting to take part in this study, I understand that:

- My participation in this evaluation is entirely at my will;
- I have the right to refuse to participate in this evaluation, and my decision for not taking part in the evaluation will not cause any penalty or loss of benefits or services to me;
- If I agree to be in the evaluation, I will be asked questions about the role of the DD Council, my involvement in developing the State Plan and other Council activities, and the results of Council's work;
- I will be interviewed by myself in a private room or office (with a family member or personal assistant if I wish).
- If I do not want to be interviewed in person, I can choose to answer questions over the telephone;
- I can choose not to answer any questions that I do not want to answer;
- If I would like the interview to stop altogether, I just need to say so and the interview will be ended;
- There will be about 59 other people taking part in this type of interview;
- The interview will last approximately ½ hour to 45 minutes;
- I will be asked for my permission to have the interview audio recorded. No one but Westat will hear the recordings or see the transcriptions of the recordings.
- Everything I say will remain confidential and will not be repeated to anyone else;
- My name or other identifying information will not be used in any reports;
- Nothing I say will have any effect on any services I or my family might receive in the future;
- Participation in this evaluation will not put me at any risk and could benefit me by improving the programs and services for people with developmental disabilities and their families; and
- I will receive reimbursement for travel and personal assistance services.

To repeat, do you understand that:

1. You do not have to participate in this interview if you do not want to?
2. You do not have to answer all of the questions and can refuse to answer specific questions?
3. Everything you say today will be kept private, and your name will not be used in any reports that Westat writes?

If you have any questions about the evaluation, please contact the director of this project, Lynn Elinson, at 412 421-8610.

CONSENT SIGNATURE:

Participant Name (please print) Participant's Signature Date

Signature of Person Conducting Informed Consent Discussion Date

Signature of Legally Authorized Representative (when appropriate) Date

Relationship to Participant (when appropriate)

If this consent form is read to the participant because the participant is unable to read the form, an impartial witness not affiliated with the project or project staff must be present for the consent and sign the following statement:

I confirm that the information in the consent form and any other written information was accurately explained to and apparently understood by the participant. The participant freely consented to take part in the evaluation.

Signature of Impartial Witness Date

Note: This signature block cannot be used for translations into another language. A translated consent form is necessary for participants who do not speak English.

FOR OFFICE USE ONLY Study ID# _____

**Developmental Disabilities Program Independent Evaluation (DDPIE)
Full-Scale Evaluation
Participant in DD Council Systems Design Activities**

I, _____, consent to participate in the Developmental Disabilities Program Independent Evaluation (DDPIE) which is funded by the Administration on Developmental Disabilities (ADD) in the U.S. Department of Health and Human Services. The purpose of the DDPIE is to conduct an independent evaluation of the Developmental Disabilities Network Programs and collaboration among them. The (DD COUNCIL NAME) is one of 20 State Councils on Developmental Disabilities selected for the evaluation. By consenting to take part in this evaluation, I understand that:

- My participation in this evaluation is entirely at my will;
- I have the right to refuse to participate in this evaluation and my decision for not taking part in the evaluation will not cause any penalty or loss of benefits or services to me;
- If I agree to be in the evaluation, I will be asked questions about my experiences with the DD Council during systems design and improvement activities (e.g., _____) and my thoughts about how these activities influenced people with developmental disabilities, family members, State service systems, and service providers;
- I will be part of a group of up to 7 other people taking part in this interview/discussion. A family member or personal assistant may also be present if I wish.
- If I do not want to be interviewed in person or as part of a group, I can choose to talk about my experiences by myself and/or over the telephone;
- I can choose not to answer any questions that I do not want to answer;
- If I would like the interview to stop altogether, I just need to say so and the interview will be ended;
- The interview will last approximately 1½ -2 hours;
- I will be asked for my permission to have the interview audio recorded. No one but Westat will hear the recordings or see the transcriptions of the recordings.
- Everything I say will remain confidential and will not be repeated to anyone else outside the group;
- My name or other identifying information will not be used in any reports;
- Nothing I say will have any effect on any services I or my family might receive in the future;
- Participation in this evaluation will not put me at any risk and could benefit me by improving the programs and services for people with developmental disabilities and their families; and
- I will receive reimbursement for travel and personal assistance services.

To repeat, do you understand that:

1. You do not have to participate in this interview if you do not want to?
2. You do not have to answer all of the questions and can refuse to answer specific questions?
3. Everything you say today will be kept private, and your name will not be used in any reports that Westat writes?

If you have any questions about the evaluation, please contact the director of this project, Lynn Elinson, at (412) 421-8610.

CONSENT SIGNATURE:

Participant Name (please print) Participant's Signature Date

Signature of Person Conducting Informed Consent Discussion Date

Signature of Legally Authorized Representative (when appropriate) Date

Relationship to Participant (when appropriate)

If this consent form is read to the participant because the participant is unable to read the form, an impartial witness not affiliated with the project or project staff must be present for the consent and sign the following statement:

I confirm that the information in the consent form and any other written information was accurately explained to and apparently understood by the participant. The participant freely consented to take part in the evaluation.

Signature of Impartial Witness Date

Note: This signature block cannot be used for translations into another language. A translated consent form is necessary for participants who do not speak English.

FOR OFFICE USE ONLY Study ID# _____

**Developmental Disabilities Program Independent Evaluation (DDPIE)
Full-Scale Evaluation
Recipient of DD Council Supported Advocacy/Leadership Training**

I, _____, consent to participate in the Developmental Disabilities Program Independent Evaluation (DDPIE) which is funded by the Administration on Developmental Disabilities (ADD) in the U.S. Department of Health and Human Services. The purpose of the DDPIE is to conduct an independent evaluation of the Developmental Disabilities Network Programs and collaboration among them. The (DD COUNCIL NAME) is one of 20 State Councils on Developmental Disabilities selected for the evaluation. By consenting to take part in this evaluation, I understand that:

- My participation in this evaluation is entirely at my will;
- I have the right to refuse to participate in this evaluation and my decision for not taking part in the study will not cause any penalty or loss of benefits or services to me;
- If I agree to be in the evaluation, I will be asked questions about my experiences with the DD Council supported Advocacy and Leadership programs, what I learned from these programs, and how I have used the knowledge and skills learned from the programs;
- I will be interviewed in person by myself in a private room or office (with a family member or personal assistant present if I wish).
- If I do not want to be interviewed in person, I can choose to talk about my experiences over the telephone;
- I can choose not to answer any questions that I do not want to answer;
- If I would like the interview to stop altogether, I just need to say so and the interview will be ended;
- There will be about 59 other people who will take part in this type of interview;
- The interview will last approximately ½ hour – 45 minutes;
- I will be asked for my permission to have the interview audio recorded. No one but Westat will hear the recordings or see the transcriptions of the recordings.
- Everything I say will remain confidential and will not be repeated to anyone else;
- My name or other identifying information will not be used in any reports;
- Nothing I say will have any effect on any services I or my family might receive in the future;
- Participation in this pilot evaluation will not put me at any risk and could benefit me by improving the programs and services for people with developmental disabilities and their families; and
- I will receive reimbursement for travel and personal assistance services.

To repeat, do you understand that:

1. You do not have to participate in this interview if you do not want to?
2. You do not have to answer all of the questions and can refuse to answer specific questions?
3. Everything you say today will be kept private, and your name will not be used in any reports that Westat writes?

If you have any questions about the evaluation, please contact the director of this project, Lynn Elinson, at (412) 421-8610.

CONSENT SIGNATURE:

Participant Name (please print) Participant's Signature Date

Signature of Person Conducting Informed Consent Discussion Date

Signature of Legally Authorized Representative (when appropriate) Date

Relationship to Participant (when appropriate)

If this consent form is read to the participant because the participant is unable to read the form, an impartial witness not affiliated with the project or project staff must be present for the consent and sign the following statement:

I confirm that the information in the consent form and any other written information was accurately explained to and apparently understood by the participant. The participant freely consented to take part in the evaluation.

Signature of Impartial Witness Date

Note: This signature block cannot be used for translations into another language. A translated consent form is necessary for participants who do not speak English.

FOR OFFICE USE ONLY Study ID# _____

G2. Protection & Advocacy Systems

Developmental Disabilities Program Independent Evaluation (DDPIE) Full-Scale Evaluation Participant in P&A Systemic Advocacy Activities

I, _____, consent to participate in the Developmental Disabilities Program Independent Evaluation (DDPIE) which is funded by the Administration on Developmental Disabilities (ADD) in the U.S. Department of Health and Human Services. The purpose of the DDPIE is to conduct an independent evaluation of the Developmental Disabilities Network Programs and collaboration among them. The (NAME OF P&A) is one of 20 Protection and Advocacy programs selected for the evaluation. By consenting to take part in this evaluation, I understand that:

- My participation in this evaluation is entirely at my will;
- I have the right to refuse to participate in this evaluation and my decision for not taking part in the evaluation will not cause any penalty or loss of benefits or services to me;
- If I agree to be in the evaluation, I will be asked questions about my experiences with the P&A during systemic advocacy activities (e.g., _____) and my thoughts about the impact of these activities;
- I will be part of a group of up to 7 other people taking part in this interview/discussion. A family member or personal assistant may also be present if I wish.
- If I do not want to be interviewed in person or in a group, I can choose to talk about my experiences by myself and/or over the telephone;
- I can choose not to answer any questions that I do not want to answer;
- If I would like the interview to stop altogether, I just need to say so and the interview will be ended;
- The interview will last approximately 1½ - 2 hours;
- I will be asked for my permission to have the interview audio recorded. No one but Westat will hear the recordings or see the transcriptions of the recordings.
- Everything I say will remain confidential and will not be repeated to anyone else outside the group;
- My name or other identifying information will not be used in any reports;
- Nothing I say will have any effect on any services I or my family might receive in the future;
- Participation in this pilot evaluation will not put me at any risk and could benefit me by improving the programs and services for people with developmental disabilities and their families; and
- I will receive reimbursement for travel and personal assistance services.

To repeat, do you understand that:

1. You do not have to participate in this interview if you do not want to?
2. You do not have to answer all of the questions and can refuse to answer specific questions?
3. Everything you say today will be kept private, and your name will not be used in any reports that Westat writes?

If you have any questions about the evaluation, please contact the director of this project, Lynn Elinson, at (412) 421-8610.

CONSENT SIGNATURE:

Participant Name (please print) Participant's Signature Date

Signature of Person Conducting Informed Consent Discussion Date

Signature of Legally Authorized Representative (when appropriate) Date

Relationship to Participant (when appropriate)

If this consent form is read to the participant because the participant is unable to read the form, an impartial witness not affiliated with the project or project staff must be present for the consent and sign the following statement:

I confirm that the information in the consent form and any other written information was accurately explained to and apparently understood by the participant. The participant freely consented to take part in the evaluation.

Signature of Impartial Witness Date

Note: This signature block cannot be used for translations into another language. A translated consent form is necessary for participants who do not speak English.

FOR OFFICE USE ONLY Study ID# _____

**Developmental Disabilities Program Independent Evaluation (DDPIE)
Full-Scale Evaluation
P&A Client**

I, _____, consent to participate in the Developmental Disabilities Program Independent Evaluation (DDPIE) which is funded by the Administration on Developmental Disabilities (ADD) in the U.S. Department of Health and Human Services. The purpose of the DDPIE is to conduct an independent evaluation of the Developmental Disabilities Network Programs and collaboration among them. The (NAME OF P&A) is one of 20 Protection and Advocacy programs selected for the evaluation. By consenting to take part in this evaluation, I understand that:

- My participation in this evaluation is entirely at my will;
- I have the right to refuse to participate in this evaluation and my decision for not taking part in the evaluation will not cause any penalty or loss of benefits or services to me;
- If I agree to be in the evaluation, I will be asked questions about my experiences with the [NAME OF P&A], what P&A staff did to help me, what happened as a result, and what I liked or disliked about the experience;
- I will be interviewed by myself in a private room or office (with a family member or personal assistant present if I wish).
- If I do not want to be interviewed in person, I can choose to talk about my experiences over the telephone;
- I can choose not to answer any questions that I do not want to answer;
- If I would like the interview to stop altogether, I just need to say so and the interview will be ended;
- There will be about 59 other people taking part in this type of interview;
- The interview will last approximately ½ hour – 45 minutes;
- I will be asked for my permission to have the interview audio recorded. No one but Westat will hear the recordings or see the transcriptions of the recordings.
- Everything I say will remain confidential and will not be repeated to anyone else;
- My name or other identifying information will not be used in any reports;
- Nothing I say will have any effect on any services I or my family might receive in the future;
- Participation in the evaluation will not put me at any risk and could benefit me by improving the programs and services for people with developmental disabilities and their families; and
- I will receive reimbursement for travel and personal assistance services.

To repeat, do you understand that:

1. You do not have to participate in this interview if you do not want to?
2. You do not have to answer all of the questions and can refuse to answer specific questions?
3. Everything you say today will be kept private, and your name will not be used in any reports that Westat writes?

If you have any questions about the evaluation, please contact the director of this project, Lynn Elinson, at (412) 421-8610.

CONSENT SIGNATURE:

Participant Name (please print) Participant's Signature Date

Signature of Person Conducting Informed Consent Discussion Date

Signature of Legally Authorized Representative (when appropriate) Date

Relationship to Participant (when appropriate)

If this consent form is read to the participant because the participant is unable to read the form, an impartial witness not affiliated with the project or project staff must be present for the consent and sign the following statement:

I confirm that the information in the consent form and any other written information was accurately explained to and apparently understood by the participant. The participant freely consented to take part in the evaluation.

Signature of Impartial Witness Date

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FOR OFFICE USE ONLY Study ID# _____

G3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service

Developmental Disabilities Program Independent Evaluation (DDPIE) Full-Scale Evaluation Consumer Advisory Committee Chair and Members

I, _____, consent to participate in the Developmental Disabilities Program Independent Evaluation (DDPIE) which is funded by the Administration on Developmental Disabilities (ADD) in the U.S. Department of Health and Human Services. The purpose of the DDPIE is to conduct an independent evaluation of the Developmental Disabilities Network Programs and collaboration among them. The (NAME OF UCEDD) is one of 20 UCEDDs selected for the evaluation. By consenting to take part in this study, I understand that:

- My participation in this evaluation is entirely at my will;
- I have the right to refuse to participate in this evaluation and my decision for not taking part in the evaluation will not cause any penalty or loss of benefits or services to me;
- I will be interviewed by myself in a private office or room (with a family member or personal assistant present if I wish).
- There will be about 59 other people who will have the same type of interview.
- If I agree to be in the study, I will be asked questions about the Consumer Advisory Committee and my experiences with the Committee;
- If I do not want to be interviewed in person, I can choose to talk about my experiences over the telephone;
- I can choose not to answer any questions that I do not want to answer;
- If I would like the interview to stop altogether, I just need to say so and the interview will be ended;
- The interview will last approximately ½ hour to 45 minutes;
- I will be asked for my permission to have the interview audio recorded. No one but Westat will hear the recordings or see the transcriptions of the recordings.
- Everything I say will remain confidential and will not be repeated to anyone else;
- My name or other identifying information will not be used in any reports;
- Nothing I say will have any effect on any services I or my family might receive in the future;
- Participation in this study will not put me at any risk and could benefit me by improving the programs and services for people with developmental disabilities and their families; and
- I will receive reimbursement for travel and personal assistance services.

To repeat, do you understand that:

1. You do not have to participate in this interview if you do not want to?
2. You do not have to answer all of the questions and can refuse to answer specific questions?
3. Everything you say today will be kept private, and your name will not be used in any reports that Westat writes?

If you have any questions about the evaluation, please contact the director of this project, Lynn Elinson, the Study Director, at 412 421-8610.

CONSENT SIGNATURE:

Participant Name (please print) Participant's Signature Date

Signature of Person Conducting Informed Consent Discussion Date

Signature of Legally Authorized Representative (when appropriate) Date

Relationship to Participant (when appropriate)

If this consent form is read to the participant because the participant is unable to read the form, an impartial witness not affiliated with the project or project staff must be present for the consent and sign the following statement:

I confirm that the information in the consent form and any other written information was accurately explained to and apparently understood by the participant. The participant freely consented to take part in the evaluation.

Signature of Impartial Witness Date

Note: This signature block cannot be used for translations into another language. A translated consent form is necessary for participants who do not speak English.

FOR OFFICE USE ONLY Study ID# _____

**Developmental Disabilities Program Independent Evaluation (DDPIE)
Full-Scale Evaluation
Recipients of UCEDD Community Services**

I, _____, consent to participate in the Developmental Disabilities Program Independent Evaluation (DDPIE) which is funded by the Administration on Developmental Disabilities (ADD) in the U.S. Department of Health and Human Services. The purpose of the DDPIE is to conduct an independent evaluation of the Developmental Disabilities Network Programs and collaboration among them. The (NAME OF UCEDD) is one of 20 UCEDDs selected for the evaluation. By consenting to take part in this evaluation, I understand that:

- My participation in this evaluation is entirely at my will;
- I have the right to refuse to participate in this evaluation and my decision for not taking part in the evaluation will not cause any penalty or loss of benefits or services to me;
- If I agree to be in the evaluation, I will be asked questions about my experiences with the UCEDD community services (e.g., _____) and my thoughts about how these services have affected me, people with developmental disabilities, their families, and the community at large;
- I will be interviewed by myself in a private office or room (with a family member or personal assistant if I wish).
- If I do not want to be interviewed in person, I can choose to talk about my experiences over the telephone;
- I can choose not to answer any questions that I do not want to answer;
- If I would like the interview to stop altogether, I just need to say so and the interview will be ended;
- There will be about 59 other people taking part in the same type of interview.
- The interview will last approximately ½ hour to 45 minutes.
- I will be asked for my permission to have the interview audio recorded. No one but Westat will hear the recordings or see the transcriptions of the recordings.
- Everything I say will remain confidential and will not be repeated to anyone else;
- My name or other identifying information will not be used in any reports;
- Nothing I say will have any effect on any services I or my family might receive in the future;
- Participation in this evaluation will not put me at any risk and could benefit me by improving the programs and services for people with developmental disabilities and their families; and
- I will receive reimbursement for travel and personal assistance services.

To repeat, do you understand that:

1. You do not have to participate in this interview if you do not want to?
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3. Everything you say today will be kept private, and your name will not be used in any reports that Westat writes?

If you have any questions about the evaluation, please contact the director of this project, Lynn Elinson, at (412) 421-8610.

