

## UCEDD SELF-DETERMINATION SELF-ASSESSMENT CHECKLIST



### Purpose of UCEDD Self-Determination Self-Assessment Checklist

The purpose of the UCEDD Self-Determination Self-Assessment Checklist is to provide UCEDDs with a straightforward tool and process to determine the **degree to which its policies, practices, and personnel, at a given point in time, are promoting the self-determination** of people with intellectual and developmental disabilities (I/DD). The result will be a profile of the organization's performance that can be used to identify areas to strengthen, and to suggest resources and best practices for desired improvements.

**Allen A. Schwartz, PhD**  
**Barbara Levitz, MSEd**  
**Ansley Bacon, PhD**  
**Mitchell Levitz**

Westchester Institute for  
Human Development and  
New York Medical College

**Tawara Goode, MA**  
National Center for Cultural Competence  
Georgetown University Center for Child  
and Human Development

Published by the  
National Training Initiative  
on Self-Determination and  
the Association of University  
Centers on Disabilities

 A National Gateway  
to Self-Determination



Funded by U.S. Department of Health and  
Human Services, Administration on  
Developmental Disabilities,  
grant no. 90-DD-0659

### Self-Determination and Self-Determination Activities

The UCEDD Self-Determination Self-Assessment Checklist adopts a **social-ecological** approach advanced by several theorists (Wehmeyer et al., 2003; Abery & Stancliffe, 1996) by which self-determination is viewed as the product of a person's capacities, interests, and dispositions interacting with his or her physical, social, and cultural environment to achieve a level of personal control and self-direction that the person views as desirable. This view theorizes self-determination as driven by the intrinsic human motivation to shape one's life and make choices, but within specific contexts and only to the extent preferred. Within the person-environment context, people make decisions based on their cultural beliefs and practices, skills, preferences, and values; monitor and regulate their own actions; and act in a goal oriented manner.

**The DD Act** defines self-determination activities as occurring when an individual with developmental disabilities, with assistance: (a) has the ability and opportunity to make *choices and decisions*, (b) has the ability and opportunity to *exercise control* over services, supports, and other assistance, (c) has the *authority to control* resources and obtain needed services, (d) has the opportunity to *participate and contribute in their communities*, and (e) has the *support, including financial*, to advocate, develop leadership skills, become trained as a self-advocate, and participate in coalitions and policy-making. This definition suggests that both the *abilities* and *motivation* of the person, and the *opportunities* presented by the environment, contribute to the degree of self-determination that can be expressed.

**Culture** is the learned and shared knowledge that specific groups use to generate their behavior and interpret their experience of the world. It includes, but is not limited to, communications, languages, practices, beliefs, values, customs, courtesies, rituals, manners of interacting, roles, relationships, and expected behaviors of a racial, ethnic, religious, political, professional, or other social group. (Gilbert, J., Goode, T., & Dunne, C., 2007; NCCC). Culture is an integral and inseparable aspect of a person's social environment. Thus, a person's culture influences the way in which self-determination is perceived, experienced, and expressed. For example, cultures often define and value interdependence and independence differently. Many within these cultures believe that families should assume a significant role in making decisions that affect individual family members or actually make the decision on behalf of an individual family member. These cultural beliefs and practices will influence if and when an individual with I/DD leaves the family home, is able to marry, can seek and maintain employment, and makes health care decisions. Culture should be viewed both as a set of critical personal characteristics and important environmental influences in understanding what self-determination means to an individual, family, or group in any given context.

## Guiding Principles of Organizational Self-Assessment

- **Self-assessment is undertaken to identify an organization's relative strengths and areas it wishes to enhance, in order to provide a structure for self-examination and constructive discussion.** These activities should focus on programmatic improvements and organizational changes that build on existing capacities to move the organization in desired directions.
- **Self-assessment is best conducted in a non-judgmental atmosphere,** with appropriate considerations for privacy, and respect for personal opinion. All those who take part in the self-assessment process must feel free to be honest in expressing their views, with no fear of repercussion or stigma.
- **All key participants in the organization must have a voice in the process.** This includes staff at all levels, including: faculty; support, service, and technical staff; students; service recipients; self-advocates; family members of people with developmental disabilities; and members of communities affected by the activities of the organization.
- **The process of self-assessment should result in a profile of the organization** that can guide the development of a set of actions to increase its capability over time in specific areas. Activities may be directed towards identifying and addressing current limitations and/or enhancing existing strengths.
- **A plan should emerge that allows the organization to take specific actions** that improve performance in relation to its mission, increase service quality, achieve strategic objectives, develop inclusiveness and cultural responsiveness, and enhance the satisfaction of people with I/DD and their families, students, faculty, and staff.

