

## THE SUPPORTING STATEMENT

### Specific Instructions

Please do not remove or alter the headings below

#### A. Justification

##### 1. Circumstances Making the Collection of Information Necessary

The Administration on Developmental Disabilities (ADD) oversees the implementation of the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) (P.L. 106-402) (42 USC 15062). The purpose of the DD Act is to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life.

As defined in the DD Act, the term "developmental disabilities" means a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments that is manifested before the individual attains age 22 and is likely to continue indefinitely. Developmental disabilities result in substantial limitations in three or more of the following functional areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and capacity for economic self-sufficiency. It is estimated that four million people in America have developmental disabilities.

The DD Act authorizes appropriations for three programs in the States to achieve the purposes of the Act:

- State Developmental Disabilities Councils;
- State Protection and Advocacy Systems to Protect the Rights of Individuals with Developmental Disabilities; and
- The National Network of University Centers for Excellence in Developmental Disabilities, Education, Research, and Service.

The current information collection, the Developmental Disabilities Programs Independent Evaluation, will examine the impact of these programs.

There are several legal and administrative requirements that as a combined constellation necessitate the collection. These include initiatives over the past several Administrations to promote accountability of federally funded programs.

The DD Act requires a system of accountability for the DD Act programs. Specifically Section 105 requires that submit to the President, Congress, and the National Council on Disability a report that describes the goals and outcomes of programs.

The Government Performance and Results Act of 1993 (GPRA) provides another basis for conducting the information collection. Among the purposes of GPRA is to: improve the confidence of the American people in the capability of the Federal Government, by systematically holding Federal agencies accountable for achieving program results; improve Federal program effectiveness and public accountability by promoting a new focus on results, service quality, and customer satisfaction; help Federal managers improve service delivery, by requiring that they plan for meeting program objectives and by providing them with information about program results and service quality; and to improve internal management of the Federal Government.

Executive Order 13450 Improving Government Program Performance calls for improving the effectiveness and efficiency of the Federal Government and promoting greater accountability of that Government to the American people.

The current Administration has outlined in the document "Building a High Performing Government". It calls for improving results and outcomes for Federal Government programs while reducing waste and inefficiency. It also calls for program evaluations.

## 2. Purpose and Use of the Information Collection

The purpose of the Developmental Disabilities Program Independent Evaluation (DDPIE) Project is to examine through rigorous and comprehensive performance-based research procedures the targeted impact of grantee activities funded under the Developmental Disabilities Assistance and Bill of

Rights Act of 2000 (DD Act). The DDPIE is divided into two phases. The first phase carried out from October 2005 – September 2008 involved the development of valid and reliable measurement matrices for determining program impact and the implementation of a pilot study. The second phase will include two stages: (1) obtaining OMB approval for the evaluation tools (e.g., data collection instruments) developed during Phase I; and (2) full implementation of the evaluation using the measurement matrices developed during Phase I and finalization of the performance standards. ADD is seeking to fund Phase II of DDPIE as a follow on to Phase I of the project.

It is not the purpose of the independent evaluation to analyze ADD's current measurement system that is used by grantees to report on their activities. Instead, the purpose is to have an objective, outside contractor use a measurement system and related evaluation tools designed specifically to determine the impact of the national DD Network programs on individuals with developmental disabilities, state service systems, and on the capacity of service providers and a wide-range of professionals to reach, treat, or assist individuals with developmental disabilities to become more independent and to participate in and contribute to community life along side of other members of the community.

The information collected through DDPIE will be used to provide in-depth performance information to several stakeholders:

- Members of Congress
- OMB and the Administration
- Grantees
- Individuals with developmental disabilities
- Family members
- Advocates
- Other federal agencies

The Administration on Developmental Disabilities will be able to use the information to make program improvements.

### 3. Use of Improved Information Technology and Burden Reduction

The components of the proposed information collection will use technology to reduce burden. This includes the use of electronic surveys and teleconferences.