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Signature of Impartial Witness Date

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Appendix H. Findings Form Templates

- H1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES**
- H2. PROTECTION AND ADVOCACY SYSTEMS**
- H3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL
DISABILITIES EDUCATION, RESEARCH, AND SERVICE**

Appendix H1. State Councils on Developmental Disabilities

- H1-1. State Plan Development**
- H1-2. Self-Advocacy and Leadership Development**
- H1-3. Community Capacity Development**
- H1-4. Identification of Promising and Effective Practices**
- H1-5. Systems Change Through Advocacy**
- H1-6. Governance and Management**

H1-1. State Plan Development

1.1 DD Council State Plans represent key issues, priorities, and needs of people with developmental disabilities and their families.

Indicators	Findings	Source
1.1.1 The process DD Councils use to develop the State Plan:		
1.1.1.1 Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families;	<ul style="list-style-type: none"> ▪ <i>What is the process for obtaining input?</i> ▪ <i>What types of stakeholders were asked to provide input?</i> 	Executive Director and Management Staff
1.1.1.2 Enables those in both urban and rural communities to participate;	<ul style="list-style-type: none"> ▪ <i>How did the process obtain input from people all over the state?</i> ▪ <i>What communities were included?</i> 	Executive Director and Management Staff
1.1.1.3 Provides opportunities for those who have never participated before to participate, particularly those who are typically unserved or underserved;	<ul style="list-style-type: none"> ▪ <i>How did the process enable people with diverse backgrounds to participate in providing input?</i> ▪ <i>What groups provided input?</i> 	Executive Director and Management Staff
1.1.1.4 Enables people with developmental disabilities to participate.	<ul style="list-style-type: none"> ▪ <i>How did the process enable people with developmental disabilities to participate?</i> ▪ <i>What accommodations were made?</i> ▪ <i>How were requests for input made?</i> 	Executive Director and Management Staff
1.1.1.5 Includes the use of feedback about current programs and activities (e.g., from participants in DD Council-funded programs; staff or grantee feedback).	<ul style="list-style-type: none"> ▪ <i>Was feedback from program activities included in development of state plan?</i> ▪ <i>What feedback was used?</i> ▪ <i>How was feedback obtained? (A8)</i> 	Executive Director and Management Staff
1.1.1.6 Includes the use of reliably collected, timely, and valid data;	<ul style="list-style-type: none"> ▪ <i>What other types of reports and data were used to develop state plan?</i> ▪ <i>What did the reports contain?</i> ▪ <i>How were they used? (A7)</i> 	Executive Director and Management Staff
1.1.2 DD Council State Plans reflect the input and data provided on the needs, priorities, and interests of people with developmental disabilities and their families.	<ul style="list-style-type: none"> ▪ <i>How did the DD Council go from feedback to a plan?</i> ▪ <i>What were the major findings from the planning process?</i> ▪ <i>Examples of how major goals and objectives reflect input and data.</i> 	Executive Director and Management Staff

1.2

DD Council planning drives DD Council activities.

Indicators	Findings	Source
<p>1.2.1 DD Council planning results in stated long-term systems change goals that are consistent with the DD Act and results in strategies to accomplish the goals.</p>	<ul style="list-style-type: none"> ▪ <i>What are the short- and long-term objectives of DD Council?</i> ▪ <i>What activities were conducted?</i> 	<p>Executive Director and Management Staff</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.2 Self-advocacy and leadership development activities are consistent with the goals and objectives in the State Plan and amendments.</p>	<ul style="list-style-type: none"> ▪ <i>What are the self-advocacy and leadership development goals and objectives of the DD Council?</i> ▪ <i>What self-advocacy and leadership activities were conducted?</i> 	<p>Executive Director and Management Staff</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.3 Community capacity development activities are consistent with the goals and objectives in the State Plan and amendments.</p>	<ul style="list-style-type: none"> ▪ <i>What are the community capacity development goals and objectives in the state Plan?</i> ▪ <i>What community capacity development activities were conducted?</i> 	<p>Executive Director and Management Staff</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.4 Promising practices that DD Councils identify, evaluate, promote, and disseminate are consistent with the goals and objectives in the State Plan and amendments.</p>	<ul style="list-style-type: none"> ▪ <i>What are the goals and objectives related to identifying, evaluating, promoting, and disseminating information on promising practices?</i> ▪ <i>What activities related to identification, evaluation, promotion, and dissemination of information on promising practices were conducted?</i> 	<p>Executive Director and Management Staff</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.5 Advocacy activities are consistent with the goals and objectives in the State Plan and amendments.</p>	<ul style="list-style-type: none"> ▪ <i>What are the advocacy goals and objectives of the DD Council?</i> ▪ <i>What advocacy activities were conducted?</i> 	<p>Executive Director and Management Staff</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.6 DD Councils address new and emerging issues not covered in the State Plan.</p>	<ul style="list-style-type: none"> ▪ <i>What procedures were used to take on new or emerging issues not covered in the State Plan</i> ▪ <i>What issues were taken on?</i> ▪ <i>What was the rationale?</i> 	<p>Executive Director and Management Staff</p>

H1-2. Self-Advocacy and Leadership Development

2.1 DD Councils provide and/or support self-advocacy and leadership development for people with developmental disabilities and/or their families.

Indicators	Findings	Source
<p>2.1.1 DD Councils provide or support self-advocacy and leadership development through education, training, and technical assistance for people with developmental disabilities and/or their families.</p>	<ul style="list-style-type: none"> ▪ <i>How was self-advocacy and leadership development supported or provided by the DD Council?</i> ▪ <i>How was participation in activities tracked?</i> 	<p>Executive Director and Management Staff Recipients of Advocacy and Leadership Education and Training</p>
<p>2.1.2 Participants in DD Council-supported self-advocacy and leadership development through education, training, and technical assistance represent a wide variety of groups and communities typically considered to be unserved or underserved.</p>	<ul style="list-style-type: none"> ▪ <i>What groups or communities participated in Council-supported self-advocacy and leadership development?</i> ▪ <i>How were they identified and recruited?</i> 	<p>Executive Director and Management Staff</p>
<p>2.1.3 DD Councils establish or strengthen “a program for the direct funding of a State self-advocacy organization led by people with developmental disabilities.”</p>	<ul style="list-style-type: none"> ▪ <i>What does the DD Council do to establish or strengthen a program for the direct funding of a State self-advocacy organization led by people with developmental disabilities?</i> 	<p>Executive Director and Management Staff</p>

2.2 Participants in self-advocacy and leadership activities supported by DD Councils use their knowledge and skills to advocate for themselves, advocate for others, and provide leadership to the developmental disabilities community and the community at large.

Indicators	Findings	Source
<p>2.2.1 DD Councils and grantees evaluate DD Council-supported self-advocacy and leadership development activities to improve their programs.</p>	<p><i>Whether and how the DD Council evaluated self-advocacy and leadership development activities?</i> <i>What they found?</i> <i>How they used the results of the evaluation?</i></p>	<p>Executive Director and Management Staff Recipients of Advocacy and Leadership Education and Training</p>
<p>2.2.2 Participants in DD Council-supported self-advocacy and leadership development activities:</p> <ul style="list-style-type: none"> ▪ Are nominated to become members of the DD Council; ▪ Become leaders or sub-committee members of the DD Council; ▪ Become members or leaders of other organizations that advocate on behalf of people with disabilities; ▪ Become members or leaders of other community organizations; ▪ Participate in DD Council or other advocacy efforts; ▪ Become an employee or volunteer of a disability advocacy organization; and ▪ Use the knowledge and skills they obtained to enhance their lives and become self-sufficient. 	<ul style="list-style-type: none"> ▪ <i>How does the DD Council follow up people who participated in self-advocacy and leadership development activities?</i> ▪ <i>How did participants benefit?</i> 	<p>Executive Director and Management Staff Recipients of Advocacy and Leadership Education and Training</p>
<p>2.2.3 DD Council-supported programs led by people with developmental disabilities [(Section 124(c)(4)(A)(ii)(I)] improve.</p>	<ul style="list-style-type: none"> ▪ <i>Progress/improvements to council supported programs led by people with disabilities?</i> 	<p>Executive Director and Management Staff</p>

H1-3. Community Capacity Development

- 3.1 DD Councils provide or support community capacity development activities that target those who potentially have an influence on the choice, inclusion, and integration of people with developmental disabilities into the community.

Indicators	Findings	Source
3.1.1 DD Councils provide or support community capacity development through information, training demonstration projects, and technical assistance to individuals and organizations that are in a position to provide people with developmental disabilities choice and inclusion in the community.	<ul style="list-style-type: none"> ▪ <i>What did the DD Council do to provide or support community capacity development?</i> ▪ <i>Whether they kept track of people who participated?</i> 	Executive Director and Management Staff Recipients of Education and Training to Improve Community Capacity

- 3.2 Information, training, demonstration projects and technical assistance provided or supported by DD Councils are responsive to the needs of people with developmental disabilities and to their families.

Indicators	Findings	Source
3.2.1 DD Councils and grantees evaluate DD Council-supported community capacity development activities to improve their programs. (process;)	<ul style="list-style-type: none"> ▪ <i>Whether DD Council evaluates community capacity development activities</i> ▪ <i>How they evaluate?</i> ▪ <i>What is the satisfaction level?</i> ▪ <i>How they used evaluation results?</i> 	Executive Director and Management Staff Recipients of Education and Training to Improve Community Capacity
3.2.2 Recipients of DD Council-supported information, training, and technical assistance: <ul style="list-style-type: none"> ▪ Transfer the knowledge and skills they obtained to their work; ▪ Improve their effectiveness in providing services or supports to people with developmental disabilities; and ▪ Improve the effectiveness of the community in including people with developmental disabilities in all aspects of life. 	<ul style="list-style-type: none"> ▪ <i>Whether and how DD Council or grantees follow up participants in community capacity development activities</i> ▪ <i>How did participants benefit?</i> 	Executive Director and Management Staff Recipients of Education and Training to Improve Community Capacity

H1-4. Identification of Promising and Effective Practices

4.1 DD Councils identify and test promising practices.

Indicators	Findings	Source
4.1.1 DD Councils identify and test promising practices in a variety of ways.	<ul style="list-style-type: none"> ▪ <i>How did the DD Council identify or test promising practices?</i> ▪ <i>What are some of the promising practices the DD Council identified?</i> 	Executive Director and Management Staff

4.2 Promising practices identified tested by DD Councils improve supports and services for people with developmental disabilities and their families and increase inclusion and choice in the community.

Indicators	Findings	Source
4.2.1 DD Councils disseminate results of efforts to identify and test promising practices.	<ul style="list-style-type: none"> ▪ <i>Whether and how the DD Council promoted promising practices shown to be effective?</i> ▪ <i>Whether and how the DD Council disseminated information on effective promising practices?</i> ▪ <i>Whether and how the DD Council disseminated information on ineffective promising practices?</i> 	Executive Director and Management Staff
4.2.2 Effective practices identified by DD Councils increase inclusion and choice in the community.	<ul style="list-style-type: none"> ▪ <i>Examples of effective or promising practices being used?</i> ▪ <i>Examples of increased inclusion and choice as a result of implementing effective practices identified by the DD Council?</i> 	Executive Director and Management Staff
4.2.3 Promising and effective practices identified by DD Councils guide future DD Council activities (e.g., become an advocacy issue).	<ul style="list-style-type: none"> ▪ <i>Examples of changes to Council activities as a result of findings or promising practices?</i> 	Executive Director and Management Staff

H1-5. Systems Change Through Advocacy

5.1 DD Councils address systems change issues that impact the lives of people with developmental disabilities and their families and promote inclusion and choice for people with developmental disabilities.

Indicators	Findings	Source
5.1.1 DD Councils use a variety of advocacy strategies to meet systems change goals and objectives.	<ul style="list-style-type: none"> ▪ <i>Examples of advocacy strategies DD Council used to meet its systems change goals and objectives?</i> 	Executive Director and Management Staff Policymakers, Collaborators, Contractors <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
5.1.2 DD Councils collaborate with local, state, and federal agencies, organizations, individuals, disability networks, coalitions, and other DD Network programs to achieve systems change goals and objectives through advocacy.	<ul style="list-style-type: none"> ▪ <i>What organizations/individuals partnered with the DD Council to meet its systems change goals</i> ▪ <i>What roles were played by each partner?</i> 	Executive Director and Management Staff Policymakers, Collaborators, Contractors

5.2 DD Council systems change efforts through advocacy facilitate changes to or maintenance of legislative, administrative, and/or organizational actions, policies, and practices that positively impact the lives of people with developmental disabilities and their families.

Indicators	Findings	Source
5.2.1 DD Council advocacy efforts support changes to or maintenance of legislation or public or social policy.	<ul style="list-style-type: none"> ▪ <i>Whether and how advocacy efforts supported (or prevented) change to legislation or social policy?</i> 	Executive Director and Management Staff Policymakers, Collaborators, Contractors
5.2.2 DD Council advocacy efforts support changes to community practice which lead to inclusion in the community, independence, and increased choice.	<ul style="list-style-type: none"> ▪ <i>Whether and how advocacy efforts supported (or prevented) changes to community practices?</i> ▪ <i>Whether and how advocacy efforts led to inclusion, independence, and increased choice? (4)</i> 	Executive Director and Management Staff Policymakers, Collaborators, Contractors

H1-6. Governance and Management

6.1 DD Councils have the capacity to fulfill their roles and responsibilities.

Indicators	Findings	Source
6.1.1 DD Council members collectively have the areas of expertise required to be an effective Council.	<ul style="list-style-type: none"> ▪ <i>What is the background of Council members?</i> ▪ <i>What are the areas of expertise of Council members?</i> 	Executive Director and Management Staff Council Chair/Council Members
6.1.2 DD Council members learn about their roles and responsibilities, the intent of the DD Act, and the DD Council in a variety of ways.	<ul style="list-style-type: none"> ▪ <i>How do Council members learn about their roles and responsibilities, DD Act, and DD Council?</i> ▪ <i>If there is an orientation, what does orientation include?</i> ▪ <i>What do Council members say about the Council mission?</i> ▪ <i>What do Council members say about some of the goals and objectives in the current State Plan?</i> 	Executive Director and Management Staff Council Chair/Council Members
6.1.3 DD Council members consistently attend DD Council meetings.	<ul style="list-style-type: none"> ▪ <i>How often does the DD Council meet?</i> ▪ <i>Is there an attendance policy? What is it?</i> ▪ 	Executive Director and Management Staff
6.1.4 DD Council staff provides members with support so they can consistently and meaningfully participate in meetings and fulfill their responsibilities.	<ul style="list-style-type: none"> ▪ <i>What supports are Council members provided so they can attend and participate in meetings?</i> ▪ <i>How satisfied are members with their supports?</i> 	Executive Director and Management Staff Council Chair/Council Members
6.1.5 DD Councils periodically conduct self-evaluations.	<ul style="list-style-type: none"> ▪ <i>How does the DD Council evaluate itself?</i> ▪ <i>What is evaluated?</i> 	Executive Director and Management Staff
6.1.6 DD Councils assess their own efficiency and effectiveness in meeting their goals and objectives.	<ul style="list-style-type: none"> ▪ <i>Whether the DD Council reviewed the performance of staff? How?</i> ▪ <i>Whether new staff received an orientation?</i> ▪ <i>Whether grantees received technical assistance?</i> 	Executive Director and Management Staff

6.2 DD Councils use a fair and transparent process to select competent and experienced grantees to implement goals and objectives in the State Plan and amendments.

Indicators	Findings	Source
6.2.1 DD Councils have a written policy or procedures for selecting competent and experienced grantees.	<ul style="list-style-type: none"> ▪ <i>How did the DD Council select grantees?</i> ▪ <i>Whether or not there is a policy for selecting grantees?</i> ▪ <i>What does the policy entail?</i> 	Executive Director and Management Staff
6.2.2 DD Councils utilize review committees composed of people who have an understanding of issues concerning people with developmental disabilities and family members and have experience in selecting and monitoring grantees.	<ul style="list-style-type: none"> ▪ <i>How did the Council review proposals?</i> ▪ <i>Whether the Council used a review committee?</i> ▪ <i>What was the composition of the review committee? (F42)</i> 	Executive Director and Management Staff
6.2.3 DD Councils have a policy or procedures for handling unsolicited proposals.	<ul style="list-style-type: none"> ▪ <i>How did the DDC handle unsolicited proposals?</i> 	Executive Director and Management Staff

6.3 DD Councils administer the work of grantees in a professional manner.

Indicators	Findings	Source
6.3.1 DD Councils issue contracts to grantees.	<ul style="list-style-type: none"> ▪ <i>Did the Council issue contracts on funded projects?</i> ▪ <i>What did the contracts contain?</i> 	Executive Director and Management Staff
6.3.2 DD Council-supported grantees meet the requirements of their contracts.	<ul style="list-style-type: none"> ▪ <i>Were the requirements of the contracts met (e.g., deadlines, deliverables)?</i> 	Executive Director and Management Staff

Appendix H2. Protection and Advocacy Systems

- H2-1. Planning and Priority Setting**
- H2-2. Intake and Assistance**
- H2-3. Individual Advocacy**
- H2-4. Systemic Advocacy**
- H2-5. Community Outreach and Education**
- H2-6. Governance and Management**

H2-1. Planning and Priority Setting

1.1 P&A Statements of Goals and Priorities (SGPs) represent key issues, priorities, and needs of people with developmental disabilities and their families.

