

Developmental Disabilities Program Independent Evaluation (DDPIE) Project

**GLOSSARY**

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**A**

**Advocacy**

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.

**Applied research**

Refers to research that is designed to solve practical problems rather than to acquire knowledge for knowledge's sake. The goal of applied research of the UCEDDs is to investigate how to improve the lives of individuals with developmental disabilities and their families.

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**B**

**Basic research** (fundamental or pure research)

Refers to research that is driven by a scientist's curiosity or interest in a scientific question. The main motivation is to expand knowledge, not to create or invent something. Basic research conducted by the UCEDDs includes research at medical centers, sometimes with animals. Basic research, conducted under the auspices of the UCEDD must be relevant to the developmental disabilities population in some way.

**Benchmark**

A broad and general statement that serves as standard by which entities may be measured or judged. Taken together, benchmarks represent DD Network programs that are effective in functioning and meet the expected outcomes of all [key functions](#).

**Blueprint**

Refers to a detailed plan of action.

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**C**

**Class action**

A procedural concept in the law that is applied in litigation to determine the rights of and remedies, if appropriate, for large numbers of people whose cases involve questions of law and fact that share common characteristics.

**Collaborator**

Refers to any person or organization who shares expertise, facilities, equipment, or financial support necessary for a common goal. For instance, in the case of the P&A systemic advocacy key function, collaborators refer to advisory groups; health, housing, employment, and other substantive human services groups; educational institutions; organizations and associations that serve individuals with developmental disabilities and their families or guardians; faith-based, ethnic, and cultural groups; parent groups; and other stakeholder groups that serve individuals with developmental disabilities and their families or guardians.

**Continuing education**

A non-degree education program that brings participants up to date in a particular area of knowledge and skills. It includes non-degree career training and upgrading, and courses that receive continuing education units (CEUs) and consists of courses, workshops, seminars, and other educational vehicles.

**Community at large**

The term “community at large” consists of members of the public; organizations, groups, or individuals that are not considered to be part of the developmental disabilities community (e.g., employers, medical associations, schools).

**Core curriculum**

A curriculum in which all or some of the subjects or courses are based on a central theme in order to correlate the subjects and the theme. *Dictionary.com Unabridged (v 1.0.1). Based on the Random House Unabridged Dictionary, © Random House, Inc. 2006.*

**Culturally competent**

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].

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**D**

**Designated State Agency**

An agency or office within the State designated to support the State Council on Developmental Disabilities (Council) in accordance with DD Act [Sec. 124(c)(2) and Sec. 125(d) of the DD Act]. The designated State agency can be (a) the Council if such Council is the designated State agency under the laws of the State, (b) a State agency that does not provide or pay for services for individuals with developmental disabilities, or (c) a State Office, including the immediate office of the Governor of the State or a State planning office.

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**F**

**Families**

Refers to a group of persons who form a household, including parents and children.

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**General public**

Refers to all residents of a state or other jurisdiction as opposed to a specific target audience.

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**I**

**Inclusion**

The term “inclusion,” used with respect to individuals with developmental disabilities, means the acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with development disabilities to (a) have friendships and relationship with individuals and families of their own choices; (b) live in homes close to community resources, with regular contact with individuals without disabilities in their communities; (c) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and (d) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities [Sec. 102(15)(A),(B),(C), and (D)].

**Indicator**

Refers to what gets measured in order to determine whether a [benchmark](#) or [performance standard](#) is being met. There are four types of indicators used in the measurement matrices. They are structural, process, output, and outcome indicators. Structural indicators (e.g., staffing, facilities, equipment, and information systems) are used to assess the DD Network’s capability to achieve goals of the DD Act through adequate and appropriate settings and infrastructures. They include, but are not limited to, staffing, facilities, and equipment, financial resources, information systems, governance and administrative structures.

Process indicators (e.g., conducting a comprehensive review) are used to assess the content and quality of the DD Network’s activities, procedures, methods, and intervention supporting practices aligned with the purpose and principles of the DD Act.

Output indicators (e.g., education and training materials) are used to assess immediate results of the DD Network’s policies, procedures, and services that can lead to achieving the purpose and principles of the DD Act.

Outcome indicators (e.g., changes in public policies and practices; consumers’ use of skills and knowledge learned from the Partners in Policymaking program) are used to assess the unique and collective contributions of the DD Network programs to achieving intermediate results for individuals with developmental disabilities and their families relating to the provision of, response to, and results of services.

### **Interdisciplinary**

Interaction among multiple disciplines on a common problem. Interdisciplinary is different from [multi-disciplinary](#) where input from multiple perspectives on a common problem is obtained without interaction among them.

### **Interdisciplinary training programs**

Refers to training programs that consist of interaction among multiple disciplines on a common problem.