4. Efforts to Identify Duplication and Use of Similar Information

ADD has a number of mechanisms for monitoring DD Network programs and ensuring that they are complying with the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). Moreover, there is a number of strategic planning and accountability requirements in the DD Act itself that programs must comply with through reports to ADD. The result is that DD Network programs are already required to provide ADD with a considerable amount of data.

A pilot study was conducted that examined whether existing data can be used for the evaluation. All recent reports submitted to ADD by pilot study programs were reviewed to determine whether data from these reports would be able to answer the questions in the pilot study questionnaires. Through a crosswalk, the approximate location of data in several reports to ADD were located that might be able to answer the questions. Then, the existing data was incorporated from those reports into questionnaire binders. For each question for which existing data had been located, evaluators determined whether the existing data was able to answer the question.

It was found that the existing data was incomplete, out of date, not related to the dates of interest or not specifically related to the indicator and question. It was also noted that there was considerable inconsistency in definitions used by each program (e.g., in the NIRS data), and differences in formatting and contents of each report. Although much of the data was useful as background, none was able to specifically answer the questions in the questionnaires, which were based directly on the benchmarks and indicators that had been developed. Moreover, because of the inconsistency in definitions and data collection methodology, data would not be considered reliable enough to meet OMB requirements and it would not be possible to combine program data for roll-up to the national level.

5. Impact on Small Businesses or Other Small Entities

Some of the programs funded by ADD described under (1) are small in comparison to others. For example, under the DD Council program, some of the programs are considered 'minimum allotment'. These Councils receive the smallest amount of funding. Because the funding formula for the DD Councils is based partly on population, typically, 'minimum allotment' DD Councils are those in States and territories with a small population.

The full-scale independent evaluation, by necessity, will produce a certain amount of burden to all of programs included in the study sample. Programs will be asked to assemble individuals to be interviewed and to collect specific materials to send to the evaluator. The questionnaires were reduced considerably so interviews will be shorter and programs will be asked to collect fewer materials.

6. Consequences of Collecting the Information Less Frequently

This is a one time project.

7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

There are no special circumstances.

8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency

Please see attachment A for information about the first Federal Register Notice and the response to comments received from this notice.

ADD made significant efforts to consult outside the Agency. These efforts are summarized below. A full listing of individuals who provided feedback for each of the activities described below is provided in Attachment B.

- *Independent contractor*: ADD solicited for an outside contractor, Westat, to conduct the independent evaluation. Westat took three years to develop the information collection instruments for the independent evaluation.
- *Advisory Panel*: As part of it's work, Westat established an Advisory Panel that included people with

developmental disabilities, family members, other consumers, advocates, researchers, representatives from the DD network programs and policy specialists.

- *Working groups:* Westat organized and conducted P&A, DD Council, UCEDD and Collaboration Working Group meetings in person and by telephone and web cast throughout the spring, summer, and fall of 2006 to consult with experts in developing the information collection instruments.
- *Feedback from Programs:* Westat provided ADD programs in each state with opportunities to provide feedback and comments on the evaluation and draft documents in 2007.
- *Pilot Study:* Westat conducted a Pilot Study in 2008. The objectives of the pilot study were to: (1) inform the revision or elimination of some the benchmarks and indicators; (2) test data collection instruments for measuring the indicators; (3) inform the further development of performance standards; (4) determine the usefulness of existing data in reports to ADD; and (5) test the logistics for a full-scale independent evaluation. There is no OMB clearance for the pilot study because information was collected from less than 9 people.
- *Validation Panels:* Westat convened Validation Panels in July 2008. Advisory Panel members made recommendations to Westat on the membership of Validation Panels within the following categories: was a person with a developmental disability or family member; was an advocate; and had a familiarity with research and policy. In addition, panel members needed to have an understanding of consumer needs; have an understanding of the purpose of the programs; have an appreciation for outcomes; be at least somewhat involved in the DD Network system; and have a proven track record of self-advocacy (e.g., DD Council members; self-advocates outside the programs). Westat also obtained a mix of urban and rural representation (with some thought to geographic representation) and a mix of senior and junior program staff. Each person reviewed the instruments and provided feedback.