Indicators	Findings	Source
1.1.1 The P&A process for planning and priority setting:		
1.1.1.1 Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families	<ul style="list-style-type: none"> ▪ <i>What is the process for obtaining input?</i> ▪ <i>What types of stakeholders were asked to provide input?</i> 	Executive Director (Management Staff) P&A Staff
1.1.1.2 Enables those in both urban and rural communities to participate	<ul style="list-style-type: none"> ▪ <i>How did the process obtain input from people from all over the state?</i> ▪ <i>What communities were included?</i> 	Executive Director (Management Staff)
1.1.1.3 Provides opportunities for those who have never participated before to participate	<ul style="list-style-type: none"> ▪ <i>How did the process enable people with diverse background to participate in providing input?</i> ▪ <i>What groups provided input?</i> 	Executive Director (Management Staff)
1.1.1.4 Enables people with developmental disabilities to participate.	<ul style="list-style-type: none"> ▪ <i>How did the process enable people with developmental disabilities to participate?</i> ▪ <i>What accommodations were made?</i> ▪ <i>How were requests for input made?</i> 	Executive Director (Management Staff)
1.1.1.5 Includes the use of feedback about current programs and activities (e.g., intake information, caseload statistics, staff and contractor feedback)	<ul style="list-style-type: none"> ▪ <i>Was feedback from program activities included?</i> ▪ <i>What feedback was used?</i> ▪ <i>How was feedback obtained?</i> 	Executive Director (Management Staff)
1.1.1.6 Includes the use of reliably collected, timely, and valid data	<ul style="list-style-type: none"> ▪ <i>What other types of reports and data were used?</i> ▪ <i>What did the reports contain?</i> ▪ <i>How were they used?</i> 	Executive Director (Management Staff)
1.1.2 SGPs reflect the stakeholder input and data obtained on the needs, priorities, and interests of the developmental disabilities community	<ul style="list-style-type: none"> ▪ <i>How did the Council go from feedback to a plan?</i> ▪ <i>What were the major findings from the planning process?</i> ▪ <i>Example(s) of how major goals and objectives reflect input and data</i> 	Executive Director (Management Staff)

1.2 P&A planning drives P&A activities.

Indicators	Findings	Source
<p>1.2.1 P&A priorities are integrated into the full range of materials provided to internal staff, members of the Board of Directors/ Commission, and the public.</p>	<ul style="list-style-type: none"> ▪ <i>How are forms and materials reflective of P&A priorities? (A12)</i> 	<p>Executive Director (Management Staff)</p>
<p>1.2.2 P&A individual advocacy caseloads are determined by the priorities in the SGP [see indicator 3.1.1]</p>	<ul style="list-style-type: none"> ▪ <i>What were the primary goals and objectives of the P&A?</i> ▪ <i>What types of individual advocacy issues were taken on?</i> 	<p>Executive Director (Management Staff)</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.3 Systemic advocacy activities reflect the goals and priorities in the SGP.</p>	<ul style="list-style-type: none"> ▪ <i>What were the primary systemic advocacy issues of the P&A?</i> ▪ <i>What were the systemic advocacy activities?</i> 	<p>Executive Director (Management Staff)</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.4 Community outreach activities reflect the goals and priorities in the SGP.</p>	<ul style="list-style-type: none"> ▪ <i>What were the main community outreach goals and objectives?</i> ▪ <i>What were the major community outreach activities?</i> 	<p>Executive Director (Management Staff)</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.5 Community education activities reflect the goals and priorities in the SGP.</p>	<ul style="list-style-type: none"> ▪ <i>What were the main community education goals and objectives?</i> ▪ <i>What were the major community education activities?</i> 	<p>Executive Director (Management Staff)</p> <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
<p>1.2.6 P&As prepare for and respond to emerging and emergency issues not covered in the SGP that have immediate impact on people with developmental disabilities.</p>	<ul style="list-style-type: none"> ▪ <i>What were emerging or emergency issues addressed?</i> ▪ <i>What was the rationale for taking these issues on?</i> ▪ <i>How did the P&A respond to them?</i> 	<p>Executive Director (Management Staff)</p>

H2-2. Intake and Assistance

2.1 P&As respond efficiently to requests for information, resources, and assistance related to issues affecting people with developmental disabilities and their families.

Indicators	Findings	Source
2.1.1 P&As have written intake procedures that meet the needs of people with disabilities and family members.	<ul style="list-style-type: none"> ▪ <i>What procedures are used for intake?</i> ▪ <i>Are there written intake procedures?</i> ▪ <i>What do the written intake procedures consist of?</i> ▪ <i>How/whether people with developmental disabilities provided input into intake procedures?</i> 	Executive Director (Management Staff) P&A Staff P&A Client
2.1.2 P&A intake staff receives training on intake procedures to better provide assistance to people with developmental disabilities and their families.	<ul style="list-style-type: none"> ▪ <i>What is the nature of the training for new intake staff?</i> ▪ <i>Whether/how are people with developmental disabilities were included in training?</i> 	Executive Director (Management Staff) P&A Staff
2.1.3 P&A intake staff follows intake procedures.	<ul style="list-style-type: none"> ▪ <i>What procedures did intake staff use?</i> 	Executive Director (Management Staff) P&A (intake) Staff

2.2 P&As respond appropriately to requests for information, resources, and assistance related to issues affecting people with developmental disabilities and their families.

Indicators	Findings	Source
2.2.1 P&As periodically assess satisfaction of clients with the assistance they receive.	<ul style="list-style-type: none"> ▪ <i>How did the P&A assess client satisfaction?</i> ▪ <i>How was feedback used?</i> 	Executive Director (Management Staff) P&A Staff
2.2.2 P&A clients are satisfied with the assistance they receive.	<ul style="list-style-type: none"> ▪ <i>What was level of satisfaction?</i> 	Executive Director (Management Staff) P&A Staff P&A Clients
2.2.3 P&As provide callers and clients with information about the grievance procedure.	<ul style="list-style-type: none"> ▪ <i>How and when did the P&A provide grievance information to those who were denied/accepted as P &A clients?</i> 	Executive Director (Management Staff)

H2-3. Individual Advocacy

3.1 P&A client caseloads reflect the priorities and needs of people with developmental disabilities and their families.

Indicators	Findings	Source
3.1.1 P&As represent individual advocacy clients on issues that are consistent with the goals and priorities in the SGA.	<ul style="list-style-type: none"> ▪ <i>What were the individual advocacy issues on which clients were represented?</i> ▪ <i>What were the priorities in the SGP?</i> 	Executive Director (Management Staff) P&A Staff P&A Client <ul style="list-style-type: none"> ▪ <i>Also in SAQ</i>
3.1.2 P&As represent people from typically unserved or underserved populations or communities.	<ul style="list-style-type: none"> ▪ <i>What populations/communities did P&A individual advocacy cases come from?</i> 	Executive Director (Management Staff) P&A Client

3.2 P&As provide high quality, professional representation to individuals.

Indicators	Findings	Source
3.2.1 P&As provide opportunities for individual advocacy staff to discuss cases in order to share ideas and learn from one another.	<ul style="list-style-type: none"> ▪ <i>How/whether individual advocacy staff shared case experiences?</i> 	Executive Director (Management Staff) P&A Staff
3.2.2 Experienced P&A legal staff reviews case files of individual advocacy staff.	<ul style="list-style-type: none"> ▪ <i>How does P&A monitor individual advocacy?</i> ▪ <i>Is there a policy?</i> ▪ <i>What is the nature of the policy?</i> 	Executive Director (Management Staff) P&A Staff
3.2.3 P&As maintain confidentiality at all times.	<ul style="list-style-type: none"> ▪ <i>How is client confidentiality maintained/assured/promised?</i> 	Executive Director (Management Staff) P&A Staff Client

3.3 P&A individual advocacy meets the client’s identified objectives.

Indicators	Findings	Source
3.3.1 P&As communicate with clients in their chosen mode of communication and in language the client can understand.	<ul style="list-style-type: none"> ▪ <i>How do P &As communicate with clients?</i> 	Executive Director (Management Staff) P&A Staff P&A Clients
3.3.2 P&A clients and their P&A representatives have a common understanding of the issues that need to be resolved on behalf of clients and the ways in which P&A representatives will try to resolve those issues.	<ul style="list-style-type: none"> ▪ <i>What is the nature of the understanding P&A representatives had with their clients?</i> 	Executive Director (Management Staff) P&A Staff P&A Clients
3.3.3 P&As meet the documented objectives of clients.	<ul style="list-style-type: none"> ▪ <i>What are the issues of cases P&As take on?</i> ▪ <i>What are the objectives?</i> ▪ <i>What do P&A representatives do for their clients?</i> ▪ <i>What information do closing letters contain?</i> 	Executive Director (Management Staff) P&A Staff P&A Clients
3.3.4 P&A clients are provided with information to file a grievance. (process; structure)	<ul style="list-style-type: none"> ▪ <i>How do staff ensure clients understand grievance process?</i> ▪ <i>What does the explanation entail?</i> 	Executive Director (Management Staff) P&A Staff

H2-4. Systemic Advocacy

4.1 P&As respond to systemic advocacy issues that meet the needs of the developmental disabilities community.

Indicators	Findings	Source
4.1.1. P&As use a variety of strategies to meet systemic advocacy goals and objectives.	<ul style="list-style-type: none"> ▪ <i>What are some systemic advocacy issues?</i> ▪ <i>What strategies are used?</i> 	Executive Director (Management Staff) Policy Makers and Collaborators Staff
4.1.2 P&As collaborate with Federal, State, and local agencies, organizations, individuals, networks, coalitions, and other DD Network programs to implement systemic advocacy activities.	<ul style="list-style-type: none"> ▪ <i>How are systemic advocacy efforts coordinated with partners/collaborators?</i> ▪ <i>What role does P & A staff play with regard to meeting systemic advocacy goals and objectives?</i> 	Executive Director (Management Staff) Policy Makers and Collaborators

4.2 P&A systemic advocacy efforts help to change or maintain legislative, administrative, and/or organizational actions, policies, and practices that reflect the needs of people with developmental disabilities and their families.

Indicators	Findings	Source
4.1.1 P&A systemic advocacy efforts support or enhance changes to or maintenance of legislation or statewide or local public policy.	<ul style="list-style-type: none"> ▪ <i>Whether and how systemic advocacy efforts supported, enhanced, or prevented changes to legislation or statewide policy?</i> 	Executive Director (Management Staff) Policy Makers and Collaborators
4.1.2 P&A systemic advocacy efforts support or enhance changes to or maintenance of statewide or local community practice or services.	<ul style="list-style-type: none"> ▪ <i>Whether and how systemic advocacy supported, enhanced, or maintained changes to statewide or local community practice or services?</i> 	Executive Director (Management Staff) Policy Makers and Collaborators

H2-5. Community Outreach and Education

5.1 P&As are a resource on developmental disability issues for the community.

Indicators	Findings	Source
5.1.1 P&As engage in outreach activities, including outreach to those who are typically unserved or underserved.	<ul style="list-style-type: none"> ▪ <i>What were examples of outreach activities implemented by the P&A?</i> ▪ <i>What populations/communities were targeted?</i> 	Executive Director P&A Staff
5.1.2 P&As provide or support training and education for people with developmental disabilities and family members to advocate for themselves.	<ul style="list-style-type: none"> ▪ <i>What were examples of training and education activities provided by the P&A for people with developmental disabilities and their families so they could advocate for themselves?</i> 	Executive Director Recipients of Community Education
5.1.3 P&As provide or support information activities, training and technical assistance to the community at large to improve access, inclusion, and choice.	<ul style="list-style-type: none"> ▪ <i>What are some examples of community education activities?</i> 	Executive Director (Management Staff) P&A Staff Recipients of Community Education
5.1.4 P&A community outreach and education are culturally competent.	<ul style="list-style-type: none"> ▪ <i>What are some examples of how community outreach and education activities were geared culturally to the target audience?</i> 	Executive Director (Management Staff) P&A Staff Recipients of Community Education

5.1 P&As are a resource on developmental disability issues for the community (continued)

Indicators	Findings	Source
5.1.5 P&A community outreach and education is understandable to people with developmental disabilities.	<ul style="list-style-type: none"> ▪ <i>Whether the outreach is understandable to people with developmental disabilities?</i> 	Executive Director (Management Staff) P&A Staff Recipients of CommEduc

5.2 P&A outreach and community education are responsive to the requests and needs of people with developmental disabilities and their families.

Indicators	Findings	Source
5.2.1 P&A outreach reaches all components of its constituency, including typically unserved or underserved populations or communities. <i>(output; process)</i>	<ul style="list-style-type: none"> ▪ <i>What groups are being reached through community outreach?</i> 	Executive Director (Management Staff) P&A Staff Recipients of Community Education
5.2.2 Recipients of P&A community education are able to understand and use what they learned in their job or everyday life.	<ul style="list-style-type: none"> ▪ <i>What did the P&A do to obtain feedback from recipients of community education?</i> ▪ <i>How were people who received community education able to advocate for themselves?</i> ▪ <i>How have recipients of community education and the community benefitted from receiving community education (e.g., improved the quality of their interactions with people with developmental disabilities and their families; changed policies; increased the number of people with developmental disabilities they served or hired)?</i> 	Executive Director (Management Staff) P&A Staff Recipients of Community Education

H2-6. Governance and Management

6.1 P&As maintain an infrastructure that enables them to conduct all key functions efficiently and effectively.

Indicators	Findings	Source
6.1.1 P&A Boards or Commissions collectively have an understanding of people with developmental disabilities and areas of expertise required to meet their responsibilities.	<ul style="list-style-type: none"> ▪ <i>What is background of board members?</i> 	Executive Director (Management Staff) Board of Directors
6.1.2 P&As hire and maintain qualified staff to effectively provide services, including services to typically unserved and underserved populations and communities.	<ul style="list-style-type: none"> ▪ <i>What is staff background?</i> ▪ <i>Whether and how staff performance is reviewed?</i> 	Executive Director (Management Staff)
6.1.3 P&As are responsive to emerging issues and emergency issues that arise suddenly.	<ul style="list-style-type: none"> ▪ <i>Whether and what are the processes in place for responding to emerging or emergency issues?</i> ▪ <i>Describe examples of emerging/emergency issues.</i> ▪ <i>What was rationale for addressing them?</i> 	Executive Director (Management Staff)
6.1.4 P&As maintain sound fiscal management to support the infrastructure.	<ul style="list-style-type: none"> ▪ <i>Whether and how an audit was performed?</i> ▪ <i>What was the result of that audit?</i> 	Executive Director (Management Staff)

6.2 P&A governance adheres to the principles and goals of the DD Act.

Indicators	Findings	Source
6.2.1 P&A Boards of Directors or Commissions are familiar with the mission and goals of the DD Act and the goals of the P&As.	<ul style="list-style-type: none"> ▪ <i>What do Board members say about mission and goals of the DD Act and the P & A?</i> ▪ <i>What activities do board or commission members participate in?</i> 	Executive Director (Management Staff) Board of Directors
6.2.2 P&A Boards of Directors or Commissions receive support from P&As so members can meaningfully participate in meetings and fulfill their responsibilities.	<ul style="list-style-type: none"> ▪ <i>What support is given so board members can participate in meetings and activities?</i> 	Executive Director (Management Staff) Board of Directors
6.2.3 P&As operate independently from the Governor and the developmental disabilities service system of their state.	<ul style="list-style-type: none"> ▪ <i>Examples of:</i> ▪ <i>No restrictions on ability and authority to litigate</i> ▪ <i>Not being financially encumbered by the governor or state developmental disabilities service system?</i> 	Executive Director (Management Staff)
6.2.4 P&A programs are physically and programmatically accessible.	<ul style="list-style-type: none"> ▪ <i>Examples of how programs are physically and programmatically accessible?</i> 	Executive Director (Management Staff)

Appendix H3. University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)

- H3-1. 5-Year Planning**
- H3-2. Interdisciplinary Pre-service Teaching and Continuing Education**
- H3-3. Basic and/or Applied Research**
- H3-4. Community Services**
- H3-5. Dissemination**
- H3-6. Governance and Management**

H3-1. 5-YEAR PLANNING

1.1 UCEDD 5-year plans represent key issues, priorities, and needs of people with developmental disabilities and their families.

Indicators	Findings	Source
1.1.1 The UCEDD process for developing the 5-year plan:		
1.1.1.1 Ensures wide and varied input from those who are knowledgeable about the needs of people with developmental disabilities and their families	<ul style="list-style-type: none"> ▪ <i>What is the process for ensuring wide and varied input?</i> ▪ <i>What types of stakeholders were asked to provide input? (1, 2, 3)</i> 	Executive Director
1.1.1.2 Enables those in both urban and rural communities and communities across the state to participate	<ul style="list-style-type: none"> ▪ <i>How did the process include obtaining input from people from all over the state?</i> ▪ <i>What communities were included?</i> 	Executive Director
1.1.1.3 Provides opportunities for those who have never participated before to participate, including those who are typically unserved or underserved	<ul style="list-style-type: none"> ▪ <i>How did the process enable people with diverse backgrounds to participate in providing input?</i> ▪ <i>What groups provided input?</i> 	Executive Director
1.1.1.4 Enables people with developmental disabilities to participate.	<ul style="list-style-type: none"> ▪ <i>How did the process enable people with developmental disabilities to participate?</i> ▪ <i>What accommodations were made?</i> ▪ <i>How were requests for input made?</i> 	Executive Director
1.1.1.5 Includes the use of feedback from current programs and activities (e.g., intake information of direct services programs, staff feedback)	<ul style="list-style-type: none"> ▪ <i>Was feedback from program activities included?</i> ▪ <i>What feedback was used?</i> ▪ <i>How was feedback obtained?</i> 	Executive Director
1.1.1.6 Includes the use of reliably collected, timely, and valid data	<ul style="list-style-type: none"> ▪ <i>What other types of reports and data were used?</i> ▪ <i>What do the reports contain?</i> ▪ <i>How were they used?</i> 	Executive Director
1.1.2 UCEDD 5-year plans reflect the stakeholder input and data provided on the needs, priorities, and interests of people with developmental disabilities and their families.	<ul style="list-style-type: none"> ▪ <i>How UCEDD went from feedback to a plan?</i> ▪ <i>Major findings from planning process.</i> ▪ <i>Example(s) of how major goals and objectives reflect input and data.</i> 	Executive Director

1.2 UCEDD planning drives UCEDD activities.

Indicators	Findings	Source
<p>1.2.1 UCEDD interdisciplinary pre-service preparation and undergraduate teaching and continuing education activities are consistent with the goals and priorities in the 5-year plan or adjustments to the plan.</p>	<ul style="list-style-type: none"> ▪ <i>What are primary education and teaching goals and objectives in 5-year plan or adjustments</i> ▪ <i>What are major undergraduate and graduate teaching and continuing education activities</i> 	<p>Executive Director</p>
<p>1.2.2 UCEDD basic and/or applied research activities (including policy analysis and program evaluation) are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.</p>	<ul style="list-style-type: none"> ▪ <i>What are primary research goals and objectives in 5-year plan or adjustments?</i> ▪ <i>What are major research activities?</i> 	<p>Executive Director</p>
<p>1.2.3 UCEDD community services (including direct services, technical assistance, and training) are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.</p>	<ul style="list-style-type: none"> ▪ <i>What are primary community services goals and objectives in 5-year plan or adjustments</i> ▪ <i>What are major community services activities /</i> 	<p>Executive Director</p>
<p>1.2.4 UCEDD dissemination activities are consistent with the goals and objectives in the 5-year plan or adjustments to the plan.</p>	<ul style="list-style-type: none"> ▪ <i>What are the primary dissemination goals and objectives in 5-year plan or adjustments</i> ▪ <i>What are the major dissemination activities?</i> 	<p>Executive Director</p>
<p>1.2.5 UCEDDs address new and emerging issues not covered in the 5-year plan or adjustments to the plan.</p>	<ul style="list-style-type: none"> ▪ <i>What new and emerging issues were addressed?</i> ▪ <i>What was the rationale for taking them on?</i> 	<p>Executive Director</p>

