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

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Background

• The DD Act was reauthorized in 2000.
• The programs/networks authorized under the legislation include:
  – State Councils on Developmental Disabilities
  – Protection & Advocacy Systems
  – University Centers for Excellence in Developmental Disabilities
• Projects of National Significance are also authorized
  – Projects of National Significance are not significantly impacted as a result of this rule.
Protection & Advocacy Systems

• The final rule clarifies access to records and access to individuals.
  – P&As investigating abuse and neglect must often devote significant time and money to access individuals and records authorized by statute.
  – The final rule details when consent is required for a P&A to gain access to either records or an individual receiving services.
  – The final rule details the relationship of P&As to HIPPA, Peer Review Records, and FERPA.
  – The final rule addresses court decisions impacting the DD Act since its last reauthorization.
Protection & Advocacy Systems

• Based on stakeholder comments, the rule seeks to bring the PADD program into alignment with other federal P&A programs to the extent possible.
• The rule also addresses items such as:
  – Confidentiality of records
  – Probable cause
  – Reporting requirements of service providers to P&As after the death of an individual with developmental disability
  – Reporting requirements for P&As
State Councils on Developmental Disabilities

- The final rule provides clarity on demonstration projects for DD Councils.
  - Some demonstration projects have lasted over 20 years.
  - The final rule will limit demonstration projects to five years, while building in some flexibility and outlining when projects can exceed these limits.
    - Within five years, a typical demonstration should have the opportunity to secure funding from another source or become an adopted practice.
- Capacity Building has been expanded from the University Centers to include all AIDD grantees.
- The final rule strengthens the independence of DD Councils from their state or territory:
  - The DD Act requires non-interference from states/territories.
The final rule brings UCEDD regulations into line with the 2000 law:

- The 1995 statute referred to UCEDDs as “University Affiliated Programs.”

The rule clarifies that a UCEDD must be a free standing entity that is part of/or associated with a university.

- There have been several instances in the recent years of universities trying to break up a UCEDD and put the grant dollars towards other disability programs within the university.

The final rule clarifies how “state” is defined in the UCEDD portion of the statute:

- For the purpose of the Act, American Samoa and CNMI are not considered States, and therefore cannot have free standing UCEDDs.
Summary

The final rule puts AIDD grantees in a strong position to carry out the DD Act’s charge and help individuals with developmental disabilities live and fully participate in the community of their choice.

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