## 9. Explanation of Any Payment or Gift to Respondents

Respondents will be compensated for any direct costs incurred to participate in interviews (e.g., travel, child care, etc.). They will not be paid otherwise for participation.

#### 10. Assurance of Confidentiality Provided to Respondents

The proposed information collection instruments have received IRB approval.

The contractor implementing this information collection activity, Westat, is firmly committed to the principle that the confidentiality of individual data obtained through Westat interviews must be protected. This principle holds whether or not any specific guarantee of confidentiality was given at time of interview (or self-response), or whether or not there are specific contractual obligations to the client. When guarantees have been given or contractual obligations regarding confidentiality have been entered into, they may impose additional requirements which are to be adhered to strictly.

Below are the procedures Westat following for maintaining confidentiality:

1. All those with access to confidential data collected through interview (e.g., transcribers) shall sign an assurance of confidentiality. This assurance may be superseded by another assurance for a particular project.

2. Transcribers (and others with access to confidential data) shall keep completely confidential the names of respondents, all information or opinions collected in the course of interviews, and any information about respondents learned incidentally during the transcribing process. Transcribers shall exercise reasonable caution to prevent access by others to interview data in their possession.

3. Unless specifically instructed otherwise for a particular project, a transcriber, upon encountering a respondent or information pertaining to a respondent that s/he knows personally, shall immediately terminate the activity and contact her/his supervisor for instructions.

Before an interview starts, respondents will be asked to sign a consent form. It will also be conveyed that

information provided during the interview will not be provided to ADD or anyone else. Respondents will also be told that they do not have to answer any questions they don't want to answer, and they may also leave the interview at any time.

11. Justification for Sensitive Questions

No questions of a sensitive nature will be asked.

12. Estimates of Annualized Burden Hours and Costs

The table below shows the total annualized burden hours and costs estimated for this information collection activity.

Estimate of Total Annualized Burden Hours and Costs for Proposed Information Collection Activities				
Total Number of Respondents	Number of Responses per Respondent	Total Average Burden Hours per Response	Total Burden Hours	Total Cost
1,380	1	148.75	4,075	\$122,250

These estimates are based on two types of activities for the proposed information collection instruments: (1) participation in interviews and completion of a self-administered questionnaire; and (2) preparation activities. The estimates for these two types of activities are described in the tables below. The first table provides estimates for participation in interviews and completion of self-administered questionnaires. The second and third tables provide estimates for the burden hours and costs associated with participating in activities that will support implementation of the proposed information collection instruments. This includes time to collect, organize, and submit advanced materials and materials collected on site; identify key informants, obtain consent; prepare agenda; schedule interviews; make logistical arrangements; and participate in an exit interview. These activities are included as part of implementing the self-administered form for the DDCs, P&As, and UCEDDs; however a breakdown is provided on this particular aspect of the information collection activity for purposes of clarity in how the estimates were derived for the self-administered form. Finally, given the variability in the hourly rates for



the different types of participants, an average hourly rate of \$30 was used for all the cost estimates.

Table 1: Estimate of Annualized Burden Hours and Costs for the Proposed Information Collection Instruments					
Instrument	Number of Respondents	Number of Responses per Respondent	Average Burden Hours per Response	Total Burden Hours	Total Cost
DD Council: Executive Director Interview	20	1	4	80	\$2,400
DD Council: Interview with Council Chair/Council Members	60	1	.75	45	\$1,350
DD Council: Group Interview with Policymakers, Collaborators, and Grantees	160	1	2	320	\$9,600
DD Council: Group Interview with Recipients of Self-Advocacy and Leadership Education and Training	100	1	.75	75	\$2,250
DD Council: Group Interview with Recipients of Education and Training to Improve Community Capacity	100	1	.75	75	\$2,250
DD Council: Self-administered Form	20	1	41.5	830	\$24,900
P&A: Executive Director Interview	20	1	4	80	\$2,400
P&A: Staff Interview	60	1	.75	45	\$1,350
P&A: Board of Directors (Commissioners)-Chair and Members	60	1	.75	45	\$1,350
P&A: Group Interview with Policymakers and Collaborators	160	1	2	320	\$9,600
P&A: Interview with	100	1	.75	75	\$2,250