H3-2. Interdisciplinary Pre-Service Preparation and Continuing Education

2.1 UCEDD curricula, training materials, and teaching are interdisciplinary.

Indicators	Findings	Source
2.1.1 UCEDD-developed curricula and syllabi incorporate the perspectives and interactions among a variety of disciplines.	<ul style="list-style-type: none"> ▪ <i>What are some examples of interdisciplinary curricula and syllabi?</i> ▪ <i>In what way are they interdisciplinary?</i> ▪ <i>What disciplines are represented?</i> 	Executive Director Current and Graduated Students Researchers and Colleagues
2.1.2 UCEDD teaching is inter-disciplinary.	<ul style="list-style-type: none"> ▪ <i>What are examples of inter-disciplinary teaching?</i> ▪ <i>In what way is the teaching interdisciplinary?</i> ▪ <i>What disciplines are represented?</i> 	Executive Director Current and Graduated Students
2.1.3 UCEDD faculty is comprised of a variety of disciplines.	<ul style="list-style-type: none"> ▪ <i>What are the disciplines represented by UCEDD faculty?</i> 	Executive Director Current and Graduated Students
2.1.4 UCEDD-developed courses use instructors from a variety of disciplines.	<ul style="list-style-type: none"> ▪ <i>What are some examples of courses with instructors from more than one discipline?</i> ▪ <i>What courses?</i> ▪ <i>What disciplines?</i> 	Executive Director Current and Graduated Students
2.1.5 UCEDD faculty and staff train students from multiple disciplines.	<ul style="list-style-type: none"> ▪ <i>How does the UCEDD provide training to students?</i> ▪ <i>What disciplines are represented among students?</i> ▪ <i>What major fields are represented among students?</i> ▪ <i>What departments?</i> ▪ <i>What courses?</i> 	Executive Director
2.1.5 UCEDDs conduct continuing education programs for a variety of professionals.	<ul style="list-style-type: none"> ▪ <i>What continuing education courses were taught?</i> ▪ <i>What types of professionals took them?</i> 	Executive Director Researchers and Colleagues
2.1.6 People with developmental disabilities and family members are an integral part of the interdisciplinary pre-service preparation and continuing education program.	<ul style="list-style-type: none"> ▪ <i>How do people with developmental disabilities and family members contribute to teaching and education at the UCEDD?</i> ▪ <i>Do staff members have developmental disabilities? Describe.</i> 	Executive Director

2.2 UCEDD faculty and teaching staff are knowledgeable and up-to-date in their field, skilled in teaching, and student-focused.

Indicators	Findings	Source
2.2.1 Courses taught or developed by UCEDD faculty and staff cover current practices and issues and contain up-to-date content.	<ul style="list-style-type: none"> ▪ <i>What courses were taught/taken?</i> ▪ <i>What current practices were covered?</i> 	Executive Director Researchers and Colleagues
2.2.2 UCEDD faculty and teaching staff are considered to be effective teachers by their students and peers.	<ul style="list-style-type: none"> ▪ <i>What do students/peers think of UCEDD faculty?</i> ▪ <i>How does UCEDD find out?</i> 	Executive Director Current and Graduated Students Researchers and Colleagues

2.3 UCEDD faculty and staff have an influence throughout the university.

Indicators	Findings	Source
2.3.1 UCEDDs sponsor, co-sponsor, or participate in disability-related seminars, presentations, or other disability-related activities within the University.	<ul style="list-style-type: none"> ▪ <i>Were UCEDDs involved in university presentations, seminars or other activities on disability? Describe.</i> ▪ <i>What was UCEDD role?</i> 	Executive Director
2.3.2 UCEDDs assist in incorporating disability content into university courses and curricula.	<ul style="list-style-type: none"> ▪ <i>Did UCEDD infuse disability content into courses?</i> ▪ <i>What courses?</i> ▪ <i>What type of content?</i> 	Executive Director
2.3.3 UCEDD faculty and staff provide their disability-related expertise to the university.	<ul style="list-style-type: none"> ▪ <i>What does UCEDD do for the University?</i> ▪ <i>Sits on committees</i> ▪ <i>Consultation on disability</i> ▪ <i>Chairs Ph.D. committees</i> ▪ <i>Describe.</i> 	Executive Director

2.4 Former students use what they learned from their experience with UCEDDs in their professional or personal lives.³²

Indicators	Findings	Source
<p>2.4.1 UCEDD-developed curricula, courses, and course content prepare students to work with and for typically unserved or underserved populations or communities.</p>	<ul style="list-style-type: none"> ▪ <i>How are students prepared to work with unserved and underserved populations?</i> ▪ <i>How are students taught about cultural competency?</i> 	<p>Executive Director Current and Graduated Students</p>
<p>2.4.2 Interdisciplinary pre-service students who completed their course of study work to benefit and affect the quality of life of people with developmental disabilities.</p>	<ul style="list-style-type: none"> ▪ <i>What happens to UCEDD students after they complete their program?</i> ▪ <i>How does the UCEDD find out what happens?</i> 	<p>Executive Director Current and Graduated Students Researchers and Colleagues</p>
<p>2.4.3 Among those students who participated in a disability studies program, disability is an important component of further education, career or their daily lives.</p>	<ul style="list-style-type: none"> ▪ <i>What happens to students who participated in disability studies program (or something similar) after they complete their program?</i> ▪ <i>How does UCEDD find out?</i> 	<p>Executive Director Researchers and Colleagues</p>
<p>2.4.4 Continuing education students apply what they learned in UCEDD continuing education courses to their work and/or daily lives.</p>	<ul style="list-style-type: none"> ▪ <i>How did continuing education students use the information they learned from UCEDD continuing education courses?</i> 	<p>Executive Director Researchers and Colleagues</p>

³² This benchmark assumes followup of students to determine the impact of UCEDD training. UCEDDs generally teach four different types of students: (1) Interdisciplinary pre-service students who are generally in a graduate or professional program (e.g., medicine, dentistry); (2) students with a concentration in disability and may come from more than one department (e.g., law, education, physiotherapy); (3) students throughout the university whose courses were infused with disability content and come from more than one department (e.g., mathematics, history, political science, journalism, English literature); and (4) continuing education students. Followup for category 1 is expected to be the most extensive. Category 3 students are not expected to be followed. Information on students in categories 2 and 4 can be obtained at the end of the course/program. Further followup is not expected.

H3-3. Basic and/or Applied Research

3.1 UCEDD research, evaluation, and/or public policy analysis are of high quality.

Indicators	Findings	Source
3.1.1 UCEDD faculty and staff publish on their disability research.	<ul style="list-style-type: none"> ▪ <i>Types of publications UCEDD faculty/staff publish in (e.g., peer-reviewed, technical reports, etc...)</i> ▪ <i>Journals in which articles were published</i> ▪ <i>Topic?</i> 	Executive Director Researchers and Colleagues
3.1.2 UCEDD faculty and staff make presentations on their disability-related research (including public policy analysis and evaluation) at conferences and meetings.	<ul style="list-style-type: none"> ▪ <i>Type of conference or meeting at which faculty and staff made presentations?</i> ▪ <i>Topic of presentation</i> 	Executive Director Researchers and Colleagues

3.2 UCEDD faculty and staff are well-recognized in their field of disability research.

Indicators	Findings	Source
3.2.1 UCEDD faculty and staff provide advice on disability related issues to local, state, federal, and international organizations.	<ul style="list-style-type: none"> ▪ <i>To what groups did UCEDD faculty provide advice?</i> ▪ <i>What type of advice did UCEDD faculty provide?</i> ▪ <i>In what format was the advice given (e.g., public testimony, member of commission)?</i> 	Executive Director Researchers and Colleagues
3.2.2 UCEDD faculty and staff review grants, manuscripts, books, articles, and other types of publications.	<ul style="list-style-type: none"> ▪ <i>Did UCEDD faculty or staff review articles or documents?</i> ▪ <i>Type of document reviewed (e.g., proposals, journal manuscript)?</i> ▪ <i>Agency/organization for which documents reviewed?</i> 	Executive Director Researchers and Colleagues
3.2.3 Disability-related publications authored or co-authored by UCEDD faculty and staff are cited by other researchers.	<ul style="list-style-type: none"> ▪ <i>This will have to be examined as a separate task</i> 	Executive Director Researchers and Colleagues

3.3 UCEDD research, evaluation, and public policy analysis supports action that has an impact on people with developmental disabilities and their families.

Indicators	Findings	Source
<p>3.3.1 Research, public policy analysis, and evaluation conducted by UCEDD faculty and staff support changes to legislation or public policy.</p>	<ul style="list-style-type: none"> ▪ <i>Changes made in legislation or public policy as result of UCEDD research (as perceived by UCEDD)</i> ▪ <i>Implications of UCEDD research for people with developmental disabilities and family members (as perceived by UCEDD)</i> ▪ <i>How changes and implications related to UCEDD research?</i> 	<p>Executive Director Researchers and Colleagues</p>
<p>3.3.2 Research, public policy analysis, and evaluation conducted by UCEDD faculty and staff support changes to services and practice provided by service providers and professionals in the community.</p>	<ul style="list-style-type: none"> ▪ <i>Changes to community practices or services as a result of UCEDD research (as perceived by UCEDD)</i> ▪ <i>Implications of UCEDD research for people with developmental disabilities and family members (as perceived by UCEDD)</i> ▪ <i>How changes to community practices or services are related to UCEDD research</i> 	<p>Executive Director Researchers and Colleagues</p>
<p>3.3.3 People with developmental disabilities participate in UCEDD research.</p>	<ul style="list-style-type: none"> ▪ <i>How did people with disabilities participate in UCEDD research (identified issues, design of questionnaires, and interpretation of findings)?</i> 	<p>Executive Director</p>

H3-4. Community Services

4.1 UCEDD community services address the needs of people with developmental disabilities and family members, as indicated in the 5-year plan and amendments.

Indicators	Findings	Source
<p>4.1.1 UCEDDs provide or support community services (i.e., training, technical assistance, and direct services/model programs) to people with developmental disabilities and their families, those who provide supports and services to people with developmental disabilities and their families, and those who potentially have an influence on the inclusion of people with developmental disabilities into the community.</p>	<ul style="list-style-type: none"> ▪ <i>What community services does UCEDD provide?</i> ▪ <i>Description</i> ▪ <i>What target audience?</i> 	<p>Executive Director Recipient/provider of community services</p>
<p>4.1.2 UCEDDs provide or support community services (i.e., training, technical assistance, and direct services/model programs) to typically unserved and underserved populations or communities, including those from racial, ethnic, or linguistic minorities.</p>	<ul style="list-style-type: none"> ▪ <i>How did UCEDD reach out to target audiences of community services?</i> ▪ <i>To whom did UCEDD reach out</i> 	<p>Executive Director</p>
<p>4.1.3 UCEDD community services are effective (i.e., met objectives), person-centered, and family-centered accessible, culturally competent.</p>	<ul style="list-style-type: none"> ▪ <i>Whether or not community services were evaluated?</i> ▪ <i>How evaluated?</i> ▪ <i>What was found?</i> 	<p>Executive Director Recipient/provider of community services Researchers and Colleagues</p>

4.2 UCEDD community services have a positive impact on people with developmental disabilities and their families, those who provide services and supports to people with developmental disabilities and their families, policy makers, and on the community at large.

Indicators	Findings	Source
<p>4.2.1 UCEDD community services (training, technical assistance, and direct services/model programs, if offered) for people with developmental disabilities and their families strengthen their capacity to meet their self-identified goals.</p>	<ul style="list-style-type: none"> ▪ <i>Examples on how recipients say they benefited from community services:</i> <ul style="list-style-type: none"> - <i>Advocating for themselves</i> - <i>Advocating for others?</i> - <i>Etc.</i> 	<p>Executive Director Recipient/provider of community services</p>
<p>4.2.2 Recipients of UCEDD supported community services (who provide supports and services to people with developmental disabilities and family members and other community professionals):</p> <ul style="list-style-type: none"> ▪ Transfer the knowledge and skills they obtained to their work; ▪ Have more contact with people with developmental disabilities; and ▪ Have more effective (e.g., relevant, meaningful, accessible) contact with people with developmental disabilities. 	<ul style="list-style-type: none"> ▪ <i>Examples given by professionals and service providers on how they benefited from community services</i> 	<p>Executive Director</p>
<p>4.2.3 Expert information provided by UCEDD faculty and staff to legislative and other decision making bodies results in:</p> <ul style="list-style-type: none"> ▪ new or revised legislation or policy (or maintenance of legislation or policy); ▪ changes in (or maintenance of) access to supports and services; and ▪ Changes in (or maintenance of) services and supports provided in the community. (<i>output and outcome</i>) 	<ul style="list-style-type: none"> ▪ <i>How did community services in which UCEDD faculty provided information to legislative and other decision making bodies benefit the community?</i> <i>Description of examples such as:</i> <ul style="list-style-type: none"> - <i>New of revised legislation or policy</i> - <i>Changes in supports or service</i> - <i>Changes in services or support provided in the community?</i> (40) 	<p>Executive Director</p>

H3-5. Dissemination

5.1 UCEDDs disseminate products that are accessible and relevant to a variety of audiences.

Indicators	Findings	Source
<p>5.1.1 The network of UCEDDs uses a variety of dissemination strategies to inform target audiences (e.g., people with developmental disabilities, researchers, families, policy makers, professional and consumer groups, paraprofessionals, students, employers, other DD Network programs, and the general public) in the state, nationally, and internationally about developmental disabilities and issues affecting people with developmental disabilities and their families.</p>	<ul style="list-style-type: none"> ▪ <i>What dissemination strategies did UCEDD use?</i> ▪ <i>Who/what were the targets?</i> 	Executive Director
<p>5.1.2. UCEDD products are disseminated in accessible and understandable formats, using universal design principles.</p>	<ul style="list-style-type: none"> ▪ Examples of: <ul style="list-style-type: none"> - Research findings translated into lay language - Accessible formats - Receiving input from people with developmental disabilities and others on products for dissemination - Target audiences of products 	Executive Director

5.2 Recipients of UCEDD products learn about and become aware of people with developmental disabilities and the issues surrounding people with developmental disabilities and their families.

Indicators	Findings	Source
<p>5.2.1 UCEDDs gauge target audience satisfaction with the products it disseminates.</p>	<ul style="list-style-type: none"> ▪ <i>How was satisfaction assessed?</i> ▪ <i>How satisfied are recipients of disseminated materials?</i> 	Executive Director
<p>5.2.2 UCEDDs are responsive to the feedback they receive on UCEDD products that are disseminated.</p>	<ul style="list-style-type: none"> ▪ <i>What did the UCEDD do with the feedback it received on disseminated materials?</i> 	Executive Director

H3-6. Governance and Management

6.1 UCEDDs leverage funding to support and maintain UCEDD programs and activities, as indicated in the 5-year plan or amendments.

Indicators	Findings	Source
6.1.1 UCEDDs apply for and receive external funding from a variety of sources. <i>(process and output)</i>	<ul style="list-style-type: none"> What are the examples of applying and receiving funding? 	Executive Director Also in SAQ
6.1.2 UCEDD external funding is consistent with identifiable needs indicated in the 5-year plan or amendments. <i>(process; output)</i>	<ul style="list-style-type: none"> How did UCEDD decide what projects to apply for? 	Executive Director

6.2 UCEDDs maintain and support involvement from Consumer Advisory Committees (CACs).

Indicators	Findings	Source
6.2.1 UCEDDs obtain the perspectives of their CAC to guide UCEDD activities. <i>(process and output)</i>	<ul style="list-style-type: none"> How were CAC members involved in the UCEDD? 	Executive Director Chair and Members of CAC
6.2.2 UCEDDs support CAC members with the tools they need to be meaningfully involved as a CAC member.	<ul style="list-style-type: none"> What supports were provided to CAC members? How satisfied were CAC members with supports they received? 	Executive Director Chair and Members of CAC
6.2.3 CACs provide meaningful input.	<ul style="list-style-type: none"> What are the examples of input provided by CAC members? What are examples of input used by UCEDD? 	Executive Director Chair and Members of CAC

6.3 UCEDDs receive support from the university.

Indicators	Findings	Source
6.3.1 Universities support UCEDDs in a variety of ways.	<ul style="list-style-type: none"> How did the university support the UCEDD? 	Executive Director

H4. COLLABORATION

4.1. DDN programs have a process for identifying, planning, and implementing collaborative efforts.

Indicators	Findings	Source
4.1.1 DD Network programs identify and document goals on which to collaborate.	<ul style="list-style-type: none"> ▪ <i>How did DD network programs identify common goals?</i> ▪ <i>What common goals were identified?</i> 	Executive Director (DD Council) Executive Director (P & A) Executive Director (UCEDD)
4.1.2 DD Network programs support and encourage collaborative efforts.	<ul style="list-style-type: none"> ▪ <i>How did each program contribute to collaborative efforts?</i> 	Executive Director (DD Council) Executive Director (P & A) Executive Director (UCEDD)

4.2. DDN programs collaborate to achieve common goals.

Indicators	Findings	Source
4.2.1 DD Network programs communicate regularly.	<ul style="list-style-type: none"> ▪ <i>How did DD Network programs:</i> <ul style="list-style-type: none"> - <i>Share information</i> - <i>Provide regular updates to one another</i> - <i>Report milestones</i> - <i>Discuss issues</i> - <i>Debrief at the end of a collaborative effort</i> 	Executive Director (DD Council) Executive Director (P & A) Executive Director (UCEDD)
4.2.2 DD Network programs show a united front to the community.	<ul style="list-style-type: none"> ▪ <i>Did the DD Network programs produce any products together? Describe. How is authorship described?</i> ▪ <i>Do DD Network programs link to one another's website?</i> ▪ <i>Do DD Network programs participate in public meetings of one another's planning process? Describe.</i> 	Executive Director (DD Council) Executive Director (P & A) Executive Director (UCEDD)
4.2.3 DD Network programs monitor progress and barriers of collaborative efforts.	<ul style="list-style-type: none"> ▪ <i>Who was the leadership on a collaborative effort?</i> ▪ <i>How was leader identified?</i> ▪ <i>How were collaborative projects monitored?</i> ▪ <i>Where/how was reporting done?</i> 	Executive Director (DD Council) Executive Director (P & A) Executive Director (UCEDD)

4.2. DDN programs collaborate to achieve common goals. (continued)

Indicators	Findings	Source
4.2.4 DD Network programs revise goals and objectives, as appropriate, to overcome barriers identified.	<ul style="list-style-type: none"> ▪ <i>What are the examples of changes to goals and objectives to respond to overcoming identified barriers?</i> 	Executive Director (DD Council) Executive Director (P & A) Executive Director (UCEDD)

4.3. Collaboration achieves outcomes that have an impact on people with developmental disabilities and their families.

Indicators	Findings	Source
4.3.1 DD Network programs collaboratively achieve common goals set by the DD Network programs (e.g., changes in community practice, improved access to services, increase in disability leaders in the community).	<ul style="list-style-type: none"> ▪ <i>What are the examples of achieved goals?</i> 	Executive Director (DD Council) Executive Director (P & A) Executive Director (UCEDD)

Appendix I. Self-Administered Questionnaires

- I1. STATE COUNCILS ON DEVELOPMENTAL DISABILITIES**
- I2. PROTECTION AND ADVOCACY SYSTEMS**
- I3. UNIVERSITY CENTERS FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES EDUCATION, RESEARCH, AND SERVICE**

11. State Councils On Developmental Disabilities

WEB-BASED QUESTIONNAIRE

OVERVIEW:

The purpose of this questionnaire is to collect information on your DD Council for a specific period in time for the DDPIE.