## UCEDD Mission and Core Functions

The UCEDD Self-Determination Self-Assessment Checklist is organized into topic areas that correspond with the statutory mission and core functions of UCEDDs. Section 153 of PL 106-402 outlines the purpose and scope of UCEDD functions. UCEDDs engage in one or more core functions in order to implement their mission. These core functions include the:

- 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;
- 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;

- Provision of **services, supports, and assistance** for all groups noted above through demonstration and model activities;
- Conduct of **research**, including basic or applied research, **evaluation**, and the **analysis of public policy** in areas that affect people with developmental disabilities and their families; and
- **Dissemination of information** related to activities undertaken to address the purpose of the law, to act as a national and international resource that includes specific substantive areas of expertise.

In addition to guiding the UCEDD in the assessment of its core functions, the Self-Determination Self-Assessment Checklist provides an additional topic area that reviews other aspects of the organization which are often the subject of self-assessment, such as mission, organizational culture, governance, and human resource policies.

## Scoring Options

The UCEDD Self-Determination Self-Assessment Checklist is not intended to produce a score, per se, but rather to produce a profile that indicates areas of strength, opportunities for improvement, and information for constructive dialogue. We have however adopted a scoring system that allows a profile to be developed which can be converted to a quantitative score if the UCEDD so desires. It is essentially a three-point scale:

**YES (Y) = 2** (The UCEDD does this most or all of the time.)

**IN DEVELOPMENT (ID) = 1** (The UCEDD is in the process of implementing or improving performance in this activity.)

**NO (N) = 0** (The UCEDD rarely or never does this.)

**NOT APPLICABLE (NA) = NO SCORE** (This activity does not apply to our UCEDD.)

A scoring system allows the UCEDD to tally up its ratings and display them graphically by each core function. A three-point scale provides the opportunity for the UCEDD to track changes over time, as certain activities move from the *NO* to the *IN DEVELOPMENT* to the *YES* rating level, and quantitative scores by core function increase. *Use of quantitative scoring and profiling is completely optional.* As already stated, the primary purposes of the checklist are to elevate the UCEDD's awareness of how its activities and policies promote self-determination, and foster productive discussion around this topic by the UCEDD community, its partners, constituents, and individuals it serves.

## Identification of Recommended Resources and On-Line Resource Library

One of the purposes of the UCEDD Self-Determination Self-Assessment Checklist is to assist the UCEDD network in identifying resources (e.g., manuals, curricula, reports, media) that can be useful in improving performance in desired areas related to supporting self-determination. As the UCEDD goes through the self-assessment process, participants in the process should take time to reflect on whether their UCEDD has policies, procedures, training materials, or other resources that could be helpful to others in promoting self-determination. Note these recommended resources at the end of each section in the specified area.

The five UCEDDs collaborating on the National Gateway to Self-Determination initiative have established a Resource Guide as an online repository for these and other resources helpful in promoting self-determination. The Resource Guide is located at the National Gateway to Self-Determination website ([www.aucd.org/ngsd](http://www.aucd.org/ngsd)). The goal is to link the need areas identified by the Checklist to appropriate resources and promising practices.

# Area 1: Pre-service Preparation and Continuing Education

## Definitions for This Section

**Interdisciplinary Pre-service Preparation.** An instructional program offered by the UCEDD that: (1) integrates knowledge and methods from two or more distinct disciplines; (2) integrates direct contributions to the field made by people with disabilities and family members; (3) examines and advances professional practice, scholarship, and policy that impacts the lives of people with developmental and other disabilities and their families; (4) is designed to advance an individual's academic or professional credentials; and (5) takes place in an academic setting or program. It may: (1) lead to the award of an initial academic degree, professional certificate, or advanced academic credential; and (2) contribute to a discipline-specific course of study offered by the UCEDD or by another academic department.

**UCEDD Discipline Specific Training.** An instructional program offered by the UCEDD that: (1) focuses on a particular professional discipline or distinct field of study; (2) integrates direct contributions to the field made by people with disabilities and family members; (3) examines and advances professional practice, scholarship, and policy that impacts the lives of people with developmental and other disabilities and their families; (4) is designed to advance an individual's academic or professional credentials; and (5) takes place in an academic setting or program.