Recipient of Community Education					
P&A: Interview with Clients	100	1	.75	75	\$2,250
P&A: Self-administered Form	20	1	41.5	830	\$24,900
UCEDD: Interview with Director	20	1	4	80	\$2,400
UCEDD: Telephone Interview with Current and Graduated Students	100	1	.75	75	\$2,250
UCEDD: Interview with the Consumer Advisory Committee	60	1	.75	45	\$1,350
UCEDD: Interview with Peer Researchers and Colleagues	100	1	.75	75	\$2,250
UCEDD: Interview with Recipients of Community Services or Members of Organizations/Agencies that are Trained to Provide Community Services	100	1	.75	75	\$2,250
UCEDD: Self-administered Form	20	1	41.5	830	\$24,900
TOTAL	1,380		148.75	4,075	\$122,250

Table 2. Summary: Estimate of Total Burden Hours and Costs for Activities to Support Administration of Proposed Information Collection Instruments					
Program type	Number of Respondents	Number of Responses per Respondent	Average Burden Hours per Response*	Total Burden Hours	Total Cost
P&A	20	1	33.5	670	\$20,100
DD Council	20	1	33.5	670	\$20,100
UCEDD	20	1	33.5	670	\$20,100

\*includes time to collect, organize, and submit advance materials and materials collected on site; identify key informants, obtain consent; prepare agenda; schedule interviews; make logistical arrangements; and participate in

an exit interview

The following table shows the breakdown for the estimates in table 2.

Table 2a. Breakdown of estimate of additional burden for each task in the DDPIE Phase 2–full-scale evaluation, by program type				
Task–DD Council	Number of respondents	Number of responses per respondent	Average burden hours per respondent	Total burden hours
Prepare agenda (including emails and phone calls with contractor staff to schedule a two-day visit, understand selection criteria for interviewees, and identify a topic for the group interview).	20	1	5	100
Track down documents on checklist of materials (including compiling, photocopying, and sending requested documents to contractor).	20	1	10	200
Select interviewees and make arrangements for their participation	20	1	10	200
Review questionnaires prior to visit.	20	1	5	100
Set up video-conference or phone conferences	20	1	3.5	70
Subtotal			33.5	670
Task–P&A	Number of respondents	Number of responses per respondent	Average burden hours per response	Total burden hours

Table 2a. Breakdown of estimate of additional burden for each task in the DDPIE Phase 2–full-scale evaluation, by program type				
Task–DD Council	Number of respondents	Number of responses per respondent	Average burden hours per respondent	Total burden hours
Prepare agenda (including emails and phone calls with contractor staff to schedule a two-day visit, understand selection criteria for interviewees, and identify a topic for the group interview).	20	1	5	100
Track down documents on checklist of materials (including compiling, photocopying, and sending requested documents to contractor).	20	1	10	200
Select interviewees and make arrangements for their participation	20	1	10	200
Review questionnaires prior to visit.	20	1	5	100
Set up video-conference or phone conferences	20	1	3.5	70
Subtotal			33.5	670
Task–UCEDD	Number of respondents	Number of responses per respondent	Average burden hours per respondent	Total burden hours
Prepare agenda (including emails and phone calls with contractor staff to schedule a two-day	20	1	5	100

Table 2a. Breakdown of estimate of additional burden for each task in the DDPIE Phase 2–full-scale evaluation, by program type