Please respond to the questions in each section of the questionnaire. Please also collect all available documentation,³³ and use the prepaid FedEx labels supplied by Westat to send the documentation to Westat.

Some of the information we are requesting may appear to overlap with information in your State Plan and PPR. However, the questions are different, and the responses are not necessarily expected to be identical to the wording or numbers in these reports. We would appreciate it if you would interpret the questions as written and not as you remember them in the State Plan and PPR. When in doubt, feel free to call Westat for assistance.

So that data from all DD Councils completing this questionnaire can be aggregated, it is important that all DD Councils consider their responses within the same time period [REPORTING PERIOD]. Therefore, please answer all questions using the following REPORTING PERIOD:

From: October 1, 2008
To: September 30, 2009

INSTRUCTIONS FOR COMPLETION:

This questionnaire is web-based and can be completed electronically, but feel free to print this questionnaire to compile all information before entering data on the web-based form. Some questions require brief, open-ended responses. For others, you will need to click the box that corresponds to the desired response. Please be sure to provide a response for every question.

PLEASE SAVE YOUR RESPONSES OFTEN. TO SAVE YOUR RESPONSES, CLICK ON THE “UPDATE” BUTTON IN THE UPPER LEFT-HAND CORNER OF THE SCREEN.

If you have any questions, please do not hesitate to contact Martha Palan (marthapalan@westat.com or 603.553.1858) or Linda Lynch (lindalynch@westat.com or 301.251.4260).

³³ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., DD Suites), a report to the DD Council, or a summary of results of a survey, audit, or performance review.

ID Number - - - -
[Completed by Westat]

A. General Questions

Name of Program _____

Executive Director _____

In case Westat needs to follow up on any responses, please complete the following table.

Name and contact information of individual(s) completing questionnaire:

Name	Section Completed	Telephone Number	Email
	General Questions DD Council Planning Self-advocacy and Leadership Development Community Capacity Development Testing Promising Practices Systems Change Governance and Management		

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

B. DD Council Planning

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

1. Please describe the three main goals of your DD Council that apply to the reporting period. Please describe up to three objectives to achieve those goals.

Goal 1: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

Goal 2: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

Goal 3: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

C. Self-advocacy and Leadership Development

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

2. What self-advocacy and leadership development activities did the DD Council implement during the reporting period?³⁴ PLEASE DESCRIBE.

3. How many people with developmental disabilities and/or family members participated in Council-supported self-advocacy and leadership development education, training, and/or technical assistance during the reporting period?

PLEASE PROVIDE DOCUMENTATION.³⁵

No documentation [CHECK IF APPLICABLE.]

Don't know [CHECK, IF APPLICABLE.]

³⁴ For the purposes of this evaluation, self-advocacy and leadership development activities include the support or provision of education, training, technical assistance, outreach, and public awareness. These activities provide people with developmental disabilities and/or family members with knowledge and skills to obtain supports and services and advocate for systems change so that their choices can meet desired lifestyle goals, including integration into the community, choice, and independence.

³⁵ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., DD Suites), a report to the DD Council, or a summary of results of a survey, audit, or performance review.

ID Number - - - -
[Completed by Westat]

4. Overall, how satisfied do you think recipients of self-advocacy and leadership development activities were with the type of assistance they received during the reporting period?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Not very satisfied
- Dissatisfied

PLEASE PROVIDE DOCUMENTATION.³⁶

No documentation [CHECK IF APPLICABLE.]

Don't know [CHECK, IF APPLICABLE.]

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

³⁶ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., DD Suites), a report to the DD Council, or a summary of survey results, audit or performance review results.

D. Community Capacity Development

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

5. What community capacity development activities did the DD Council implement during the reporting period?³⁷ PLEASE DESCRIBE.

6. How many people participated in community capacity development activities supported by the DD Council during the reporting period?

PLEASE PROVIDE DOCUMENTATION.³⁸

No documentation [CHECK IF APPLICABLE.]

Don't know [CHECK, IF APPLICABLE.]

³⁷ For the purposes of this evaluation, community capacity development activities provide communities with the capacity to support the inclusion of people with developmental disabilities in every aspect of community life. Community capacity development includes increasing community awareness, knowledge, skills, and abilities and improving the infrastructure for service delivery throughout the State.

³⁸ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., DD Suites), a report to the DD Council, or a summary of results of a survey, audit, or performance review.

ID Number - - - -
[Completed by Westat]

7. Overall, how satisfied do you think recipients of community capacity activities were with the type of assistance they received during the reporting period?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Not very satisfied
- Dissatisfied

PLEASE PROVIDE DOCUMENTATION.³⁹

No documentation [CHECK IF APPLICABLE.]

Don't know [CHECK, IF APPLICABLE.]

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

³⁹ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., DD Suites), a report to the DD Council, or a summary of results of a survey, audit, or performance review.

E. Testing Promising Practices

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

8. What activities related to identifying or testing promising practices did the DD Council implement during the reporting period?⁴⁰ PLEASE PROVIDE SPECIFIC EXAMPLES.

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

⁴⁰ For purposes of this evaluation, promising practices are defined as new approaches to serving people with developmental disabilities and their families that have not yet been tested (evaluated) for effectiveness.

F. Systems Change and Advocacy Activities

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

9. Which of the goals listed in Question 1 are systems change issues? ⁴¹ [CHECK ALL THAT APPLY.]

- Goal 1
- Goal 2
- Goal 3

10. If you did not include all systems change goals as a response to Question 1 above, what other systems change goals pertain to this reporting period? PLEASE DESCRIBE.

No others [CHECK, IF APPLICABLE.]

⁴¹ For the purposes of this evaluation, systems change includes improvements in community capacity, coordination of systems, and customization of supports and services to people with developmental disabilities and their families and results in changes to (or maintenance of) legislation, policy, or funding.

ID Number - - - -
[Completed by Westat]

11. What activities did the DD Council implement during the reporting period to meet its systems change objectives? PLEASE PROVIDE SPECIFIC EXAMPLES.

12. What populations or communities were the target audiences for the DD Council's systems change objectives during the reporting period?⁴² PLEASE DESCRIBE.

No specific target audience of a population or community [CHECK, IF APPLICABLE.]

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

⁴² A target audience is a specified audience for which your objective is designed. For example, if one of your objectives is to provide legislators with an understanding of developmental disabilities issues, the target audience would be legislators.

G. Governance and Management

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

13. What is the total number of positions or slots on your DD Council (including those positions or slots that may not have been filled during the reporting period)?
-
14. How many DD Council members were on your Council during the reporting period (i.e., how many positions were filled)?
-
15. How many of those DD Council members:
- a. Have a developmental disability?

 Don't know [CHECK, IF APPLICABLE.]
 - b. Have a cognitive disability (among those with a developmental disability)?

 Don't know [CHECK, IF APPLICABLE.]
 - c. Have knowledge of policy and laws related to people with disability?

 Don't know [CHECK, IF APPLICABLE.]
 - d. Have knowledge of business or finance?

 Don't know [CHECK, IF APPLICABLE.]
 - e. Represent a minority in the state?

 Don't know [CHECK, IF APPLICABLE.]

PLEASE NOTE THAT OVERLAP AMONG THE CATEGORIES MAY OCCUR.

ID Number - - - -
[Completed by Westat]

16. What is the minimum number of meetings per year DD Council members are required to attend according to the DD Council's attendance policy?

No attendance policy on minimum number of Council meetings required.
[CHECK, IF APPLICABLE.]

17. How many DD Council members attend at least the minimum number of Council meetings required in the Council's attendance policy?

Not applicable.

Please collect all available documentation noted in this questionnaire and return it in the stamped, self-addressed envelope provided by Westat.

Thank you for your assistance in completing this questionnaire.

12. Protection and Advocacy Systems

WEB-BASED QUESTIONNAIRE

OVERVIEW:

The purpose of this questionnaire is to collect information on the Protection and Advocacy for Developmental Disabilities (PADD) program for a specific period in time for the DDPIE. QUESTIONS APPLY TO THE PADD PROGRAM ONLY.

Please respond to the questions in each section of the questionnaire. Please also collect all available documentation⁴³ and use the prepaid FedEx labels supplied by Westat to send the documentation to Westat.

Some of the information we are requesting may appear to overlap with information in your Statement of Goals and Priorities (SGP) and PPR. However, the questions are different, and the responses are not necessarily expected to be identical to the wording or numbers in these reports. We would appreciate it if you would interpret the questions as written and not as you remember them in the SGP and PPR. When in doubt, feel free to call Westat for assistance.

So that data from all P&As completing this questionnaire can be aggregated, it is important that all P&As consider their responses within the same time period [REPORTING PERIOD]. Therefore, please answer all questions using the following REPORTING PERIOD:

From: October 1, 2008
To: September 30, 2009

INSTRUCTIONS FOR COMPLETION:

This questionnaire is web-based and can be completed electronically, but feel free to print this questionnaire to compile all information before entering data on the web-based form. Some questions require brief, open-ended responses. For others, you will need to click the box that corresponds to the desired response. Please be sure to provide a response for every question.

PLEASE SAVE YOUR RESPONSES OFTEN. TO SAVE YOUR RESPONSES, CLICK ON THE “UPDATE” BUTTON IN THE UPPER LEFT-HAND CORNER OF THE SCREEN.

If you have any questions, please do not hesitate to contact Martha Palan (marthapalan@westat.com or 603.553.1858) or Linda Lynch (lindalynch@westat.com or 301.251.4260).

⁴³ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., “DAD”), a report to the Board of Directors/Commission, or a summary of results of a survey, audit, or performance review.

ID Number - - - -
[Completed by Westat]

A. General Questions

Name of Program _____

Executive Director _____

In case Westat needs to follow up on any responses, please complete the following table.

Name and contact information of individual(s) completing questionnaire:

Name	Section Completed	Telephone Number	Email
	A. General Questions B. P&A Planning C. Contacts with the P&A, Intake and Assistance D. Individual Advocacy E. Systemic Advocacy F. Community Outreach and Education G. Governance and Management		

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

B. P&A Planning

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

1. Please describe the three main goals of your P&A that apply to the reporting period. Please describe up to three objectives to achieve those goals.

Goal 1: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

Goal 2: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

Goal 3: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

ID Number - - - -
[Completed by Westat]

C. Contacts with the P&A, Intake and Assistance

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

2. How many initial calls did the P&A receive during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

3. How many intake forms did the P&A complete during the reporting period?

There were more initial calls than intake forms (i.e., an intake form is NOT completed for all calls). [CHECK, IF APPLICABLE.]

4. What is the maximum amount of time in which your P&A must respond to initial calls made to the P&A?

No. days No. hours

No requirement for maximum response time [CHECK, IF APPLICABLE.]

ID Number - - - -
[Completed by Westat]

5. How many initial calls did the P&A respond to within the maximum response time required during the reporting period?

PLEASE PROVIDE DOCUMENTATION.⁴⁴

No documentation [CHECK IF APPLICABLE.]

Don't know [CHECK, IF APPLICABLE.]

No requirement for maximum response time [CHECK, IF APPLICABLE.]

Remember to click on the" UPDATE" button in the upper left-hand corner of your screen to save your responses.

⁴⁴ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., “DAD”), a report to the Board of Directors/Commission, or a summary of results of a survey, audit, or performance review.
review

D. Individual Advocacy

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

6. How many new individual advocacy cases⁴⁵ were opened during the reporting period?
[PLEASE DO NOT INCLUDE INDIVIDUAL ADVOCACY CASES OPENED PRIOR TO THE REPORTING PERIOD AND CARRIED OVER OR OPENED AS A NEW CASE.]

7. How many new individual advocacy cases opened during the reporting period required the use of each of the following individual advocacy interventions:

- a. Technical assistance in self-advocacy
- b. Short-term assistance
- c. Investigation/monitoring
- d. Negotiation
- e. Mediation/alternative dispute resolution
- f. Administrative hearings
- g. Litigation
- h. Other, please specify _____
- i. Other, please specify _____

⁴⁵ If a P&A opens a separate case for each case problem or issue, the response to this question is expected to be greater than the number of new individual advocacy clients taken on during the reporting period.

ID Number - - - -
[Completed by Westat]

8. How many individual advocacy cases opened during the reporting period addressed emerging or emergency issues⁴⁶ not anticipated in the SGP?

9. How many individual advocacy cases were closed during the reporting period?

10. Among those cases closed during the reporting period, how many had been opened in a previous reporting period?

11. Among individual advocacy cases closed during the reporting period, how many separate client objectives were *addressed*?

12. Among individual advocacy cases closed during the reporting period, how many client objectives were *met*?⁴⁷

⁴⁶ An emerging issue is one that draws the attention of the P&A and continues to unfold as a possible issue to address immediately, in the near future, or within the next planning and priority setting process. An emergency issue is one that demands immediate action (e.g., an abuse and neglect situation, an impending legislative or policy action that would result in a loss of benefits or rights, or a private provider action that would jeopardize the health and welfare of an individual(s) with a developmental disability).

⁴⁷ We assume that each client will have at least one objective and some may have more than one. Therefore, the number of separate client objectives will likely be more than the total number of clients for whom a case was closed during the reporting period.

ID Number - - - -
[Completed by Westat]

13. Overall, how satisfied do you think P&A clients were with the assistance they received during the reporting period?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Not very satisfied
- Dissatisfied

PLEASE PROVIDE DOCUMENTATION.⁴⁸

- No documentation [CHECK, IF APPLICABLE.]
- Don't know [CHECK, IF APPLICABLE.]

14. How satisfied do you think P&A clients were with the efficiency of the process for meeting their requests (e.g., the P&A responded quickly) during the reporting period?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Not very satisfied
- Dissatisfied

PLEASE PROVIDE DOCUMENTATION.⁶

- No documentation [CHECK, IF APPLICABLE.]
- Don't know [CHECK, IF APPLICABLE.]

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

⁴⁸ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., “DAD”), a report to the Board of Directors/Commission, or a summary of results of a survey, audit, or performance review.

E. Systemic Advocacy

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

15. Which of the goals listed in Question 1 are systemic advocacy issues?⁴⁹ [CHECK ALL THAT APPLY.]

- Goal 1
- Goal 2
- Goal 3

16. If you did not include all systemic advocacy goals as a response to Question 1 above, what other systemic advocacy goals pertain to this reporting period? PLEASE DESCRIBE.

No others [CHECK, IF APPLICABLE.]

⁴⁹ For the purpose of this evaluation, a systemic advocacy goal seeks to influence or secure positive long-term changes that remove barriers and address discriminatory practices to ensure that the collective rights and interests of people with developmental disabilities are upheld.

ID Number - - - -
[Completed by Westat]

17. What populations or communities were the target audiences for your P&A's systemic advocacy objectives addressed during the reporting period?⁵⁰ PLEASE DESCRIBE.

No specific target audience of a population or community [CHECK, IF APPLICABLE.]

Remember to click on the" UPDATE" button in the upper left-hand corner of your screen to save your responses.

⁵⁰ A target audience is a specified audience for which your objective is designed. For example, if one of your objectives is to reduce abuse and neglect among individuals in tribal communities, the target audience would be individuals in tribal communities.

F. Community Outreach and Education

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

18. On which populations and communities did the P&A focus for outreach activities (e.g., ethnic or racial minorities, specific types of developmental disabilities, specific rural communities that are hard to serve) during the reporting period?⁵¹ PLEASE LIST.

No specific focus on populations or communities [CHECK, IF APPLICABLE.]

⁵¹ For the purpose of this evaluation, outreach consists of efforts to connect or bring awareness to P&A ideas or practices to other organizations, groups, target audiences or the general public. The goal of outreach is to identify underserved and unserved populations who might benefit from P&A services and programs.

ID Number - - - -
[Completed by Westat]

19. On which populations and communities did the P&A focus for community education activities (e.g., ethnic or racial minorities, specific types of developmental disabilities, specific rural communities that are hard to serve) during the reporting period?⁵² PLEASE LIST.

No specific focus on populations or communities [CHECK, IF APPLICABLE.]

Remember to click on the” UPDATE” button in the upper left-hand corner of your screen to save your responses.

⁵² For the purpose of this evaluation, community education consists of informing the public at large and people with developmental disabilities about the rights and value of people with developmental disabilities in their community and empowering people with developmental disabilities to advocate for themselves and others.

G. Governance and Management

As a reminder, when answering questions in this section, refer to the following reporting period:

From: October 1, 2008
To: September 30, 2009

20. What is the total number of positions or slots on your P&A Board of Directors/ Commission (including those positions or slots that may not have been filled during the reporting period)?

