



# A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

**AUCD - Pre-Con Workshop 3**

## **Incorporating a New Self- Assessment Process on Self-Determination in Plan Development for UCEDDs**

Westchester Institute for Human Development UCEDD  
New York Medical College, Valhalla, NY

As part of the  
NTI-SD Gateway Consortium

AUCD

Sunday, November 6, 2011

# Importance of Self-Determination

- The link between scaling-up training on self-determination, the Envisioning Forums, and the Self-Advocacy Summits;
- The role of self-determination in the future direction of the network, and of critical activities of the DD community;
- The value of using the UCEDD Self-Determination Self-Assessment process; and
- The importance of incorporating Self-Determination into future UCEDD plan development.



# Introduction

- ADD and AUCD have been active in promoting self-determination so that every individual can set the direction of his or her own life.
- This workshop will describe a new ***UCEDD Self-Determination Self-Assessment Checklist*** developed by the National Gateway to Self-Determination: National Training Initiative.
- We will share lessons learned by other UCEDDs in field testing this self-assessment process.
- We will discuss strategies and resources to support the use of this tool in order to incorporate self-determination in the development of UCEDD 5-year plans.
- This presentation is also designed to increase the participant's knowledge and understanding of self-determination.



# Purpose of the *Checklist*

- The purpose of the ***UCEDD Self-Determination Self-Assessment Checklist***, is to provide UCEDDs with a tool and process to determine the degree to which its policies, practices, and personnel are promoting self-determination for people with I/DD and their families.
- The result will be a profile of the organization's performance that can be used to identify areas for strengthening, and to suggest resources and best practices for improvement.



# Purpose of the *Checklist*

- In addition, information acquired from the self-assessment can be used to develop and incorporate self-determination goals, objectives and activities in UCEDD five year plans.
- This will support the NTI-SD goal of “scaling-up” self-determination nationally through enhanced training, research, and service.



# DD Act Definition of Self-Determination Activities

*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.*



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

# Self-Determination in Everyday Life

- Making key decisions on my own.
- Being in charge of my own choices.
- Taking responsibility for my decisions and choices.
- Making good decisions about my health, work, home life, daily schedule, money, and more.
- Advocating for myself.



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

# Why the SD Self-Assessment Checklist is Important to Self-Advocates

- More professionals will learn how to support us.
- People will better understand why SD is so important.
- More people with I/DD will learn new skills about how to make choices and advocate for themselves.
- More self-advocates will become involved in their UCEDDs and other organizations.



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*



# Role of Self-Advocates and the CAC

Self-advocate members of the UCEDD's CAC play an important role as participants and partners in:

- The self-assessment process
- UCEDD 5-Year Plan development



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

# Part II: *The SD SA Checklist*

- This is a **Draft**. Please do not disseminate.
- Review of Guiding Principles and Scoring System
- Section by section review of Checklist.
  - Read section introduction and all items.
  - Think about items in relation to your UCEDD.
  - Consider how your UCEDD might “score” on the system.
  - Record any resources on newsprint that you know about, which promote SD.
- Please hold insights, suggestions, and questions until the Q and A at the end.



# Guiding Principles of Self-Assessment

- Undertaken for self-improvement
- Identifies strengths and challenges
- Conducted in non-judgmental atmosphere
- Full participation by all parties
- Results in an organizational profile
- Leads to an action plan
- Allows for the evaluation of progress



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

# Optional Scoring System

- Each item may be scored:
  - Yes = 2
  - In development = 1
  - No = 0
  - Not applicable = no score
- Scoring the items in each section produces a profile
- Can track changes over time
- Scoring for internal use only, to track change over time - not intended for reporting



# Organization of the Checklist

- Sections for each UCEDD core function:
  - *Pre-service preparation and continuing education (4 items)*
  - *Training and technical assistance (8 Items)*
  - *Community services, supports, and assistance (7 items)*
  - *Research, evaluation, analysis of public policy, and Information dissemination (7 items)*
- Added section on mission, culture, and governance  
*(4 items)*



# 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: \_\_\_\_\_

# 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.

---



# The Field Test

- Ten representative UCEDDs identified by WIHD and AUCD.
- Anonymous and voluntary.
- Conducted during August and September 2011.
- General guidelines only - strict process was not defined.
- Results of self-assessment remained private with UCEDDs - they only completed a post-survey questionnaire.



# Panel: Some UCEDD Experiences

- What are your general impressions from the *Checklist* field test conducted by your UCEDD?
- What were the benefits and positive outcomes from implementing the *Checklist* at your UCEDD?
- Based on your UCEDD's experience, how would you advise other UCEDDs to implement the *Checklist*?



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

# Findings from the Field Test

- Self-determination is viewed as a high priority.
- The *Checklist* raised awareness of how the UCEDD could better promote self-determination.
- The *Checklist* was seen as helpful in the development of the UCEDD five year plan.
- Most, but not all, UCEDDs were able to include SAs, family members, and people from diverse ethnic/cultural groups in the Checklist process.
- Two thirds of the field test UCEDDs had resources available to promote SD and share with the network.



# Findings from the Field Test

- The field test sites viewed all five sections of the Checklist as highly relevant to the goal of promoting SD
- Most UCEDDs did not use the scoring system.
- UCEDDs varied enormously in the number of people involved in the process, and how much time they spent.
- Estimates ranged from 1 person/hour to several hundred person/hours, and from 1 person involved to as many as 55.
- This indicates that the tool itself is flexible and can be administered in different ways.



# Suggested Improvements

- Simplify language and item complexity
- Create more accessibility for participating SAs, family members, and members of diverse groups
- Adopt a scale metric for scoring, rather than Y/N
- Add “Not Sure/Don’t Know” as option besides N/A
- Make form more compatible with screen reading software



# Part IV: Using the Checklist as a Tool for the UCEDD 5-Year Plan

- **Self-Determination:** A Required Component of the UCEDD Plan Development ADD Guidance Document (review highlights of handout)



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*



# 5-Year Plan Development

- How can we apply what we learn from the SD Self-Assessment Checklist to areas of emphasis in our 5-Year Plan?



A National Gateway to Self-Determination

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*

# Example: Health Goal Across Core Functions

1. Develop a training curriculum for medical students in I/DD and secondary health conditions (***pre-service preparation***).
2. Develop a professional module on how health professionals can help patients with I/DD self-manage secondary health conditions (***training; community service***).
3. Conduct follow-up study to measure knowledge retained, and impact on SAs' health practices and life style changes (***research***).
4. Employ a self-advocate as co-trainer.



# Next Steps

- The revised version of the *Checklist* will be available mid-December.
  - Changes will be based on Field Test and *feedback from this workshop!*
  - Anyone have more ideas or suggestions for improvement?
- Continue to add resources to the NGSD Resource Guide, at: [www.aucd.org/ngsd](http://www.aucd.org/ngsd) (click on “Resource Guide”)



# NTI SD Consortium Members and Website

**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  
New York Medical College**

**Tamar Heller, PhD; Institute on Disability and Human Development  
University of Illinois at Chicago**

**Hill Walker, PhD; Center on Human Development  
University of Oregon**

---

Visit us at: [www.aucd.org/ngsd](http://www.aucd.org/ngsd)



**A National Gateway to Self-Determination**

*funded by the US Department of Health and Human Services, Administration on Developmental Disabilities*