

Attachment C
Definitions and Measures

I. DEFINITIONS:

AREA OF EMPHASIS

The DD Act of 2000 requires that the UCEDD address, directly or indirectly, one or more of the following "areas of emphasis" related to:

- Quality assurance activities,
- Education and early intervention activities,
- Child care-related activities,
- Health-related activities,
- Employment-related activities,
- Housing-related activities,
- Transportation-related activities,
- Recreation-related activities, and
- Other services available or offered to individuals in a community, including formal and informal community supports, that affect their quality of life.

In keeping with that statutory language, each of those areas of emphasis are defined as follows.

Quality assurance activities: The term quality assurance activities means advocacy, capacity building, and systemic change activities that result in improved consumer- and family-centered quality assurance and that result in systems of quality assurance and consumer protection that- (A) include monitoring of services, supports, and assistance provided to an individual with developmental disabilities that ensures that the individual- (i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and (ii) will not be subject to the inappropriate use of restraints or seclusion; (B) include training in leadership, self-advocacy, and self-determination for individuals with developmental disabilities, their families, and their guardians to ensure that those individuals- (i) will not experience abuse, neglect, sexual or financial exploitation, or violation of legal or human rights; and (ii) will not be subject to the inappropriate use of restraints or seclusion; or (C) include activities related to interagency coordination and systems integration that result in improved and enhanced services, supports, and other assistance that contribute to and protect the self-determination, independence, productivity, and integration and inclusion in all facets of community life, of individuals with developmental disabilities.

Education and early intervention activities: The term education activities means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities being able to access appropriate supports and modifications when necessary, to maximize their educational potential, to benefit from lifelong educational activities, and to be integrated and included in all facets of student life. In addition, the term early intervention activities means advocacy, capacity building, and systemic change activities provided to individuals and their families to enhance- (A) the development of the individuals to maximize their potential; and (B) the capacity of families to meet the special needs of the individuals.

Child care-related activities: The term child care-related activities means advocacy, capacity building, and systemic change activities that result in families of children with developmental disabilities having access to and use of child care services, including before-school, after-school, and out-of-school services, in their communities.

The term health-related activities means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities, in their communities. Activity records for which

Health-Related activities: The term health-related activities means advocacy, capacity building, and systemic change activities that (a) enhance awareness, change behavior, or create environments that support good health practices and (b) result in individuals with developmental disabilities having access to and use of coordinated health, dental, mental health, and other human and social services, including prevention activities.

Employment-related activities: The term employment-related activities means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities acquiring, retaining, or advancing in paid employment, including supported employment or self-employment, in integrated settings in a community.

Housing-related activities: The term housing-related activities means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of housing and housing supports and services in their communities, including assistance related to renting, owning, or modifying an apartment or home.

Transportation-related activities: The term transportation-related activities means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of transportation.

Recreation-related activities: The term recreation-related activities means advocacy, capacity building, and systemic change activities that result in individuals with developmental disabilities having access to and use of recreational, leisure, and social activities, in their communities.

Other: If 'Other' is selected as an area of emphasis, the following sub-options will be made available:

- Other - Assistive Technology,
- Other - Cultural Diversity,
- Other - Leadership, and
- Other.

The *other–assistive technology* area of emphasis option applies to any activity that assists an individual with a disability and their family/caregivers in the selection, acquisition, or use of an assistive technology device.

The *other-cultural diversity* area of emphasis option applies to any activity that provides or focuses on the provision of 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.

The *other-leadership* area of emphasis option applies to any activity that enhances the potential of health care, allied health, or related personnel to improve the health, developmental, or functional status of children and adults with disabilities, and equips personnel with the knowledge and skills required to enhance the systems of care and support for people with disabilities and their families.

If simply *other* is selected, explanatory text must be provided.

COMMUNITY SERVICES - DIRECT SERVICES AND DEMONSTRATION PROJECTS

Direct Services and Demonstration Projects may include a variety of services, supports, and assistance for individuals with disabilities or special health care needs, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community. These services could be related to a wide array of areas, such as education, child care, health, employment, housing, transportation, recreation, and other areas.