21. How many individuals were on the P&A Board/Commission during the reporting period?

22. How many of those Board/Commission members:

a. Have a developmental disability?

Don't know [CHECK, IF APPLICABLE.]

b. Have a cognitive disability (among those with a developmental disability)?

Don't know [CHECK, IF APPLICABLE.]

c. Have an understanding of the developmental disabilities population?

Don't know [CHECK, IF APPLICABLE.]

d. Have knowledge of policy and laws related to people with disability?

Don't know [CHECK, IF APPLICABLE.]

e. Have knowledge of business or finance?

Don't know [CHECK, IF APPLICABLE.]

f. Represent a minority in the state?

Don't know [CHECK, IF APPLICABLE.]

PLEASE NOTE THAT OVERLAP AMONG THE CATEGORIES MAY OCCUR.

23. How many grievances were made during the reporting period by individuals because they did not have their cases taken on by the P&A?

Don't know [CHECK, IF APPLICABLE.]

Please collect all available documentation noted in this questionnaire and use the FedEx label supplied by Westat to send the documentation to Westat.

Thank you for your assistance in completing this questionnaire.

**DEVELOPMENTAL DISABILITIES PROGRAM INDEPENDENT EVALUATION
(DDPIE)**

**13. University Centers for Excellence in Developmental
Disabilities Education, Research, and Service**

WEB-BASED QUESTIONNAIRE

The purpose of this questionnaire is to collect information on the University Centers of Excellence (UCEDD) program for a specific period in time.

Please respond to the questions in each section of the questionnaire. Please also collect all available documentation,⁵³ and use the prepaid FedEx labels supplied by Westat to send the documentation to Westat.

Some of the information we are requesting may appear to overlap with information in your 5-year Plan and Annual Report. However, the questions are different, and the responses are not expected to be identical to the wording or numbers in those reports. We would appreciate it if you would interpret the questions as written and not as you remember them in the 5-year Plan and Annual Report. When in doubt, feel free to call Westat for assistance.

So that data from all UCEDDs can be aggregated, it is important that all UCEDDs consider their responses within the same time period [REPORTING PERIOD]. Therefore, please answer all questions using the following REPORTING PERIOD:

From: July 1, 2008
To: June 30, 2009

INSTRUCTIONS FOR COMPLETION:

This questionnaire is web-based and can be completed electronically, but feel free to print this questionnaire to compile all information before entering data on the web-based form. Some questions require brief, open-ended responses. For others, you will need to click the box that corresponds to the desired response. Please be sure to provide a response for every question.

PLEASE SAVE YOUR RESPONSES OFTEN. TO SAVE YOUR RESPONSES, CLICK ON THE “UPDATE” BUTTON IN THE UPPER LEFT-HAND CORNER OF THE SCREEN.

If you have any questions, please do not hesitate to contact Martha Palan (marthapalan@westat.com or 603.553.1858) or Linda Lynch (lindalynch@westat.com or 301.251.4260).

⁵³ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., NIRS), a summary of survey results, or a report to the CAC or a university administrator.

ID Number - - - -
[Completed by Westat]

A. General Questions

Name of Program _____

Executive Director _____

In case Westat needs to follow up on any responses, please complete the following table.

Name and contact information of individual(s) completing questionnaire:

Name	Section Completed	Telephone Number	Email
	A. General Questions		
	B. UCEDD Planning		
	C. Interdisciplinary Pre-Service Preparation and Continuing Education		
	D. Basic and/or Applied Research		
	E. Community Services		
	F. Dissemination		
	G. Governance and Management		

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

B. UCEDD Planning

As a reminder, when answering questions in this section, refer to the following reporting period:

From: July 1, 2008
To: June 30, 2009

1. Please describe the three main goals of your UCEDD that apply to the reporting period. Please describe up to three objectives to achieve those goals.

Goal 1: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

Goal 2: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

Goal 3: _____

Objective 1: _____

Objective 2: _____

Objective 3: _____

ID Number - - - -
[Completed by Westat]

2. Which of the goals listed in Question 1 are systems change issues?⁵⁴ [CHECK ALL THAT APPLY.]

- Goal 1
- Goal 2
- Goal 3

3. If you did not include all systems change goals in your response to Question 1 above, what other systems change goals pertain to this reporting period? PLEASE DESCRIBE.

No others [CHECK, IF APPLICABLE.]

Remember to click on the” UPDATE” button in the upper left-hand corner of your screen to save your responses.

⁵⁴ For the purposes of this evaluation, systems change includes improvements in community capacity, coordination of systems, and customization of supports and services to people with developmental disabilities and their families and results in changes to (or maintenance of) legislation, policy, or funding.

ID Number - - - -
[Completed by Westat]

C. Interdisciplinary Pre-Service Preparation and Continuing Education

As a reminder, when answering questions in this section, refer to the following reporting period:

From: July 1, 2008
To: June 30, 2009

4. What were the major undergraduate and graduate teaching and continuing education activities implemented by the UCEDD during the reporting period (e.g., courses taught to interdisciplinary pre-service students, curricula and syllabi developed, integration of disability content into university courses)?

PLEASE DESCRIBE.

ID Number - - - -
 [Completed by Westat]

5. What disciplines were represented among UCEDD-affiliated faculty and staff during the reporting period (e.g., audiology, speech-language pathology, education, nursing, nutrition, occupational therapy, pediatrics, physical therapy, psychiatry, psychology, social work)?

PLEASE LIST EACH DISCIPLINE AND THE NUMBER OF FACULTY OR STAFF MEMBERS WHO FALL WITHIN EACH DISCIPLINE.

No.	Discipline	No. of faculty or staff
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

- We have more than 10 disciplines to report. A list of the additional disciplines and number of students has been sent along with other documentation to Westat.
 [CHECK IF APPLICABLE.]

6. What disciplines were represented among interdisciplinary pre-service students during the reporting period (e.g., medicine, occupational therapy, nutrition, epidemiology, nursing)?

PLEASE LIST EACH DISCIPLINE AND THE NUMBER OF STUDENTS WHO FALL WITHIN EACH DISCIPLINE.

No.	Discipline	No. of students
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

- We have more than 10 disciplines to report. A list of the additional disciplines and number of students has been sent along with other documentation to Westat.
 [CHECK IF APPLICABLE.]

ID Number - - - -
[Completed by Westat]

7. What major fields were most commonly represented among students participating in a disability studies program during the reporting period?

PLEASE LIST EACH MAJOR FIELD AND THE NUMBER OF STUDENTS WHO FALL WITHIN EACH DISCIPLINE.

No.	Major fields	No. of students
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

- We have more than 10 major fields to report. A list of the additional major fields and number of students has been sent along with other documentation to Westat. [CHECK IF APPLICABLE.]
- There is no disability studies program. [CHECK IF APPLICABLE.]

ID Number - - - -
 [Completed by Westat]

8. What departments were represented among students who took courses infused with disability content during the reporting period?

PLEASE LIST EACH DEPARTMENT AND THE NUMBER OF STUDENTS WHO FELL WITHIN EACH DEPARTMENT.

No.	Departments	No. of students
1		
2		
3		
4		
5		
6		
7		
8		
9		
10		

- We have more than 10 departments to report. A list of the additional departments and number of students has been sent along with other documentation to Westat. [CHECK IF APPLICABLE.]

9. What types of professionals (e.g., teachers, occupational therapists, audiologists) were represented among people who took UCEDD-supported continuing education courses during the reporting period?

PLEASE LIST EACH TYPE OF PROFESSION AND THE NUMBER OF INDIVIDUALS WHO FELL WITHIN EACH TYPE OF PROFESSION.

Types of professionals	No. of professionals
------------------------	----------------------

- Did not collect information on the types of professions of continuing education recipients. [CHECK IF APPLICABLE.]

ID Number - - - -
[Completed by Westat]

10. How did students rate UCEDD-affiliated faculty and staff who taught them during the reporting period?

- Extremely effective
- Very effective
- Effective
- Somewhat effective
- Not at all effective

PLEASE PROVIDE DOCUMENTATION.⁵⁵

No documentation [CHECK, IF APPLICABLE.]

Don't know [CHECK, IF APPLICABLE.]

11. How many interdisciplinary pre-service students graduated or completed their program during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

12. How many students who participated in a disability studies program graduated during the reporting period?

No disability studies program [CHECK, IF APPLICABLE.]

Don't know [CHECK, IF APPLICABLE.]

⁵⁵ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., NIRS), a summary of survey results, or a report to the CAC or a university administrator.

ID Number - - - -
[Completed by Westat]

13. Does your UCEDD contact interdisciplinary pre-service students who are completing their program to determine their future plans?
- Yes [PLEASE CONTINUE TO QUESTION 14.]
- No [PLEASE SKIP TO QUESTION 15.]
14. Response to contact with interdisciplinary pre-service students
- a. When you contacted interdisciplinary pre-service students about their future plans, how many responded?
-
- Don't know [CHECK, IF APPLICABLE.]
- b. How many interdisciplinary pre-service students who graduated or completed their program during the reporting period found work in a position that would benefit people with developmental disabilities?
-
- Don't know [CHECK, IF APPLICABLE.]
15. Does your UCEDD contact disability studies program students who are graduating to determine their future plans?
- Yes [PLEASE CONTINUE TO QUESTION 16]
- No [PLEASE SKIP TO QUESTION 17.]
- No disability studies program [PLEASE SKIP TO QUESTION 17.]

ID Number - - - -
[Completed by Westat]

16. Response to contact with disability studies program students

- a. When you contacted disability studies program students about their future plans, how many responded?

Don't know [CHECK, IF APPLICABLE.]

- b. How many students who participated in a disability studies program and graduated or completed their program during the reporting period found work in a position that would benefit people with developmental disabilities?

Don't know [CHECK, IF APPLICABLE.]

- c. How many students who participated in a disability studies program and graduated or completed their program during the reporting period were accepted into a graduate program that could benefit people with developmental disabilities?

Don't know [CHECK, IF APPLICABLE.]

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

D. Basic and/or Applied Research

As a reminder, when answering questions in this section, refer to the following reporting period:

From: July 1, 2008
To: June 30, 2009

17. What were the major basic and/or applied research activities of your UCEDD during the reporting period (e.g., writing grant and contract proposals, implementing research project, writing up results for publication) implemented by the UCEDD? PLEASE DESCRIBE.

18. What was the total number of UCEDD-affiliated faculty and staff during the reporting period?⁵⁶

Don't know [CHECK, IF APPLICABLE.]

⁵⁶ For the purposes of this evaluation, UCEDD-affiliated faculty and staff are individuals with a university or faculty appointment (tenure, non-tenure, or adjunct) and who have a designated official role with the UCEDD (e.g., at least some proportion of their salary is funded under the UCEDD's budget or a UCEDD grant or contract; work for a university academic department and are released from some of their departmental academic responsibilities in order to work with the UCEDD; are funded by the university fully or partially to be a UCEDD faculty member; work for an academic department but do some work for the UCEDD in addition to their departmental academic responsibilities).

19. Publications in Peer-reviewed Journals⁵⁷

- a. Among those counted in Question 18 above, how many UCEDD-affiliated faculty or staff published at least one disability-related research article in a peer-reviewed journal during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

- b. Considering the UCEDD-affiliated faculty and staff counted in Question 18 above, how many articles in a peer-reviewed journal did they publish during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

20. Authorships of Technical Reports, Articles, or Chapters in Books

- a. Among those counted in Question 18 above, how many UCEDD-affiliated faculty or staff authored or co-authored a disability-related technical report or article, or disability-related chapters in books during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

- b. Considering the UCEDD-affiliated faculty and staff counted in Question 18 above, how many disability-related technical reports, articles or chapters in books did they author or co-author during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

⁵⁷ Please include publications on studies (i.e., new data collection), reviews of literature, meta-analyses, and any other types of disability-related articles that were published in a peer-reviewed journal. Publications that are in press and were accepted during the reporting period may be included in the response and online publications may be included for publications that appeared during the reporting period if publication online in that journal means it is accepted for subsequent publication in the journal (even if the publication date of the journal is after the reporting period).

21. Presentations

- a. Among those counted in Question 18 above, how many UCEDD-affiliated faculty or staff presented on their disability-related research (including public policy analysis and evaluation) at conferences or meetings held during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

- b. Considering the UCEDD-affiliated faculty and staff counted in Question 18 above, how many disability-related research presentations did they make during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

22. Among those counted in Question 18 above, how many UCEDD-affiliated faculty or staff served on disability-related advisory groups, boards of directors, commissions, Governor's Councils, legislative committees, school boards, or other groups to study or advise on disability-related issues during the reporting period? [PLEASE INCLUDE ONLY THOSE GROUPS AND BOARDS ON WHICH FACULTY OR STAFF SERVED AS A UCEDD REPRESENTATIVE AND NOT IN A PERSONAL CAPACITY.]

Don't know [CHECK, IF APPLICABLE.]

23. Among those counted in Question 18 above, how many UCEDD-affiliated faculty or staff gave public testimony, made presentations, or provided consultation to legislators and other public officials during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

ID Number - - - -
[Completed by Westat]

24. Among those counted in Question 18 above, how many UCEDD-affiliated faculty or staff participated in national or international task forces or other committees related to disability during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

25. Among those counted in Question 18 above, how many UCEDD-affiliated faculty or staff reviewed articles for a peer review journal, books or book chapters, or other publications during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

26. Among those counted in Question 18 above, how many UCEDD-affiliated faculty or staff participated in a funding agency's grant review committee during the reporting period?

Don't know [CHECK, IF APPLICABLE.]

Remember to click on the "UPDATE" button in the upper left-hand corner of your screen to save your responses.

ID Number - - - -
[Completed by Westat]

E. Community Services

As a reminder, when answering questions in this section, refer to the following reporting period:

From: July 1, 2008
To: June 30, 2009

27. What were the major community services activities (e.g., direct services, technical assistance, and training) implemented by the UCEDD during the reporting period? PLEASE DESCRIBE.

Remember to click on the" UPDATE" button in the upper left-hand corner of your screen to save your responses.

F. Dissemination

As a reminder, when answering questions in this section, refer to the following reporting period:

From: July 1, 2008
To: June 30, 2009

28. What were the major dissemination activities (e.g., interaction with the mass media; planning and conducting public information forums; presentations to community groups; development and distribution of pamphlets, brochures, newsletters, and research briefs; development of videos and films; maintenance of websites) implemented by the UCEDD during the reporting period? PLEASE DESCRIBE.

29. To what extent were target audiences of your dissemination activities satisfied with UCEDD products they received or participated in during the reporting period?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Not very satisfied
- Dissatisfied

PLEASE PROVIDE DOCUMENTATION.⁵⁸

- No documentation [CHECK, IF APPLICABLE.]
- Don't know [CHECK, IF APPLICABLE.]

Remember to click on the" UPDATE" button in the upper left-hand corner of your screen to save your responses.

⁵⁸ Documentation is tangible evidence – such as a report from a data collection and analysis system (e.g., NIRS), a summary of survey results, or a report to the CAC or a university administrator.

ID Number - - - -
[Completed by Westat]

G. Governance and Management

30. Please complete the following table on funding applied for by the UCEDD between July 1, 2007 and June 30, 2009 and the status of each application.

[PLEASE NOTE: FOR THIS QUESTION, THE REPORTING PERIOD BEGINS ON JULY 1, 2007.]

Name of project	Funding source	Amount	Date submitted	Status of application ⁵⁹	If accepted, startup date
-----------------	----------------	--------	----------------	-------------------------------------	---------------------------

We have more than 13 projects to report. A list of the additional project with relevant details has been sent along with other documentation to Westat. [CHECK IF APPLICABLE.]

Please collect all available documentation noted in this questionnaire and use the FedEx label supplied by Westat to send the documentation to Westat.

Thank you for your assistance in completing this questionnaire.

⁵⁹ A = Accepted; D = Denied; UR = Under Review

Appendix J. Letter From ADD Commissioner to DD Network Programs



DEPARTMENT OF HEALTH & HUMAN SERVICES

ADMINISTRATION FOR CHILDREN AND FAMILIES

370 L'Enfant Promenade, S.W.

Washington, D.C. 20447

June 22, 2010

Dear Colleagues,

First of all, I want to express my sincere appreciation to all of you who have welcomed me so warmly over the past three months. I am humbled and happy to have the opportunity to serve in this capacity in President Obama's Administration, and thrilled to be working with all of you! Thank you for all of your support.

I am writing today to acknowledge and address the concerns that have been expressed to ADD regarding the *Developmental Disabilities Program Independent Evaluation* being conducted by Westat. The study is currently being conducted in 20 states, based upon a comprehensive examination of each program's structures, processes, outputs and achievements; the relationships among these concepts; and collaboration among the three programs in each state.

I have spent a fair amount of time and energy reviewing the history of this project, the intent of the evaluation, and the comments from the network regarding the instruments and process. I have talked to a number of sources about the project, including ACF's Office of Policy, Research and Evaluation, who also examined the study and provided feedback.

I have come to the following conclusions and determinations:

- At this point, nearly five years into the process, additional significant changes to the study protocol would be cost-prohibitive, and no additional savings could be recovered should we terminate the evaluation early. Additionally, the vast majority of grantees participating in the study have already completed most of the time-consuming work, and changes to the information collection process would have an adverse impact without saving any time for the participants.
- As the study has unfolded, ADD has received consistent feedback about the difficulty in utilizing a quantitative framework for understanding and assessing program impact. The study design has shifted substantially from this original concept, and is now using a descriptive approach to collect information through on-site interviews, surveys, and review of documents as a way to document program effectiveness and achievements through qualitative information.
- As such, ADD and Westat have worked together to re-conceptualize the original "evaluation" as a "national study" that demonstrates program achievements and effectiveness, and we are now calling the project the *National Independent Study of the Administration on Developmental Disabilities Programs*. The study will also include the development of suggested qualitative performance criteria based upon narrative descriptions, as opposed to quantitative measurement systems. The proposed performance criteria will be reviewed by stakeholders for validation purposes and revised according to consensual feedback, but will not include performance targets for explaining

program impact. The statement of work for the project is being revised to reflect that the study is no longer concerned with measuring program impact using quantitative performance standards. The performance criteria will be used to describe the overall program effectiveness and achievements, but will not represent an evaluation of any individual grantee.