Task–DD Council	Number of respondents	Number of responses per respondent	Average burden hours per respondent	Total burden hours
visit, understand selection criteria for interviewees, and identify a topic for the group interview).				
Track down documents on checklist of materials (including compiling, photocopying, and sending requested documents to contractor).	20	1	10	200
Select interviewees and make arrangements for their participation	20	1	10	200
Review questionnaires prior to visit.	20	1	5	100
Set up video-conference or phone conferences	20	1	3.5	70
Subtotal		5	33.5	670
Total of additional estimated total program burden for all three programs			100.5	2,010

13. Estimates of Other Total Annual Cost Burden to Respondents and Record Keepers

There will be no cost to the respondents. The cost will be incurred by the Federal government.

14. Annualized Cost to the Federal Government

Total cost is \$1,500,000 for a two year time period or \$750,000 per year. For each program, the cost is \$500,000 total for a two year time period or \$250,000 per year.

15. Explanation for Program Changes or Adjustments

This is a new project.

16. Plans for Tabulation and Publication and Project Time Schedule

<b>Task 2: Implement Independent Evaluation Study</b>			
Subtask 2.1	Develop a Plan for Implementing the Study	1 electronic copy	Within 2 months of start date
Subtask 2.2	Identify Study Sample and Contact Participants	1 electronic copy	Within 3 months of start date
Subtask 2.3	Use Evaluation Tools to Collect Data		Within 6 months of start date
Subtask 2.4	Train Research Staff on the Use of Evaluation Tools		Within 4 months of start date
<b>Task 3: Finalize Performance Standards for the National DD Network Programs and Include in Final Package to ADD</b>			
Subtask 3.1	Further Develop Performance Standards by Building Upon Work Conducted in Phase I	1 electronic copy	24 months
Subtask 3.2	Finalize the Performance Standards for the Measurement Matrices	1 electronic copy	24 months
Subtask 3.3	Organize Performance Standards into Measurement Matrices	1 electronic copy	24 months
Subtask 3.4	Incorporate Performance Standards into the Measurement Matrices and Submit as One Package for Use by ADD	2 hard copies, 1 electronic copy	24 months
<b>Task 4: Synthesize Findings and Develop Recommendations</b>			
Subtask 4.1	Synthesize Findings	1 electronic copy	24 months
Subtask 4.2	Develop	1 electronic	24 months

	Recommendations	copy	
<b>Task 5: Progress Reports</b>			
Subtask 5.1	Periodic Progress Reports to ADD Grantees	Electronic when requested	As requested
Subtask 5.2	Quarterly technical progress reports	1 electronic copy	Quarterly
Subtask 5.3	Develop and submit to PO final report with recommendations	2 hard copies, 1 electronic copy	24 months

17. Reason(s) Display of OMB Expiration Date is Inappropriate

Not applicable

18. Exceptions to Certification for Paperwork Reduction Act Submissions

Not applicable

**B. Statistical Methods (used for collection of information employing statistical methods)**

1. Respondent Universe and Sampling Methods

Programs will be selected using stratified random sampling procedures. The only stratification variable will be four geographic region designated by the U.S. Census: Northeast, Midwest, South, and West. Three territories will be included – District of Columbia, Puerto Rico, and Guam – because they each have all three DD Network programs. District of Columbia and Puerto Rico will be included in Region 3 (South). Guam is included in Region 4 (West).

Once programs have been identified, the table below shows the individuals that will be interviewed.

<b>Respondent</b>	<b>Potential Respondent Universe</b>	<b>Sample Number</b>
DD Council: Executive Director Interview	55	20
DD Council: Interview with Council Chair/Council	440	60

Members		
DD Council: Group Interview with Policymakers, Collaborators, and Grantees	5,500	160
DD Council: Group Interview with Recipients of Self-Advocacy and Leadership Education and Training	2,750	100
DD Council: Group Interview with Recipients of Education and Training to Improve Community Capacity	2,750	100
DD Council: Self-administered Form	55	20
P&A: Executive Director Interview	57	20
P&A: Staff Interview	855	60
P&A: Board of Directors (Commissioners)- Chair and Members	1,140	60
P&A: Group Interview with Policymakers and Collaborators	5,700	160
P&A: Interview with Recipient of Community Education	5,700	100
P&A: Interview with Clients	5,700	100
P&A: Self-administered Form	57	20
UCEDD: Interview with Director	68	20
UCEDD: Telephone	3,400	100