**UCEDD Continuing Education.** Seminar(s) or courses of instruction offered by the UCEDD that: (1) serve to maintain professional credentials; (2) encourage professionals to expand their knowledge base and stay up-to-date on new developments; and (3) award certificates of completion or CEUs (or their equivalents).

1.1 Are faculty and staff that provide UCEDD services **specifically trained to promote the self-determination** of people with I/DD (i.e., is it part of their orientation and/or staff development training)?

Y  ID  N  NA

• If **Yes** or **In Development to 1.1**, which staff receive training on this topic? (check all that apply)

- Administration, general operations
- Attorneys/legal staff
- Faculty/instructors
- Medical personnel (e.g., MDs, Dentists, RNs, LPNs)
- Public relations/fund raising staff
- Research faculty/staff
- Social workers/case managers/service coordinators
- Students/interns
- Therapists (e.g., OT, PT, ST)
- UCEDD project and/or grant staff
- Volunteers
- Other: \_\_\_\_\_

• If either **Yes** or **In Development to 1.1**, does this training include information on multi-cultural beliefs and practices related to promoting self-determination?

Y  ID  N  NA



# Area 2: Training and Technical Assistance

## Definitions for this Section

**Community Services – Training.** Training provided by UCEDD faculty/staff to enhance knowledge of a variety of community members (individuals with developmental and other disabilities, their families, professionals, paraprofessionals, policy-makers, students, or others in the community).

**Community Services – Technical Assistance.** Direct problem-solving services provided by UCEDD faculty/staff to assist individuals with developmental and other disabilities, families, programs, agencies, or other entities in improving their outcomes, services, management, and/or policies.

(**Note:** Technical Assistance may be provided in person, by digital and electronic media such as websites and webinars, by telephone, video, 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 people served.)

**2.1** Does your UCEDD conduct **community training** that specifically promotes an understanding of the importance of self-determination to and for people with I/DD?

Y  ID  N  NA

• If either **Yes** or **In Development to 2.1**, which audiences receive such training? (check all that apply)

- Adults with I/DD
- Aging agencies and organizations administrators/staff
- Businesses/potential employers
- Children/adolescents with I/DD
- Community organizations/clubs/civic groups
- Cultural or ethnic organizations
- Developmental Disability Council members
- Direct support staff
- Disabilities services providers, agency administrators/staff
- Early intervention, child care, Head Start program administrators/staff
- Employment/vocational rehab agency administrators/staff
- Faith-based organizations/spiritual communities
- Family members of people with I/DD
- Family support and/or advocacy organizations
- General public
- Government officials/policy makers/legislators
- Hospital/health agency administrators/staff
- Medical personnel (e.g., MDs, Dentists, RNs, LPNs)
- Mental health/substance abuse agency administrators/staff
- Postsecondary education faculty/administrators
- Protection and Advocacy agency staff
- State/local general education teachers/administrators
- State/local special education teachers/administrators
- Therapists (e.g., OT, ST, PT)
- Transportation agencies/providers/staff
- Other: \_\_\_\_\_

**2.2** Does your UCEDD provide **technical assistance to community organizations** with the explicit goal of increasing that organization's promotion of self-determination for the people it supports?

Y  ID  N  NA

• If either **Yes** or **In Development to 2.2**, which types of organizations receive such technical assistance? (check all that apply)

- Aging agencies and organizations
- Community organizations/clubs/civic groups
- Corporations/businesses/other potential employers
- Cultural or ethnic organizations
- Developmental Disability Council
- Direct support staffing agencies
- Disabilities services provider agencies
- Early intervention, child care, Head Start programs
- Employment/vocational rehab agencies
- Faith-based organizations/spiritual communities
- Family support and/or advocacy organizations
- Hospitals, clinics, and other health/medical organizations
- Governmental units
- Law enforcement/fire fighters/EMT
- Mental health/substance abuse agencies
- Postsecondary education programs/community colleges
- Protection and Advocacy agency
- State/local general education programs
- State/local special education programs
- Transportation agencies
- Other: \_\_\_\_\_

**2.3** Are there **specific training and/or technical assistance activities** conducted by your UCEDD that are designed to increase the capability of **people** with I/DD to:

2.3.1 make choices, decisions, and solve problems as independently as possible?

Y  ID  N  NA

2.3.2 live independently and/or become more self-sufficient?

Y  ID  N  NA

2.3.3 work, volunteer, and contribute to their communities?