COMMUNITY SERVICES - TECHNICAL ASSISTANCE

Technical Assistance (TA) is defined as direct problem-solving services provided by faculty/staff to assist individuals, programs, and agencies in improving their services, management, policies, and/or outcomes. TA may be provided in person, by electronic media such as telephone, video, or e-mail, and by other means. The following are examples of technical assistance: needs assessment; program planning or development; curriculum or materials development; administrative or management consultation; legislative testimony; program evaluation and site reviews of external organizations; advisory group participation; policy development; coalition building; and consultation to service providers about clients.

COMMUNITY SERVICES - TRAINING

Community training is conceptualized as training that serves to benefit the community by enhancing the knowledge of community members and/or maintaining the professional credentials of those that directly serve the community. Community training is distinct from *Interdisciplinary Pre-Service Preparation and Continuing Education* in that it encompasses any other types of training, including educational activities (a) offered for a variety of audiences; (b) offered for a specific audience; and/or (c) where professional certificates, certificates of completion, or CEUs (or their equivalents) are awarded.

CONSUMER

The customer to whom a service or product is designed for and delivered to.

CORE FUNCTIONS

The DD Act of 2000 identifies that the core functions of the UCEDD program shall include:

- Provision of interdisciplinary pre-service preparation and continuing education of students and fellows, which may include the preparation and continuing education of leadership, direct service, clinical, or other personnel to strengthen and increase the capacity of states and communities.
- Provision of community services that provide training or technical assistance for individuals with developmental disabilities, their families, professionals, paraprofessionals, policy-makers, students, and other members of the community and that may provide services, supports, and assistance for the persons through demonstration and model activities.
- Conduct of research, which may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families.
- Dissemination of information related to activities undertaken to address the purpose of this title, especially dissemination of information that demonstrates that the network authorized under this subtitle is a national and international resource that includes specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances.

DEVELOPMENTAL DISABILITY

The DD Act defines a developmental disability as a severe, chronic disability of an individual that:

- Is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22;
- Is likely to continue indefinitely;
- Results in substantial functional limitations in 3 or more of the following areas of major life activity:
 - Self-care,
 - Receptive and expressive language,
 - Learning,
 - Mobility,
 - Self-direction,
 - Capacity for independent living, and
 - Economic self-sufficiency; and
- Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

DISCIPLINE

Discipline refers to the major field in which the trainee is pursuing their degree/program of study. Trainee data is captured on the following disciplines:

- Audiology
- Dentistry/Pediatric Dentistry
- Education – General and Special
- Genetics
- Health Administration
- Human Development
- Interdisciplinary
- Medicine
- Nursing
- Nutrition
- Occupational Therapy
- Occupational Therapy
- Pediatrics
- Physical Therapy
- Psychiatry
- Psychology
- Social Work
- Speech-Language Pathology
- Other

INFORMATION DEVELOPMENT AND DISSEMINATION

Information development and dissemination equip programs to serve as a resource to various constituents on a local, regional, state, national, and international scope, through the provision of specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances. Information development and dissemination might include product dissemination, public awareness projects, and other types of initiatives.

MEASURABLE GOAL

A tangible, measurable outcome or output, the specific and intended result to be achieved within an explicit timeframe and against which actual results are compared and assessed.

PRE-SERVICE PREPARATION AND CONTINUING EDUCATION

Takes place in an academic setting or program that may (a) lead to the award of an initial academic degree or certificate; (b) include internship, practicum, fellowship, or residency activities; or (c) represent advancement in academic credentials through a course of study.