Interview with Current and Graduated Students		
UCEDD: Interview with the Consumer Advisory Committee	1,360	60
UCEDD: Interview with Peer Researchers and Colleagues	3,400	100
UCEDD: Interview with Recipients of Community Services or Members of Organizations/ Agencies that are Trained to Provide Community Services	500,000	100
UCEDD: Self-administered Form	68	20

## 2. Procedures for the Collection of Information

See response to question 1 for information about sampling procedures.

Westat recommends a design and methodology for the full-scale evaluation that is similar to the one used in the pilot study. This design is composed of the collection of both qualitative and quantitative data. Like the pilot study, qualitative data should be collected in key informant interviews of program staff, Council and Board members, Consumer Advisory Committee members, and others who have received services or participated in activities supported by Developmental Disabilities (DD) Network programs. Westat also recommends that quantitative data be collected with a new data collection instrument (a self-administered form for each program).

Logistically, collection of qualitative data was feasible to implement in the pilot study and enabled Westat evaluators to collect the type of information needed to measure the

indicators drafted at the time of the pilot study. Because there was some difficulty in collecting some of the quantitative data during an in-person interview, Westat developed an additional form to collect such data. All forms contain a specific "reporting period" that will be designated by Westat. Those completing the form will be asked only to consider data that apply to the reporting period. In that way, data from all states and programs will be able to be rolled up to the national level.

Since the self-administered questionnaire was not tested in the pilot study, we recommend that Westat be given the opportunity to conduct cognitive testing and pre-testing prior to field implementation.

### 3. Methods to Maximize Response Rates and Deal with Nonresponse

Westat will use multiple methods to increase response rate, including in-person interviews, electronic surveys, telephone interviews, follow-up calls, and follow-up on site. As a result, ADD expects a very high response rate. If there are non-responses, Westat will follow-up with the respondents to determine reasons for the non-response and provide assistance.

### 4. Test of Procedures or Methods to be Undertaken

A pilot study was conducted for this information collection activity. The objectives of the pilot study were to: (1) inform the revision or elimination of some the benchmarks and indicators; (2) test data collection instruments for measuring the indicators; (3) inform the further development of performance standards; (4) determine the usefulness of existing data in reports to ADD; and (5) test the logistics for a full-scale independent evaluation.

Programs were selected for the pilot study by excluding those programs that met ADD's exclusion criteria (e.g., Executive Director was a member of the Advisory Panel or Working Group; program had no or a new Executive Director), stratifying according to ADD's inclusion criteria,<sup>1</sup> and

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<sup>1</sup>Criteria for the UCEDD programs included: geographic diversity (e.g., rural/urban); geographic region of the United States (west, midwest, and east); participation in MTARS in 2005 - 2007; organizational structure (is and is not in a medical school); and training model (e.g., is and is not a LEND program). Criteria for the DDC programs included: geographic diversity (e.g., rural/urban); geographic region of the United States (west, midwest, and

randomly selecting programs within each stratum. Selected programs were notified by a letter from the Commissioner of ADD, and Westat followed up with an email. Ten DD Network programs in seven states participated in the pilot study (Exhibit 2).

