Developmental Disabilities Assistance and Bill of Rights Act of 2000 Final Rule

Jennifer Johnson, PhD
Andrew Morris, MPH
Administration on Disabilities
July 31, 2015
Background

- The DD Act was reauthorized in 2000
- There are three programs/networks authorized under the Act
  - State Councils on Developmental Disabilities
  - Protection & Advocacy Systems
  - University Centers for Excellence in Developmental Disabilities
- The Projects of National Significance are also authorized
  - The Projects of National Significance did not have any significant changes through this rule process
Preamble background

• Effective Date: August 26, 2015
• Councils: (from Statute)
  – 70% of funds must be set aside for Council goals
  – 60% of Council members must be people with DD or their family members
  – States must have a functioning P&A for the Council to receive their award
• P&As: (from Statute)
  – Increased access to records from the 2000 Act – not from new rule
  – States must provide information on adequacy of HCBS services to P&As
  – Majority of governing board (51%) must be people with disabilities or their family members
• UCEDDs: (from Statute)
  – New UCEDDs must target underserved or unserved States or populations
  – $500,000 plus inflation trigger amount for new UCEDDs
• Titles II and III of the Act have been authorized (Family Support and Programs for Direct Workers Who Assist Individuals with DD)
  – No Money has been appropriated
Preamble background

• Commissioner refers to Commissioner of the “Administration on Disabilities” as there is no longer a Commissioner for AIDD
• No new regulations concerning Class Action lawsuits
• UCEDD definition placed into regulation at chapter 1388
• Education of Policy Makers:
  – Networks and grantees are to follow current AIDD policy
    • Offer balanced and non-partisan information consistent with the principles of the DD Act (See 2001 Guidance ADD-01-1)
    • Non-federal funds may be used for other activities in accordance with other applicable laws
    • AIDD plans to develop Guidance on “Advocacy”
Preamble & Section by Section Discussion of Rule

Section 1385.1 General
• The Act changed PADD to PAIR, since ED has a PAIR program the rule has referenced the P&A program as PADD

Section 1385.2 Purpose
• Updated language from 1997 regulation that the rule implements the 2000 statute

Section 1385.3 Definitions
• A number of statutory definitions in the NPRM had been changed, we changed them back to the statute based on comments received
Preamble & Section by Section Discussion of Rule

Section 1385.3 cont’d

• Definitions that are of particular note:
  – Accessibility
  – AIDD
  – Advocacy Activities
  – Capacity Building Activities
    • Note this now applies to all networks
  – Developmental Disability
  – State
Preamble & Section by Section Discussion of Rule

Section 1385.4 Rights of Individuals
• Slight variation from 1997 rule, changes applicable to Councils and UCEDDs

Section 1385.5 Program Accountability and Indicators of Progress – now [Reserved]
• Removed language from NPRM based on negative feedback from grantees and have reserved the section for future rules
• Reporting requirements are already established through OMB
• The section did address collaboration and AIDD may issue guidance on the topic in the future
Section 1385.6 Employment of Individual with Disabilities
• Updated from 1997 rule to meet current law and ADA
• Loss of federal funds if out of compliance

Section 1385.7 Reports to the Secretary
• Was not in previous rule
• New requirements (as in NPRM):
  – All plans, applications, and reports must label goals, activities, and results in following areas:
    • Areas of emphasis
    • Type of activity
    • Category of measure of progress
• This will be included in monitoring by project staff
Preamble & Section by Section Discussion of Rule

Section 1385.8 Formula for Determining Allotment

- Formula has been removed from regulation
- FY 2016 formula will stay the same – guidance this week
- FY 2017 formula will be released in the fall for public comment through the guidance process with a 45 day comment period
- April 1st deadline will be met to put estimates up on AIDD website
- IM was issued 7/28/2015 through email and is available on the AIDD website
Preamble & Section by Section Discussion of Rule

Section 1385.9 Grants Administration

• Some changes in CFR references at the last minute as HHS updated their CFRs for grants management
Preamble & Section by Section Discussion of Rule

Part 1387 – Projects of National Significance
• No comments were received
• In 1387.1(b) AIDD made an administrative change and PNS announcements are no longer required to be published in the Federal Register, as it is not required by the Act
Part 1388 – UCEDDs

Part 1388 – General

- The UCEDD section was reorganized and updated from the NPRM based on comments that asked to have a UCEDD defined.

**Section 1388.1 – Definitions**

- We added the definition of State to this chapter to highlight the difference between the definition of State between UCEDDs and the other DD networks
- Under current law CNMI and American Samoa are not allowed to be independent UCEDDs
Preamble & Section by Section Discussion of Rule

Section 1388.2 – Purpose

• In (a)(1) education of policymakers
• In (a)(2) interdisciplinary research required
• In (a)(2) the phrase “as defined by the Secretary” was removed as we have defined what a UCEDD is
• In (b) conduct NTI on emerging needs
Preamble & Section by Section Discussion of Rule

Section 1388.3 – Core Functions

• Besides renumbering of the Section, no changes were made from the NPRM
• This section was not in the previous rule
• (a) interdisciplinary training required and explained
• (b) (1) & (2) community services requirements explained
• (c) research requirements
• (d) dissemination requirements
Preamble & Section by Section Discussion of Rule

Section 1388.4
• NTI overview

Section 1388.5 – Applications
• Besides renumbering, several technical changes were made
  – (2)(i) application goals must be developed in coordination with the CAC
  – (2)(ii) consistent with the Council and P&A goals to the extent feasible
  – (5) CAC structure was put into the rule from the statute
  – (d)(1) peer review process of grant applications to be inclusive of individuals with DD
Preamble & Section by Section Discussion of Rule

1388.6 – Governance and Administration

• The NPRM had removed the Governance and Administration section of this chapter. AIDD reinserted based on comments received in order to protect the structure of the UCEDD within the university setting
  – AIDD believes this will help with the several UCEDDs who have had their universities try to break up the UCEDDs and redirect their funding towards other parts of the university and this will prevent that
• (f) senior professional staff
• (k) although State agencies are not listed as required collaboration it is implied
Preamble & Section by Section Discussion of Rule

1388.7 – Five-Year Plan and Annual Report

- The section was renumbered from the NPRM, no other changes were made
- New section to this rule per 2000 law
- If out of compliance federal funds can be restricted or taken away
- In (2) amendments to the five year plan must be approved by AIDD
- In (3) annual report due July 30th each year
  - If not submitted by July 30, considered to be out of compliance
Summary

The final rule strengthens the ability of AIDD grantees to help individuals with developmental disabilities to live and fully participate in the community of their choice.

For more information about the rule:
Andrew Morris
Phone: (202) 357 – 3424
Email: andrew.morris@acl.hhs.gov