Y  ID  N  NA

2.3.4 manage their own health and health care, make healthy choices, and/or interact more effectively with health care providers?

Y  ID  N  NA

2.3.5 form friendships, expand social networks, and use social skills?

Y  ID  N  NA

2.3.6 address bias, discrimination, and stigma they may encounter due to race, ethnicity, culture, disability, or spoken language?

Y  ID  N  NA

- 2.4** Are there **specific training and/or technical assistance activities** conducted by your UCEDD that are designed to increase the capacity of **organizations** to:
- 2.4.1 provide environmental supports, technologies, and opportunities for people with I/DD to be self-determining?  
 Y  ID  N  NA
- 2.4.2 support the formation and operation of local self-advocacy groups?  
 Y  ID  N  NA
- 2.4.3 influence public attitudes toward inclusion of people with I/DD in all aspects of community life?  
 Y  ID  N  NA
- 2.4.4 identify and address multi-cultural and linguistic needs and preferences among individuals with I/DD and families as they relate to promoting self-determination?  
 Y  ID  N  NA
- 2.5** With respect to the training activities described in questions 2.3 and 2.4, does your UCEDD **measure the impact of such training** (e.g., measure skills acquired, changes in behavior, or other outcomes of the training)?  
 Y  ID  N  NA
- 2.6** With respect to the technical assistance activities described in questions 2.3 and 2.4, does your UCEDD **measure the impact of such technical assistance** (e.g., measure changes in organizational behavior, culture, service design, or other outcomes of the technical assistance)?  
 Y  ID  N  NA
- 2.7** Do the UCEDD faculty and staff that provide training and/or technical assistance typically **include as co-trainers/consultants:**
- people with I/DD?  
 Y  ID  N  NA
  - family members of people with I/DD?  
 Y  ID  N  NA
  - individuals who are representative of the racial, ethnic, cultural groups in the geographic area, state, territory, or tribal community?  
 Y  ID  N  NA
- 2.8** If either **Yes** or **In Development** to any of the people listed in 2.7, are these co-trainers/consultants **prepared by the UCEDD** to assume these training and/or technical assistance roles?  
 Y  ID  N  NA



# Area 3: Community Services, Supports, and Assistance

## Definitions for this Section

**Community Services – Model Services.** Specialized services delivered with the intention to enhance the well being and status of the recipient and not for testing new practices, and may be integrated with training, research, and/or dissemination functions.

**Community Services – Demonstration Services.** Services that field test promising or exemplary practices and may be integrated with training, research, and/or dissemination functions.

**3.1** Are the **policies and procedures** that govern the UCEDD's community services delivery (i.e., model services and demonstration services) periodically reviewed and, if indicated, adapted to maximize opportunities for participant choice, control, and/or self-management?  
 Y  ID  N  NA

- If either **Yes** or **In Development to 3.1**, specifically what participant opportunities are maximized? (check all that apply)
  - To maximize participant **choice**?  Y  ID  N  NA
  - To maximize participant **control**?  Y  ID  N  NA
  - To maximize participant **self-management**?  Y  ID  N  NA

**3.2** Does the UCEDD offer culturally and linguistically appropriate model and/or demonstration services that promote **community participation, contribution, self-sufficiency and/or independence**?  
 Y  ID  N  NA

- If either **Yes** or **In Development to 3.2**, which model and/or demonstration services are offered? (check all that apply)
  - Adaptive technologies
  - Case management/service coordination
  - Community navigation/participation training
  - Employment training/supports
  - Health self-management and medical decision-making training
  - Healthy lifestyles and wellness promotion
  - Housing
  - Independent living skills training
  - Parenting training
  - Sexuality training
  - Training in relationship-building and social network formation
  - Transportation
  - Other: \_\_\_\_\_



## Area 4: Research and Information Dissemination

### Definitions for this Section

**Research.** Implementation of basic and applied research, program evaluation, and analysis of public policy on issues impacting individuals with intellectual and developmental disabilities.

**Basic Research.** Research for the purpose of extending knowledge by adding to the existing body of knowledge in the discipline. Such research has a general orientation.

**Applied Research.** Research for the purpose of solving an immediate, practical problem. Such research is oriented to a particular problem.

**Field Test.** A test to examine a promising or exemplary service technique or method using the conditions under which it is designed to operate (can be thought of as applied research).

**Evaluation.** A form of research to assess the merits of a product, program, or practice. The application of results is at a given site or sites and this is the primary focus of the evaluation. Evaluation results aid in decision making in a specific situation.