**Exhibit 2. Programs that participated in the pilot study**

State Developmental Disabilities Councils	Protection and Advocacy Systems	University Centers of Excellence
New Hampshire DD Council (collaboration only)	New Hampshire Protection and Advocacy Agency Disabilities Rights Center	University of New Hampshire Institute on Disability
Ohio Developmental Disabilities Council	Ohio Legal Rights Service	University of Iowa - Center for Disabilities and Development
Wyoming Council on Developmental Disabilities	Disability Law Center of Alaska	University of California, Los Angeles - Tarjan Center
New Mexico State Council on Developmental Disabilities		

Preparation for the pilot study consisted of the development of all data collection instruments, obtaining IRB approval,<sup>2</sup>

east); participation in MTARS in 2005 - 2007; organizational structure (is and is not own DSA); and allotment size (e.g., minimum, non-minimum). Criteria for the P&A programs included: geographic diversity (e.g., rural/urban); geographic region of the United States (west, midwest, and east); participation in MTARS in 2005 - 2007; organizational structure (is and is not in State agency); P&A model (legal versus advocacy approach), and allotment size (e.g., minimum, non-minimum).

<sup>2</sup> The Westat IRB is a specially constituted committee established to protect the rights and welfare of human subjects who participate in Westat projects. The IRB operates under procedures set forth in the regulations of the U.S. Department of Health and Human Services and in the Federalwide Assurance (FWA) granted to Westat by the Office for Human Research Protections (OHRP). IRB approval is required before research may begin, continue, or be changed by the research team.

and staff training. Questionnaires were developed to be consistent with the benchmarks and indicators that had been developed as of December 24, 2007. Westat had been advised by the Advisory Panel to be over- instead of under-inclusive to make sure that indicators were not eliminated prematurely. Thus, the number of indicators that were included as of December 24, 2007 was 78 for DD Councils, 97 for P&As, 118 for UCEDDs, and 18 for collaboration.

Questionnaires were developed for each key informant (interviewee) (e.g., people with developmental disabilities, family members, policy makers, collaborators, researchers/colleagues, current and former students, Consumer Advisory Committee members, members of boards of directors or commissions, and recipients of education and training on developmental disabilities). All three programs had recommended that the evaluation use the data already being submitted to ADD instead of collecting new data. Thus, a critical aspect of questionnaire development was conducting a crosswalk between indicators and information provided by ADD programs in reports submitted to ADD and determining whether data from these reports could be used in the evaluation.

Data collection, which took place between January 28, 2008 and April 11, 2008, consisted primarily of semi-structured in-person individual and group key informant interviews and individual telephone interviews. In-person interviews were conducted during a 2-day program visit. Telephone interviews were scheduled either before or after each site visit depending on the availability of persons to be interviewed.

After programs were notified by ADD about their selection for the pilot study and sent a followup email by Westat, Westat worked with the Executive Director and staff of each selected program to schedule dates and times for the visit and interviews, identify key informants, and develop an agenda for the site visit. A followup letter was sent to each program to confirm the dates of the visit, describe the visit further, and provide a copy of all questionnaires.

Questionnaires were administered by trained Westat staff to program personnel and program target audiences. Permission was requested from respondents to audio record all

interviews. Recordings were transcribed after the site visit. In addition to data collection through interview, Westat also obtained a variety of materials from each of the programs participating in the pilot study.

Conduct of the pilot study resulted in three types of findings: (1) findings related to benchmarks, and indicators; (2) findings related to logistics for data collection; and (3) findings related to existing data. Findings on the questions that related to the benchmarks and indicators assisted in revising the benchmarks and indicators and developing examples of performance standards. The revised documents were presented to Validation Panels (described below). Logistical findings (what did and did not work well in the pilot study) were incorporated into Westat's recommendations for data collection in the full-scale evaluation.

Findings on the use of existing data from reports to ADD led Westat to conclude that very little of what is currently included in reports to ADD will be able to be used in the full-scale evaluation. For the most part, definitions and report format varied among all programs; reports covered different time periods than the indicators will be addressing; and many of the indicators were not addressed in these reports (particularly outcomes). Although these reports were useful in providing interviewers with background on each program, they were not useful for measuring the indicators for the ADD independent evaluation. Chapter 5 of this report makes recommendations on how ADD might revise reporting requirements so that reports to ADD might be able to be used in future national-level evaluations.

5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

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