- In order to truly reflect the partnership between ADD and grantees in implementing the DD Act, I believe ADD itself should have been included in the study. As such, the project is being expanded to include an assessment of the agency, including the direct and indirect technical assistance provided, to better understand how we support the grantees in achieving the purposes of the Act. One component of this assessment will include surveying all of the DD Network grantees (not just the study participants) about ADD's efficiency and effectiveness. I hope all of you will choose to participate in the survey, and provide us with your honest input.
- Finally, I do think ADD programs will benefit from distribution of a report from an independent source providing in-depth information regarding the activities of the programs. Hopefully this report will be a helpful tool for policymakers, demonstrating the excellent work done throughout the DD Network, as well as some of the challenges experienced by the grantees.

I want to thank the 60 DD Programs selected for the evaluation for their cooperation and participation, even when components of the process have been burdensome and time-consuming. Thank you for your willingness to assist and accommodate the evaluation team in the data collection, surveys and site visits.

I hope this provides some reassurance about the National Study. Please do not hesitate to contact me with any questions or concerns on this, or any other, matter.

Sincerely,



Sharon Lewis
Commissioner
Administration on Developmental Disabilities

Appendix K. Letter to Obtain Panel Recommendations

- K1. LETTER TO OBTAIN RECOMMENDATIONS FOR PANEL MEMBERS –
NON-PARTICIPANTS IN NATIONAL STUDY**

- K2. LETTER TO OBTAIN RECOMMENDATIONS FOR PANEL MEMBERS –
PARTICIPANTS IN NATIONAL STUDY**

K1. Letter to Obtain Recommendations for Panel Members – Non-Participants In National Study

Letter to obtain recommendations for panel members – Non-participants in National Study

Dear _____:

As you know, the Administration on Developmental Disabilities (ADD) is conducting a study to examine the effectiveness and achievements of the three DD Network programs. As one of the final steps in this process, ADD has asked Westat to use the information that we collected from 60 DD Network programs to develop draft performance standards for the three programs. Performance standards are defined as expectation[s] that must be met to be appraised at a particular level of performance. The goal of developing performance standards is to provide ADD and its grantees with information that could help demonstrate the effectiveness of network programs and progress that is being made toward the goals laid out in the DD Act.

I am writing to seek your recommendations of individuals to participate in the process of developing draft performance standards. Based on the data collected from your colleagues, the Westat study team is currently in the process of developing draft performance standards. Although we are comfortable that these reflect the work of the ADD grantees based on the information collected from the programs, it is critical that people who are familiar with and have a direct stake in these programs provide their input. We are seeking from you the names of up to five individuals who have a strong commitment to the developmental disabilities community and have knowledge and experience with DD Councils, P&As, and/or UCEDDs.

The standards development process will consist of assembling three panels – one for each program – to review and rate draft performance standards. Each panel will contain up to 20 members who will be selected to participate in this process. There will be an attempt to ensure that panels have a diversity of perspectives according to the characteristics of programs (e.g., LEND program and medical school status for the UCEDDs, allotment size and public/private status for the DD Councils and P&As) and geographic location.

Panel members will be asked to attend an hour-long webinar in April to become acquainted with (1) what led up to this process, and (2) the process for rating draft performance standards. Following the webinar, there will be two rounds in which they will be asked to review and rate the draft performance standards. Each round will consist of reviewing background materials and rating 20-25 draft standards and accompanying draft performance criteria. They will also be asked to provide any comments and suggestions to the draft performance standards. Overall, the full process is expected to take approximately one month. Westat will incorporate the feedback from panel members into recommendations to ADD regarding the draft performance standards.

To participate in this process, it will not be necessary to travel; panel members will be able to provide their input by computer (or on paper if they prefer). It is expected that each of two rounds of ratings will take up to 4 hours, and Westat will arrange for any assistance that may be required to participate in the process. An honorarium of \$100 will be offered for those who are allowed to accept it.

Below this email is a form for you to complete with names of individuals you would like to recommend for these panels. Please feel free to recommend individuals from your own organization, other DD Network programs, and individuals in your community and state with whom you collaborate. I would appreciate it if you would reply with recommendations by March 9, 2011.

This panel process is extremely important to obtaining stakeholder feedback on draft performance standards. I look forward to receiving your recommendations.

Sincerely,

Lynn Elinson

Lynn Elinson, Ph.D.
Westat
Associate Director
Health Studies Sector
(412) 421-8610
(240) 314-5844
(240) 314-2344 (Westat fax)
(240) 848-1855 (mobile)

K2. Letter to Obtain Recommendations for Panel Members – Participants In National Study

Letter to obtain recommendations for panel members – Participants in National Study

Dear _____:

Thank you for your time and contributions to the Administration on Developmental Disabilities National Study. As a participant in the National Study of the Administration on Developmental Disabilities Programs, you and your colleagues have provided critical information to help the Administration on Developmental Disabilities (ADD) better understand the operations and achievements of the DD Network programs. I realize that your participation took time away from your other responsibilities. I appreciate your willingness to assist us in conducting the study.

As one of the final steps in this process, ADD has asked Westat to use the information that we collected from the programs to develop **draft** performance standards for DD Network programs. Performance standards are defined as expectation[s] that must be met to be appraised at a particular level of performance. The goal of developing performance standards is to provide ADD and its grantees with information that could help demonstrate the effectiveness of network programs and progress that is being made toward the goals laid out in the DD Act.

I am writing to seek your recommendations of individuals to participate in the process of developing **draft** performance standards. Based on the data collected from you and your colleagues, the Westat study team is currently in the process of developing **draft** performance standards. Although we are comfortable that these reflect the work of the ADD grantees based on the information collected from the programs, it is critical that people who are familiar with and have a direct stake in these programs provide their input. We are seeking from you the names of up to five individuals who have a strong commitment to the developmental disabilities community and have knowledge and experience with DD Councils, P&As, and/or UCEDDs.

The standards development process will consist of assembling three panels – one for each program – to review and rate **draft** performance standards. Each panel will contain up to 20 members who will be selected to participate in this process. There will be an attempt to ensure that panels have a diversity of perspectives according to the characteristics of programs (e.g., LEND program and medical school status for the UCEDDs, allotment size and public/private status for the DD Councils and P&As) and geographic location.

Panel members will be asked to attend an hour-long webinar in April to become acquainted with (1) what led up to this process, and (2) the process for rating **draft** performance standards. Following the webinar, there will be two rounds in which they will be asked to review and rate the **draft** performance standards. Each round will consist of reviewing background materials and rating 20-25 draft standards and accompanying draft performance criteria. They will also be asked to provide any comments and suggestions to the **draft** performance standards. Overall, the full process is expected to take approximately one month. Westat will incorporate the feedback from panel members into recommendations to ADD regarding the **draft** performance standards.

To participate in this process, it will not be necessary to travel; panel members will be able to provide their input by computer (or on paper if they prefer). It is expected that each of two rounds of ratings will take up to 4 hours, and Westat will arrange for any assistance that may be required to participate in the process. An honorarium of \$100 will be offered for those who are allowed to accept it.

Below this email is a form for you to complete with names of individuals you would like to recommend for these panels. Please feel free to recommend individuals from your own organization, other DD Network programs, and individuals in your community and state with whom you collaborate. I would appreciate it if you would reply with recommendations by **March 9, 2011**.

This panel process is extremely important to obtaining stakeholder feedback on **draft** performance standards. I look forward to receiving your recommendations.

Sincerely,

Lynn Elinson

Lynn Elinson, Ph.D.
Westat
Associate Director
Health Studies Sector
(412) 421-8610
(240) 314-5844
(240) 314-2344 (Westat fax)
(240) 848-1855 (mobile)

Recommendations for Standards Panel Members

Name	Email address	Telephone number	Familiarity with DD Network programs (check all that apply)			Willing to participate on more than one DD Network panel (Y/N)	Self-advocate (Y/N)	Family member (Y/N)	Program staff (State, program, position)
			DDC	P&A	UCEDD				

K-7

Comments:

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Appendix L. Letters of Invitation

- L1. LETTER OF INVITATION FROM ADD COMMISSIONER JOIN DRAFT STANDARDS PANEL**

- L2. LETTER FROM ADD COMMISSIONER – INVITATION TO REVIEW AND COMMENT ON STANDARDS/PERFORMANCE CRITERIA**

L1. Letter of Invitation from Add Commissioner Join Draft Standards Panel

[DATE]

[PANEL MEMBER NAME]

[ADDRESS] «Position»«Organization»«Address»

Dear [DR./MR./MS.] [LAST NAME]:

A few years ago, the Administration on Developmental Disabilities (ADD) engaged Westat, a private health research company, to study the DD Network programs and identify the important achievements of the program. Westat collected data from DD Network programs in 19 states and one territory (all randomly selected) to understand the different ways in which these programs are implemented under the DD Act. As a final step in that study, Westat is using the data the study team collected to develop draft performance standards and criteria for recommendations to ADD.

You have been recommended by your colleagues to participate as a member of the [State Developmental Disabilities Councils (DD Council)/the Protection and Advocacy (P&A) System/the University Centers for Excellence in Developmental Disabilities Education, Research, & Service (UCEDD)] Draft Standards Panel being convened by Westat, and I would be most grateful if you would accept this invitation. The goal of developing performance standards is to provide ADD and its grantees with information that could help demonstrate the effectiveness of developmental disabilities network programs and progress that is being made toward the goals laid out in the DD Act. It is critical that people, like yourself, who are familiar with and have a strong stake in these programs, provide their input on the validity of the criteria that will be recommended to ADD.

The DD Council/P&A/UCEDD Draft Standards Panel will contain approximately 20 members. You and the other panel members have been selected to participate in this process because of your commitment to the developmental disabilities community and your knowledge and experience with DD Councils/P&As/UCEDDs. If you agree to participate, you will be asked to attend an hour-long webinar in April. The webinar will give you some background on what led up to the Draft Standards Panel process and what panel members will be asked to do. Following the webinar, you will be provided with written materials consisting of 9-12 draft standards and accompanying performance criteria. You will be asked to review an initial and revised version of these materials and rate each draft standard and performance criterion contained in each version. You will also be asked to provide any comments and suggestions for the draft standards and performance criteria. Overall, the process is expected to take approximately one month. Once your feedback is received, Westat will incorporate it into recommendations to ADD.

To participate in this process, it will not be necessary to travel; you will be able to provide your input by computer (or if you prefer, on paper). It is expected that each of two rounds of ratings will take approximately 4 hours. Westat will provide you with any assistance you may require. In addition, you will receive an honorarium of \$100 if you are allowed to accept it.

Within the next few days, someone from Westat will be contacting you to provide you with additional details and answer any questions you might have. I urge you to agree to become a panel member to work toward improving the performance measurement and reporting systems for the DD Network programs.

Sincerely,

Sharon Lewis

L2. Letter from ADD Commissioner – Invitation to Review and Comment on Standards/Performance Criteria

Dear _____:

The Administration on Developmental Disabilities (ADD) is asking for your help. A few years ago, ADD hired a company named Westat to study the Developmental Disabilities (DD) Network programs:

- The State Developmental Disabilities Councils (DD Councils),
- The Protection and Advocacy (P&A) System, and
- The University Centers for Excellence in Developmental Disabilities Education, Research, & Service (UCEDDs).

Westat is now writing a final report. Part of the report will suggest ways to show how well the DD Programs work, and where there might be things to improve.

I would like you to tell us what you think about Westat's suggestions. It is important for people like you who care about DD programs to comment on these ideas and whether they make sense to you.

The DD Council/P&A/UCEDD Draft Standards Panel will contain about 20 members. If you agree to help, you will be asked to participate in an hour-long webinar later in April. The webinar will give you some background on what led up to this point in the process and what you will be asked to do.

After the webinar, you will get written materials consisting of approximately 20-25 suggestions for rating the DD Programs. You will be asked to comment on these materials. Westat staff will be available to help you answer the questions over the phone if that would be helpful to you. It is important that you answer the questions from your own perspective.

After the panel's initial comments, Westat will make some changes. Then you will be asked to comment again on the new version. Again, Westat staff can help you communicate your comments by phone if you choose.

Overall, the whole process is expected to take about one month. Once Westat has the feedback from all of the panel members, they will put it all together into recommendations for ADD.

To participate in this process, you will not need to travel. You will be able to share your ideas and comments by computer (or if you prefer, by telephone). It is expected that each of these two sessions will take about 4 hours. Westat will provide you with any assistance you may require. In addition, you will receive \$100 as a thank you for your time, if you are allowed to accept it.

Within the next few days, someone from Westat will be contacting you to provide you with more details and answer any questions you might have. I hope you will become a panel member to work toward improving the rating and reporting systems for the DD Network programs.

Sincerely,

Sharon Lewis

Appendix M. Draft Standards Panels –State Councils on Developmental Disabilities, Protection and Advocacy Systems, University Centers for Excellence in Developmental Disabilities Education, Research, and Service

State Councils on Developmental Disabilities

Panel Participant	Affiliation
Michael Brogioli	National Association of Councils on Developmental Disabilities
Kelly Buckland	National Council on Independent Living
Vikki Day	South Dakota Council on Developmental Disabilities
Curt Decker	National Disability Rights Network
Debra Dowds	Florida Developmental Disabilities Council, Inc.
	Institute on Disabilities
Celia Feinstein	Temple University, Pennsylvania
Ed Holen	Washington State DD Council
Eric Jacobson	Governor's Council on Developmental Disabilities for Georgia
George Jesien	Association of University Centers on Disabilities
Heidi Lawyer	Virginia Board for People with Disabilities
	Developmental Disabilities Institute
Barbara LeRoy	Wayne State University, Michigan
Anna Lobosco	New York State Developmental Disabilities Planning Council
Claire Mantonya	Utah Developmental Disabilities Council
Graham Mulholland	Pennsylvania Developmental Disabilities Council
Julie Petty	Self-Advocate
Holly Riddle	North Carolina Council on Developmental Disabilities
Carol Risley	California State Council on Developmental Disabilities
Dan Shannon	Massachusetts Developmental Disabilities Council
Beth Swedeen	Wisconsin Board for People with Developmental Disabilities
Marcia Tewell	Colorado Developmental Disabilities Council
	National Association of State Directors of Developmental Disabilities Services
Nancy Thaler	
Eric Treat	Self-Advocate
Lee Vorderer	Human Services Research Institute
Liz Weintraub	Council on quality and Leadership
Colleen Wieck	The Minnesota Governor's Council on Developmental Disabilities
Wanda Willis	Tennessee Council on Developmental Disabilities
Tammy Yeomans	Self-Advocate

State Protection and Advocacy Systems

Panel Participant	Affiliation
Catherine Blakemore	Disability Rights California
David Braddock	University of Colorado System
Lynn Breedlove	Disability Rights Wisconsin
Michael Brogioli	National Association of Councils on Developmental Disabilities
Elmer Cerano	Michigan Protection and Advocacy Services, Inc.
Curt Decker	National Disability Rights Network
Debra Dowds	Florida Developmental Disabilities Council, Inc.
Mary Lee Fay	Office of Developmental Disability Services Oregon Department of Human Service
Cathy Ficker-Terrill	The Institute on Public Policy for People with Disabilities
Jane Gallivan	Office of Adults with Cognitive & Physical Disability Services
Mary Anne Harvey	The Legal Center, Colorado
George Jesien	Association of University Centers on Disabilities
Dana McClain	Disability Rights Center
Maryellen McDonald	Disability Rights Florida
James Meadours	Disability Rights Texas
Maria N. Reyes Medina	Puerto Rico University Center for Excellence on Developmental Disabilities
Charles Moseley	National Association of State Directors of Developmental Disabilities Services
Peri Jude Radecic	Arizona Center for Disability Law
Andrew Riggle	Disability Law Center The Community Legal Center, Utah
Lois Simpson	Advocacy Center, Louisiana
Vicki Smith	Disability Rights North Carolina
Deborah Spitalnik	The Elizabeth M. Boggs Center on Developmental Disabilities UMDNJ-Robert Wood Johnson Medical School, New Jersey
Betsy Valnes	National Youth Leadership Network
Betty Williams	Self Advocates Becoming Empowered

**National Network of University Centers for Excellence in Developmental Disabilities Education,
Research, and Service**

Panel Participant	Affiliation
Ansley Bacon	Westchester Institute for Human Development, New York
Robert Bacon	Center for Disabilities and Development – University of Iowa
Elizabeth Bishop	Boling Center - University of Tennessee
Michael Brogioli	National Association of Councils on Developmental Disabilities
Ann Cameron Caldwell	The Arc of the United States
Robin Cooper	National Association of State Directors of Developmental Disabilities Services
Curt Decker	National Disability Rights Network Institute on Disabilities
Celia Feinstein	Temple University, Pennsylvania
Bryce Fifield	Center for Persons with Disabilities - Utah State University
Karen Flippo	Institute for Community Inclusion - University of Massachusetts
George Jesien	Association of University Centers on Disabilities
John Johnson	San Diego State University, California
Barbara LeRoy	Developmental Disabilities Institute - Wayne State University, Michigan
Anna Lobosco	New York State Developmental Disabilities Planning Council Consumer Advisory Board
Marilyn Martinez	University of New Mexico Center for Development and Disability
Ari Ne'eman	Autistic Self-Advocacy Network
Laura Nuss	Developmental Disabilities Services, Washington, DC
Curtis Richards	Institute for Educational Leadership, Washington, DC
Cordelia Robinson	JFK Partners - University of Colorado, Denver The Elizabeth M. Boggs Center on DD
Deborah Spitalnik	UMDNJ-Robert Wood Johnson Medical School, New Jersey
Marc Tasse	Nisonger Center - Ohio State University
Matthew Wangeman	Institute for Human Development - Northern Arizona University
Michael Wehmeyer	Kansas University Center on Developmental Disabilities

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Appendix N. Webinar Presentation Powerpoint

Slide 1



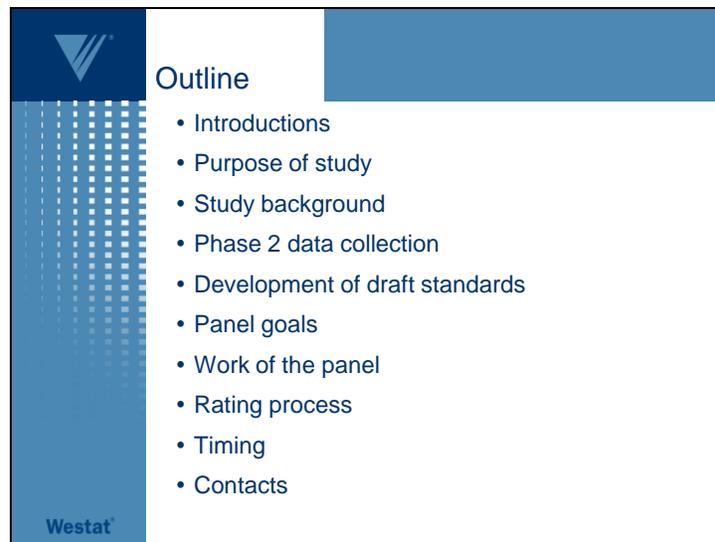
National Independent
Study of the ADD
Programs