**Analysis of Public Policy.** A process that usually begins with problem definition and yields alternatives. It has a specific client and a single point of view, a short time horizon, and an openly political approach.

**Participatory Action Research (PAR).** Research which involves all relevant parties in actively examining together current action (which they experience as problematic) in order to make a change or improvement. They do this by critically reflecting on the historical, political, cultural, economic, geographic, and other contexts which have contributed to the current state. Action research involves utilizing a systematic cyclical method of planning, taking action, observing, evaluating (including self-evaluation), and critical reflecting prior to planning the next cycle. The actions have a set goal of addressing an identified problem.

**Information Development and Dissemination.** Distribution of knowledge-based information through UCEDD-developed products and activities.

---

**4.1** Does your UCEDD conduct **research related to promoting the self-determination** of people with I/DD (e.g., basic, applied, field test, evaluation, policy analysis, participatory action research)?

Y  ID  N  NA

• If either **Yes** or **In Development to 4.1**:

– Do UCEDD research procedures take into account **cultural and linguistic barriers** related to conducting research in diverse communities?

Y  ID  N  NA

– Are research designs reviewed to assure that **diversity (i.e., cultural, linguistic, geographical, socio-economic) is represented in the subject sample**, as appropriate to the need to generalize findings and conclusions?

Y  ID  N  NA

– Is **PAR** undertaken by the UCEDD that is relevant to the issues and needs confronting **members of the communities** whom the UCEDD serves?

Y  ID  N  NA

**4.2** Are people with I/DD typically involved in the **design, implementation, and/or analysis of research** conducted by the UCEDD?

Y  ID  N  NA

**4.3** Are people with I/DD typically involved in the **dissemination of the results of research** conducted by the UCEDD?

Y  ID  N  NA

**4.4** Do people with I/DD who are **racially, ethnically, and/or linguistically diverse** **participate** in research activities conducted by the UCEDD?

Y  ID  N  NA

**4.5** Does the UCEDD **periodically disseminate research findings** and/or policy papers (its own or from other sources) that promote the self-determination of people with I/DD, with the intent to inform and influence constituency groups, stakeholders, and others in the general public?

Y  ID  N  NA

**4.6** If either **Yes** or **In Development to 4.5**, are finding and reports disseminated in **languages other than English**?

Y  ID  N  NA





## Acknowledgements

The development of this Checklist was supported in part by the National Training Initiative in Self-Determination (“A National Gateway to Self-Determination”) funded by the U.S. Department of Health and Human Services, Administration for Children and Families, Administration on Developmental Disabilities, through contract number HHS-2008-ACF-ADD-DD-0081 awarded to the Institute for Human Development at the University of Missouri, Kansas City.

The authors would like to thank the following individuals for their invaluable assistance in the preparation of this instrument:

- **Hill Walker**, Center on Human Development, University of Oregon;
- **Alison Ball**, Center for Excellence in Developmental Disabilities for the College of Education, University of Oregon;
- **Dawn Rudolph** and **Crystal Pariseau**, Association of University Centers on Disabilities; and
- **Marilyn Vitale**, **David O’Hara**, and **John Maltby** of the Westchester Institute for Human Development and New York Medical College.

## UCEDD Leadership Consortium – National Gateway to Self-Determination

Carl F. Calkins, PhD, Co-PI; Institute for Human Development, University of Missouri-Kansas City  
Michael Wehmeyer, PhD, Co-PI; Kansas University Center on Developmental Disabilities,

University of Kansas

Ansley Bacon, PhD; Westchester Institute for Human Development and New York Medical College  
Tamar Heller, PhD; Institute on Disability and Human Development, University of Illinois, Chicago  
Hill Walker, PhD; Center on Human Development, University of Oregon

### Suggested Citation:

Schwartz, A. A., Levitz, B., Bacon, A.,  
Goode, T., Levitz, M. (2011, October).  
*UCEDD Self-Determination Self-  
Assessment Checklist*. Silver Spring, MD:  
National Training Initiative in Self-  
Determination.

### Publishers:

National Training Initiative on  
Self-Determination  
and  
Association of University Centers on  
Disabilities (AUCD)

Correspondence concerning this  
publication should be directed to:

Allen A. Schwartz, PhD  
Westchester Institute for  
Human Development  
Room 307, Cedarwood Hall  
Valhalla, NY 10595-1681  
aschwartz@wihd.org

### Art Design and Production:

Crystal Pariseau, AUCD