PRODUCTS/PUBLICATIONS

Category & Definition	Includes	Excludes
<p>Refereed journal articles Scholarly articles that have been accepted for <i>print or electronic</i> publication in a scholarly journal that uses a blind reviewing strategy and external reviewers.</p>	<ul style="list-style-type: none"> • Scholarly articles accepted for publication in refereed journals 	<ul style="list-style-type: none"> • Editorials, book reviews, and other non-scholarly articles accepted for publication in refereed journals • Publications included in “Non-refereed publications” or “Periodicals”
<p>Non-refereed publications Materials prepared without a blind reviewing strategy for <i>print or electronic</i> publication that offers (a) an account, description or explanation of a single thing or class of things; (b) reference information on a particular topic; or (c) basic, technical, analytical, investigative, or evaluative information.</p>	<ul style="list-style-type: none"> • Monographs • Research, consultancy, or technical reports • Guides • Handbooks • Whitepapers • Commissioned evaluative or investigative reports 	<ul style="list-style-type: none"> • Grant or contract progress reports • Publications included in “Periodicals” • Publications included in “Public Awareness Materials” • Editorials, book reviews, and other non-scholarly articles accepted for publication in non-refereed publications
<p>Books/book chapters Books or book chapters that are (a) written solely by the identified author(s), (b) scholarly, (c) bound, and (d) offered for sale.</p>	<ul style="list-style-type: none"> • Textbooks aimed at a university audience • Research monographs published by university departments or presses • Books published by privately-funded companies or university departments/ presses • Professional books 	<ul style="list-style-type: none"> • Creative works such as novels • Commissioned evaluative or investigative reports • Research, consultancy, or technical reports • Textbooks that are aimed at secondary, primary or preschool students
<p>Audio/Visual Materials, Software, Web Portals <i>A/V:</i> Materials <i>initially prepared</i> to present information in an audible and/or pictorial form. <i>Software:</i> Organized collections of computer data and instructions. <i>Web Portal:</i> a website or service that offers a broad array of resources and services, such as forums, search engines, databases, etc.</p>	<ul style="list-style-type: none"> • CDs, DVDs, videotapes, or audiotapes • Software (system or application) • Web Portals 	<ul style="list-style-type: none"> • Web pages • Alternate format <i>versions</i> (Braille, audiotape, etc.) of a product • Conference presentations • PowerPoint slides • Poster presentations • Radio/television interviews
<p>Educational Modules Written educational units designed to drive instruction by identifying the (a) skills and concepts to be taught, (b) teaching strategies to be used, and (c) evaluation methods to be used to measure student achievement.</p>	<ul style="list-style-type: none"> • Curricula, courses, or training programs • Distance, asynchronous, or web-based modules • Textbooks that are aimed at secondary, primary or preschool students 	<ul style="list-style-type: none"> • Conference presentations • Poster presentations • PowerPoint slides
<p>Doctoral Dissertations and Master’s Theses The required final paper prepared by a candidate for an academic</p>	<ul style="list-style-type: none"> • Dissertations and theses accepted by relevant Committees 	<ul style="list-style-type: none"> • Undergraduate or honors theses • Prospectuses, IRB approvals, or interim drafts of dissertations or

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institution's master or doctoral degree.		theses
Periodicals Materials prepared for <i>print or electronic</i> publications that are not refereed and are issued at either fixed intervals or on an occasional basis.	<ul style="list-style-type: none"> • Articles or editorials published in newspapers, newsletters, or magazines • Issue briefs 	<ul style="list-style-type: none"> • Publications included in "Non-refereed publications"
Public Awareness Materials Print or electronic materials prepared to increase public awareness on a topic or topics.	<ul style="list-style-type: none"> • Brochures • Pamphlets • Radio/television interviews • Press Releases 	<ul style="list-style-type: none"> • Publications included in "Periodicals"

RESEARCH

Research and Evaluation may include basic or applied research, evaluation, and the analysis of public policy in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families. Research and evaluation may entail functions such as proposal development, report writing, experimental/quasi-experimental design projects, interviews, focus groups, surveys, data entry, data analysis, and other types of functions. Research and evaluation functions may support measurement of progress, in areas such as of consumer satisfaction, collaboration, and improvement.

TRAINEES

Trainees include graduate and undergraduate students, fellows, residents, professionals, paraprofessionals, or others who receive training as described in *Interdisciplinary Preservice Preparation and Continuing Education*. Individuals who receive the types of training described in *Community Services: Training* are not included in the definition of trainees.

II. EXPLANATION OF GPRA MEASURE:

MEASURE 1:

The first GPRA measure for the UCEDD program focuses on impact on individuals with developmental disabilities:

The percent of individuals with developmental disabilities who are receiving direct services through activities in which UCEDD-trained professionals are involved.

To gather data for this measure, the following question will be asked of interdisciplinary preservice preparation and continuing education UCEDD trainees at 1, 5, and 10 years post-training:

What is the number of individuals with developmental disabilities who are receiving direct services through activities in which you are involved.