### **Intake process**

Intake is a process whereby a request for service is made by or for a person and it is then determined whether and what kind of service is to be provided. It is usually the first step taken by a staff when a client seeks help. For instance, P&A intake staff route customers to the appropriate form of assistance. I&R is one form of assistance that P&As provide. Customers may also receive individual advocacy services, or their issue may be relevant to a systemic advocacy issue.

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### **Key function**

Refers to a group of activities that are implemented to achieve expected outcomes. All activities of DD Network programs (i.e., Councils, UCEDDs, and P&As) should fall under one of the key functions.

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**L**

**Linguistic competence**

Refers to the capacity of an organization and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities (from Tawara Goode and Wendy Jones, Georgetown University UCEDD, Center for Child and Human Development, 6/06).

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**M**

**Multi-disciplinary**

Input from multiple perspectives on a common problem without interaction among them. Multi-disciplinary is different from [interdisciplinary](#) where interaction occurs among multiple disciplines on a common problem.

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**O**

**Office of Management and Budget (OMB)**

The White House office that is responsible for devising and submitting the president's annual budget proposal to Congress, as well as administering the Paper Work Reduction Act. The OMB establishes guidelines for federally funded research contracts with respect to research standards and data collection instruments and procedures, and reviews and approves (or disapproves) proposed studies funded under all government contracts.

**Outreach**

Efforts made to connect or bring awareness of one's ideas or practices to other organizations, groups, target audiences or the general public. The goal of outreach is to identify underserved and unserved populations.

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**P**

**Performance standard**

A statement of the expectations or requirements that DD Network programs should be achieving, doing, or having.

**Plan of correction**

An immediate response implemented to rectify a specific situation. Responses can include enforcement of a policy, procedure, or ruling; removal of barriers; or other actions or ceasing of an action(s) in the interest of preserving or advancing the rights of individuals with developmental disabilities and their families or guardians.

**Policy maker**

The term “policy maker” refers to any person with the power to influence or determine policies and practices at a national, regional, or local level. Policy makers may include the governor of the State, State or local legislators, those who make recommendations to the governor and or legislators, and heads of public agencies (or departments within those agencies) that provide services and supports to people with developmental disabilities and their families.

**Public awareness**

The process of informing the general population and increasing the level of consciousness about people with developmental disabilities.

**Public education**

Planned and responsive efforts specifically designed to promote, preserve, and enhance public awareness of the role and services of DD Network programs and consciousness of the legal and human rights and value of individuals with developmental disabilities through training, direct instruction, and other structured interactions.

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**S**

**Self-advocacy**

Self-advocacy refers to an individual’s ability to effectively communicate, convey, negotiate, or assert his or her own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions.<sup>1</sup> For instance, people with developmental disabilities (and their families) speak up for themselves. Although people with developmental disabilities may call upon the support of others, they are entitled to be in control of their own resources and how they are directed. Self-advocacy is about having the right to make life decisions without undue influence or control by others.

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<sup>1</sup> VanReusen, A. K., Bos, C. S., Schumaker, J. B., & Deschler, D. D. (1994). Self-advocacy strategy for education and transition planning. Lawrence, KS: Edge Enterprises.

**Self-determination**

The principle that individuals should have the right to determine their own fate or course of action without compulsion.

**Service providers**

Persons (or groups) who provide services to people with developmental disabilities and their families. Services include health care, education, transportation, financial planning, assistance with certain activities of daily living (e.g., functional mobility, personal hygiene, grooming), or assistance with instrumental activities of daily living (e.g., shopping, financial management).

**Stakeholder**

A group of people who have an interest in a particular decision, either as individuals or representatives of a group. 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.

**State systems**

Refers to programs, services, policies, and regulations in the State.

**Statement of Goals and Priorities (SGP)**

Federal statute and regulation require each State Protection and Advocacy (P&A) System to prepare and submit to public comment a Statement of Goals and Priorities (SGP) for the P&A for Developmental Disabilities (PADD) program for each coming fiscal year. While the P&A is mandated to protect and advocate under a range of different Federally authorized disabilities programs, only the PADD program requires an SGP. Following the required public input for the coming fiscal year, P&As submit the final version of this SGP to the Administration on Developmental Disabilities (ADD).

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**T**

**Target audience**

The group for which a key function is intended. For instance, in the case of Advocacy and Leadership Development key function, the target audience consists of people with developmental disabilities and their families.

**Technical assistance**

The delivery of information on a one-on-one or small group basis. Technical assistance is relevant to an identified issue (e.g., helping coalitions establish bylaws or filing; helping statewide self-advocacy groups write a whitepaper on related issues) and is usually delivered informally.

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**U**

**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 (Sec. 102(32) of the DD Act).

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