Draft Performance
Standards Panels

April 21, 26 and 27, 2011

Westat

Slide 2

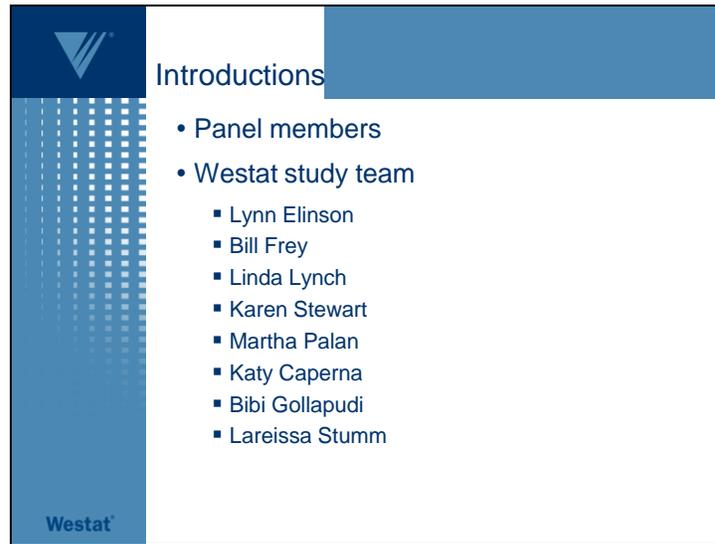


Outline

- Introductions
- Purpose of study
- Study background
- Phase 2 data collection
- Development of draft standards
- Panel goals
- Work of the panel
- Rating process
- Timing
- Contacts

Westat

Slide 3



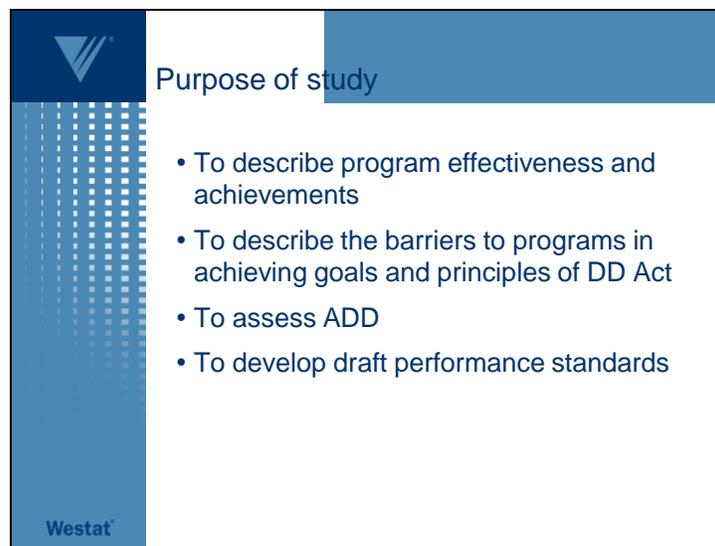
Slide 3 features a blue header with a white triangle icon on the left and the title "Introductions" in white text. The main content area is white with a blue vertical bar on the left containing a white dotted pattern. The "Westat" logo is in the bottom left corner. The text lists panel members and the Westat study team.

Introductions

- Panel members
- Westat study team
 - Lynn Elinson
 - Bill Frey
 - Linda Lynch
 - Karen Stewart
 - Martha Palan
 - Katy Caperna
 - Bibi Gollapudi
 - Lareissa Stumm

Westat

Slide 4



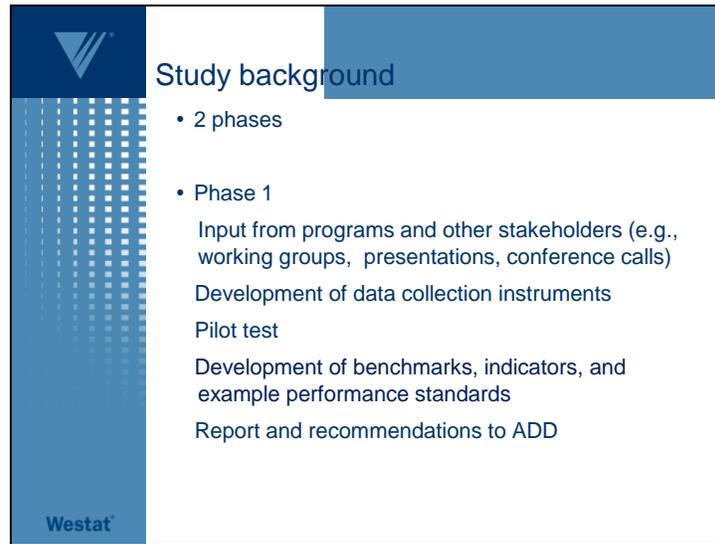
Slide 4 features a blue header with a white triangle icon on the left and the title "Purpose of study" in white text. The main content area is white with a blue vertical bar on the left containing a white dotted pattern. The "Westat" logo is in the bottom left corner. The text lists the purpose of the study.

Purpose of study

- To describe program effectiveness and achievements
- To describe the barriers to programs in achieving goals and principles of DD Act
- To assess ADD
- To develop draft performance standards

Westat

Slide 5

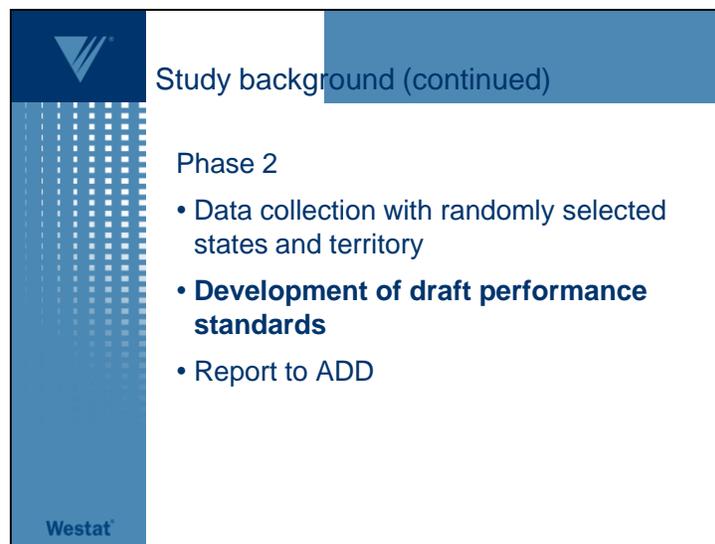


Study background

- 2 phases
- Phase 1
 - Input from programs and other stakeholders (e.g., working groups, presentations, conference calls)
 - Development of data collection instruments
 - Pilot test
 - Development of benchmarks, indicators, and example performance standards
 - Report and recommendations to ADD

Westat

Slide 6



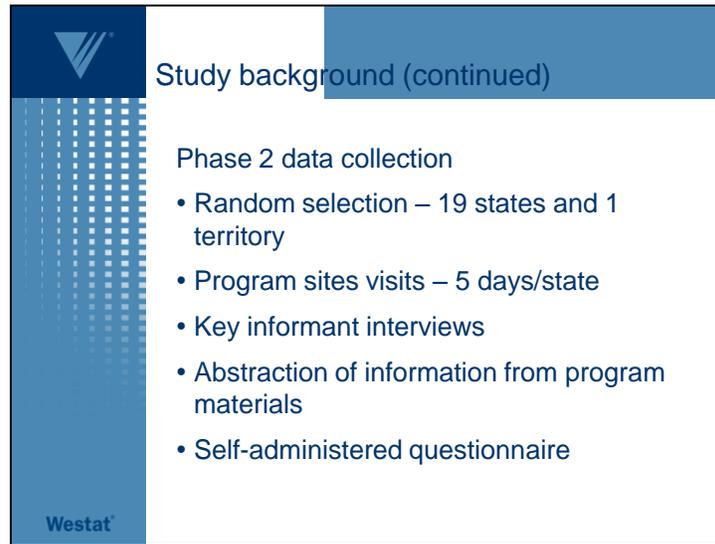
Study background (continued)

Phase 2

- Data collection with randomly selected states and territory
- **Development of draft performance standards**
- Report to ADD

Westat

Slide 7



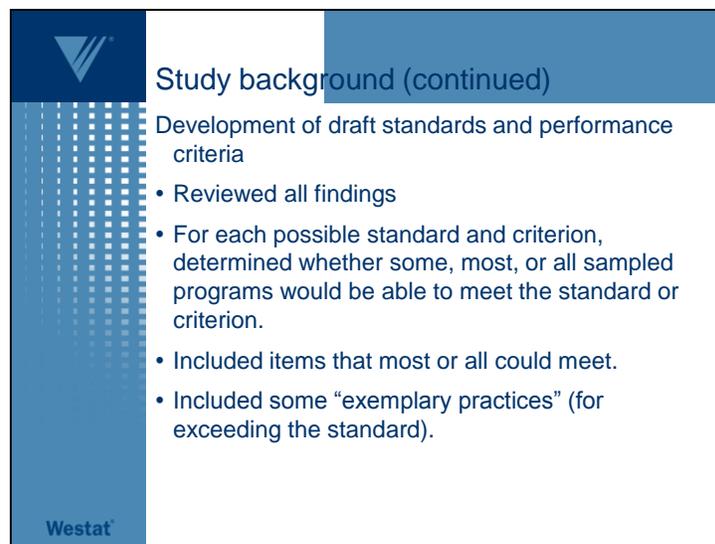
Study background (continued)

Phase 2 data collection

- Random selection – 19 states and 1 territory
- Program sites visits – 5 days/state
- Key informant interviews
- Abstraction of information from program materials
- Self-administered questionnaire

Westat

Slide 8



Study background (continued)

Development of draft standards and performance criteria

- Reviewed all findings
- For each possible standard and criterion, determined whether some, most, or all sampled programs would be able to meet the standard or criterion.
- Included items that most or all could meet.
- Included some “exemplary practices” (for exceeding the standard).

Westat

Slide 9



Panel goal

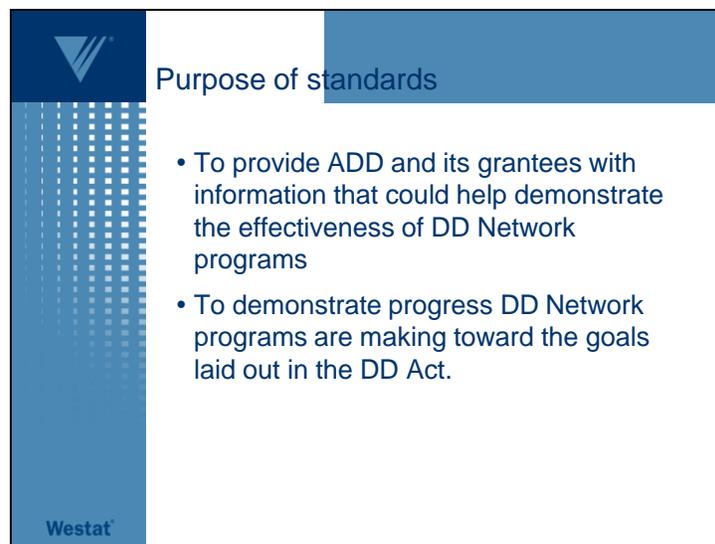
Using draft standards developed by Westat, to assist in developing draft standards for:

- DD Councils
- P&As
- UCEDDs
- Collaboration among the three programs

Westat

This slide features a blue header with a white triangle icon on the left and the text 'Panel goal' on the right. The main content area is white with a blue vertical bar on the left containing a pattern of white dots. The text describes the use of draft standards developed by Westat for DD Councils, P&As, UCEDDs, and collaboration among these programs. The Westat logo is in the bottom left corner.

Slide 10



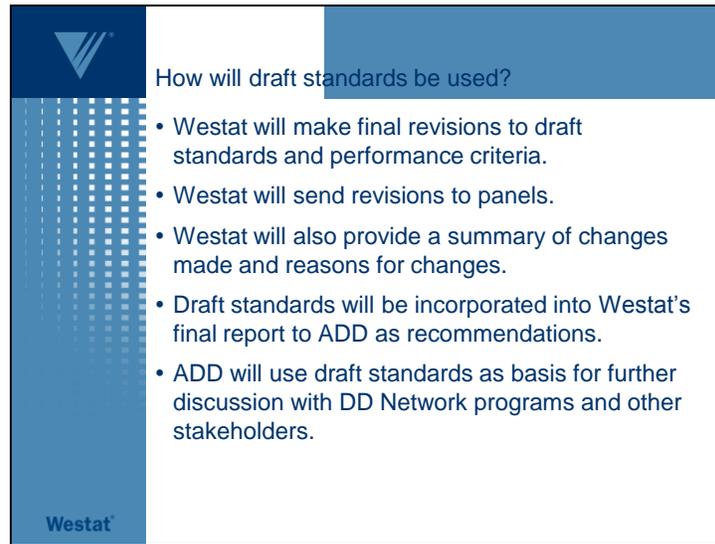
Purpose of standards

- To provide ADD and its grantees with information that could help demonstrate the effectiveness of DD Network programs
- To demonstrate progress DD Network programs are making toward the goals laid out in the DD Act.

Westat

This slide features a blue header with a white triangle icon on the left and the text 'Purpose of standards' on the right. The main content area is white with a blue vertical bar on the left containing a pattern of white dots. The text lists two purposes: providing information to demonstrate effectiveness and demonstrating progress toward goals in the DD Act. The Westat logo is in the bottom left corner.

Slide 11



How will draft standards be used?

- Westat will make final revisions to draft standards and performance criteria.
- Westat will send revisions to panels.
- Westat will also provide a summary of changes made and reasons for changes.
- Draft standards will be incorporated into Westat's final report to ADD as recommendations.
- ADD will use draft standards as basis for further discussion with DD Network programs and other stakeholders.

Westat

Slide 12



Work of the Draft Standards Panels

- Review materials
- Rate standards and performance criteria

Westat

Slide 13



Work of the Draft Standards Panels (continued)

Materials will consist of:

- Instructions
- List of draft standards
- Rating materials
- Contact information (for questions and assistance)

Westat

Slide 14



Rating Process – Electronic or Paper

Electronic

- Rating materials will be sent to panel member as email attachment.
- Panel member saves attachment on hard drive with new file name.
- Panel member completes ratings (saving often).
- Panel member sends completed rating file to Westat as email attachment.

Westat

Slide 15



Rating Process – Electronic or paper
(continued)

Paper (if requested)

- Westat sends printed copy of standards and performance criteria to panel members.
- Package includes return FedEx label.
- Panel member completes ratings.
- Panel member returns completed ratings to Westat by FedEx.

Westat

Slide 16

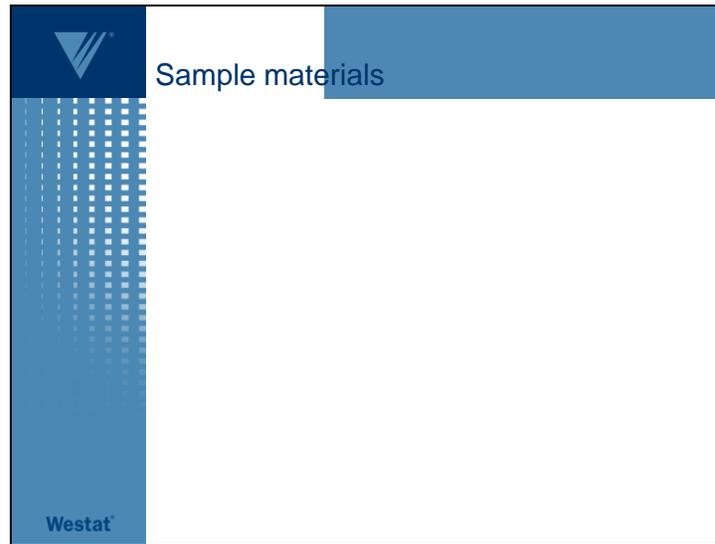


Rating Process – Electronic or Paper
(continued)

- Westat will provide assistance to anyone who needs it.

Westat

Slide 17



Slide 18

Steps to rating process

- Step 1. Panel members rate version 1.
- Step 2. Panel members send ratings to Westat.
- Step 3. Westat makes revisions based on Panel ratings, comments, and revision rules.
- Step 4. Westat sends Panel version 2.
- Step 5. Panel members rate version 2.
- Step 6. Westat makes revisions based on Panel ratings, comments, and revision rules.
- Step 7. Westat sends version 3 to panels. Version 3 will be included as recommendations in report to ADD.

Slide 19

Revision Rules

- ▶ If 75% or more of the panel members agree with a standard, it will remain without rewording.
- ▶ If 75% or more of the panel members disagree with a standard, it will be eliminated.
- ▶ If 75% or more of the panel members indicate that a performance criterion meets or exceeds the standard, it will remain without rewording.
- ▶ If 75% or more of the panel members indicate that a performance criterion is not relevant to meeting the standard, it will be eliminated.

Slide 20

Revision Rules (continued)

- ▶ All suggested standards and performance criteria from version 1 will be added to version 2 so they can be rated.
- ▶ All rewordings of the same standard or performance criterion will be listed and considered together. Comments will also be considered.

Slide 21

Tentative Timing	
Task	Date
Webinars	April 21, 26, 27
Westat sends out Version 1 to Panels	April 27
Panels return ratings to Westat	May 11
Westat sends out Version 2 to Panels	June 1
Panels return ratings to Westat	June 15
Westat sends out Version 3 to Panels	June 30

Westat

Slide 22



Contacts

- Lynn Elinson
lynnelinson@westat.com
1-800-937-8281, Ext. 5844
- Linda Lynch
lindalynch@westat.com
1-800-937-8281, Ext. 4280
- Karen Stewart
karenstewart@westat.com

Westat

Slide 23



Contacts (continued)

- Martha Palan
marthapalan@westat.com
401-289-0285
- Bibi Gollapudi – bibigollapudi@westat.com
1-800-937-8281, Ext. 7558

Westat