The question will be accompanied by the following definition for “Direct Services” to guide the respondent:

“Direct Services” include direct activities related to quality assurance, education and early intervention, child care, health, employment, housing, transportation, recreation, or any other care, services or supports provided directly to individuals with developmental disabilities and their family members. Examples include:

- Training or educating individuals with developmental disabilities and their family members.
- Providing therapeutic child care, clinical services, or other direct services to individuals with a developmental disability and their family members.
- Providing technical assistance directly to individuals with developmental disabilities and their family.
- Conducting research that includes a direct service component or intervention with individuals with developmental disabilities and their family members as subjects.
- Supervising professionals, paraprofessionals, or students who are providing direct services to individuals with developmental disabilities and their family members.

MEASURE 2:

The second GPRA measure captures information about the outcomes for UCEDD trained professionals:

The percent of UCEDD trainees who demonstrate leadership in the developmental disabilities field at 1, 5, and 10 years after completion of UCEDD training.

The following question will be asked of interdisciplinary preservice preparation and continuing education UCEDD trainees at 1, 5, and 10 years post-training:

Are you in a leadership position in the field of developmental disabilities?

The question will be accompanied by the following definition for “Leadership” to guide the respondent:

“Leadership” refers to any training, community service, research, or dissemination activities that enhance the capacity of systems, professionals, or other stakeholders to make positive changes for people with developmental disabilities in the areas of quality assurance, education and early intervention, child care, health, employment, housing, transportation, or recreation. The UCEDD leadership measure could be demonstrated in the following areas:

- *Academics:* Teaching or mentoring as a faculty member in a developmental disability-related field, conducting developmental disability-related research, providing consultation/technical assistance in developmental disability-related areas, publishing and presenting in key developmental disability-related areas, and/or procuring grants and other funding.
- *Clinical:* Developing guidelines for specific developmental disability-related conditions; participating as officer or chairperson of committees on state, national, or local clinical organizations, task forces, community boards, etc.; serving as a clinical expert for UCEDD trainees; researching, publishing, or making key presentations on developmental-disability-related clinical issues; and/or serving in a clinical leadership position as director, team leader, chairperson, etc.
- *Public Policy (education, health, social services):* Holding a leadership position in a government entity or local, state, or national public organization; conducting strategic planning; participating in program evaluation and public policy development; procuring grant and other funding; influencing legislation; and/or publishing or making key presentations on developmental-disability-related policy issues.
- *Advocacy:* Leading formal advocacy efforts at the community, state, regional, and national levels; and/or influencing positive change in the developmental disability field through creative promotion, support, and activities.
- *Community Supports:* Holding a leadership position at local, state, or national level to conduct, monitor, or evaluate

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community-based services and supports; leading activities to effect systems change that benefits people with developmental disabilities; developing service models that increase the independence, productivity, and community integration of people with developmental disabilities; and/or providing consultation/technical assistance in promising practices in community-based supports for people with developmental disabilities.

III. MEASUREMENT METHODS

Improvement Measures

Interdisciplinary Pre-Service Preparation and Continuing Education	All measures related to <i>Interdisciplinary Pre-Service Preparation and Continuing Education</i> should report on the total number trained in the appropriate area of emphasis during the fiscal year.
Community Services: Training and TA	All measures related to <i>Community Services: Training and TA</i> should report on the total number of individuals in the community reached in the appropriate area of emphasis during the fiscal year.
Community Services: Direct Services & Demonstration Projects	All measures for <i>Community Services: Direct Services & Demonstration Projects</i> should report on the total number of individuals in the community who received services in the appropriate area of emphasis during the fiscal year.
Research	All measures related to <i>Research</i> activities should report on the: <ul style="list-style-type: none"> • Total number of research activities in the appropriate area of emphasis during the fiscal year, and • Total number of evaluation activities in the appropriate area of emphasis during the fiscal year.
Information Dissemination	All measures related to <i>Information Dissemination</i> should report on the: <ul style="list-style-type: none"> • Total number of products developed in the appropriate area of emphasis during the fiscal year. • Total number of products in the appropriate area of emphasis disseminated during the fiscal year.

Consumer Satisfaction Measures

Interdisciplinary Pre-Service Preparation and Continuing Education	<p><i>Numerator:</i> Total number of trainees reporting being satisfied and highly satisfied.</p> <p><i>Denominator:</i> Total number trainee responses.</p> <p>For consistency across the grantees reporting on consumer satisfaction, below is the item that should be used to gather responses from trainees:</p> <p><i>Which of the following best reflects your level of satisfaction with the knowledge and skills gained from the training (Circle one please)?</i></p> <p><i>highly satisfied satisfied satisfied somewhat not at all satisfied</i></p>
	<p><u><i>Response rate:</i></u></p> <p><i>Numerator:</i> Total number of surveys returned</p> <p><i>Denominator:</i> Total number of surveys distributed</p>

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<p>Community Services: Training and TA</p>	<p><i>Numerator:</i> Total number of individuals reporting being satisfied and highly satisfied.</p> <p><i>Denominator:</i> Total number individuals responding.</p> <p>For consistency across the grantees reporting on consumer satisfaction, below is the item that should be used to gather responses from individuals in the community receiving training and technical assistance:</p> <p><i>Which of the following best reflects your level of satisfaction with the training and/or technical assistance received (Circle one please)?</i></p> <p><i>highly satisfied satisfied satisfied somewhat not at all satisfied</i></p> <hr/> <p><u><i>Response rate:</i></u> <i>Numerator:</i> Total number of surveys returned</p> <p><i>Denominator:</i> Total number of surveys distributed</p>
<p>Community Services: Direct Services & Demonstration Projects</p>	<p><i>Numerator:</i> Total number of individuals reporting being satisfied and highly satisfied.</p> <p><i>Denominator:</i> Total number individuals responding.</p> <p>For consistency across the grantees reporting on consumer satisfaction, below is the item that should be used to gather responses from individuals in the community receiving direct services:</p> <p><i>Which of the following best reflects your level of satisfaction with the services received (Circle one please)?</i></p> <p><i>highly satisfied satisfied satisfied somewhat not at all satisfied</i></p> <hr/> <p><u><i>Response rate:</i></u> <i>Numerator:</i> Total number of surveys returned</p> <p><i>Denominator:</i> Total number of surveys distributed</p>
<p>Information Dissemination</p>	<p><i>Numerator:</i> Total number of individuals reporting being satisfied and highly satisfied.</p> <p><i>Denominator:</i> Total number individuals responding.</p> <p>For consistency across the grantees reporting on consumer satisfaction, below is the item that should be used to gather responses from consumers on the research and evaluation activities.</p> <p><i>Having used _____ (title of publication) _____, which of the following best reflects your level of satisfaction with the quality of this product (Circle one please)?</i></p> <p><i>highly satisfied satisfied satisfied somewhat not at all satisfied</i></p>

	<p><u>Response rate:</u> <i>Numerator:</i> Total number of surveys returned</p> <p><i>Denominator:</i> Total number of surveys distributed</p>

IV. CONFIDENTIALITY

When ever collecting consumer satisfaction data, UCEDDs must ensure the protection of the informant’s confidentiality to the extent permitted by law. Information gathering techniques for the collection of consumer satisfaction data are to be conducted without inclusion of names or other identifying information of the respondents. Respondents are to be assured that the information they provide is confidential and will be used for the stated purpose for which they were collected. In addition, respondents are to be assured that their participation evaluating satisfaction is voluntary. In keeping with ADD practices with respect to cultural competence and the ADA, alternative formats must be made available.

In conducting the evaluative activities, the UCEDDs will ensure the respondents’ confidentiality in a variety of formats, including oral and written statements. If UCEDDs use written survey techniques, a standard written statement about confidentiality must be included. All statements about confidentiality will explain that responses are voluntary, confidential information will not be shared with others, and that answers will be used for the purpose for which they were collected. In keeping with agency practices with respect to cultural competence issues, literacy, and visual or auditory ability, alternative formats will be made available.

When recording information collected through the various evaluative activities, the UCEDDs must maintain a coding system that protects the identity, if known, of the respondent. Measures should be taken to ensure the confidentiality of files, including the use of locked file cabinets and passwords on computers where data is kept.

None of the data that is entered into NIRS will be confidential. No personally identifiable information should appear in NIRS.