

Webinar Synopsis: DD Act Final Rule

On August 5, 2015, the Administration on Intellectual and Developmental Disabilities (AIDD), a division of the Administration for Community Living, hosted a public webinar about the [final rule](#) for the [Developmental Disabilities Assistance and Bill of Rights Act](#) (PL 106-402). The call included an introduction from Administration on Disability (AoD) Commissioner Aaron Bishop and an overview of key provisions of the rule from AoD Policy Analyst Andrew Morris and AIDD Deputy Director Jennifer Johnson. A question and answer session followed. Highlights of the call are included below.

Download the webinar [PowerPoint slides](#).

Introduction

Commissioner Bishop began the call by thanking participants and highlighting the importance of the rule and its role in addressing the challenges that individuals and entities have faced with the developmental disabilities (DD) network. He noted that the purpose of the rule was to clarify a number of issues for State Protection and Advocacy Systems ([P&As](#)), State Councils on Developmental Disabilities ([DD Councils](#)), and University Centers for Excellence in Developmental Disabilities ([UCEDDs](#)) as they implement the specific provisions of the DD Act.

Overview of Key Provisions

Background: The DD Act was reauthorized in 2000 and had previously been authorized in 1995. The previous DD Act rule was released in 1997, making this the first new DD Act rule in eighteen years and the first based on the 2000 reauthorization.

Updated Capacity Building Definition: Prior to 2000, only the UCEDDs were charged with capacity building. Per the 2000 reauthorization, all DD Act programs now engage in capacity building. The final rule includes an updated definition of capacity building that accounts for this change.

Projects of National Significance: In addition to the P&As, DD Councils, and UCEDDs, Projects of National Significance ([PNS](#)) are also authorized under the DD Act. The rulemaking process will not result in any significant changes to PNS, however. The rule makes one administrative change, no longer requiring PNS funding opportunity announcements to be printed in the Federal Register. This requirement is not a part of the federal statute; in the future, announcements will be released through [the ACL e-mail listserv](#) and other technical listservs.

P&A Authorities: The final rule does not give any new authority to P&As, whose current authority was granted by the 2000 law. The rule does clarify the statute in some areas where P&As and the public have had questions.

P&A Access to Individuals and Records: P&As must often pursue legal action to achieve the access granted to them by law. While courts have generally sided with the P&As, legal battles can drain resources and delay time-sensitive investigations. The new rule details when consent is and is not required for P&As to have access to records and to individuals receiving services.

P&A Access and Consent: In cases of death and suspected abuse or neglect, consent to gain access is not required. The only requirement is that the P&A provide written notice to a service provider 24 hours prior to access.

P&A Access to Records: The rule details the relationship of P&As to peer review records and to records covered by the Health Insurance Portability and Accountability Act (HIPPA) and the Family Educational Rights and Privacy Act (FERPA). It also addresses federal court decisions regarding access to records that have been made since 2000 when the DD Act was last reauthorized and since the notice of proposed rulemaking was issued.

PADD and Other P&A Programs: Protection and Advocacy for Individuals with Developmental Disabilities (PADD) is one of eight funding streams for P&As. Based on comments it received, AIDD worked to align PADD with other federal P&A programs to the greatest extent possible.

Definition of Service Provider: The final rule removes the definition of “service provider” included in the notice of proposed rulemaking. This change recognizes that “service provider” has an evolving definition. Under the law, any person or entity that provides services to an individual is a service provider.

P&As and Reporting: Chapters 1385 and 1386 of the rule address reporting requirements for the P&As. AIDD will conduct monitoring to ensure compliance with the law and the rule, and it will work with any P&As that are not to achieve compliance.

DD Councils and Demonstration Projects: One notable change for DD Councils in the final rule is a time limit on demonstration projects. Some demonstration projects last 20 or more years. Such projects no longer fit the definition of a demonstration; they are established practices. The rule sets a five-year limit on demonstration projects and outlines requirements for projects to continue beyond five years. Requirements include providing data and a detailed explanation of why funding cannot be obtained from other sources.

DD Council State Plans: The DD Act requires non-interference from states and territories for DD Councils and P&As. Under the new rule, DD Councils are no longer required to seek approval of their state plans from the designated state agencies. DD Councils will have to show AIDD that they shared the plan with the designated state agency.

UCEDD Structure: The rule makes clear that a UCEDD is a freestanding entity that is part of, or associated with, a host university. There have been instances of universities attempting to take grant money from AIDD and spread it to different parts of the university, for other disability programs. The rule clarifies that this is not allowable.

Definition of “State” for UCEDDs: The rule clarifies the definition of “state” in the UCEDD portion of the statute. For the purposes of the statute, American Samoa and the Northern Mariana Islands are not considered states and cannot have freestanding UCEDDs. Through a partnership with Hawaii, both territories are a part of the Pacific Basin UCEDD.

For more information about the final rule, see the [DD Act Final Rule Toolkit](#).

Webinar participants submitted the following questions during a brief Q&A session:

- 1. The final rule includes failure to develop a discharge plan as neglect. Will P&As have unlimited access to any ICS/IDD resident without a discharge to Community Services Plan under the guise of neglect?**

As the rule says, the discharge plans are considered part of planning meetings, so I believe that is considered neglect if the person is discharged without a discharge plan. There are requirements in the rule that P&As have access to planning meetings and discharge plans.

- 2. Will the P&A have access to internal quality assurance reviews and reports?**

Yes. P&As have access to all records, including records not prepared by the service provider. So, it is all records that are in possession of the service provider's property regarding that individual.

That includes peer review records, internal quality assurance reviews, and other reports regarding that individual. If the P&A is conducting an investigation or has probable cause to suspect abuse or neglect, the service provider has to provide access to those records, even if they are conducting an investigation.

- 3. If a complaint of discrimination comes into a hotline, does the rule allow for all information gathered to be disclosed?**

The P&A has to follow the rule and the statute around confidentiality, so they cannot disclose information regarding an individual for an investigation. They have to meet the confidentiality requirements.

- 4. Regarding state (DD) Councils, is Partners in Policymaking considered a demonstration project? Does this fall under the five-year rule?**

Currently, that depends on the Council. A Council can submit it as a demonstration project, or a Council can submit it as an activity. If councils do submit it as a demonstration project, the project time limit would apply. So this is an opportunity for a Council, in the new five-year state plan due next August, to determine which projects are demonstrations and which are activities of the Council.

- 5. Please review the section of the rule that strengthens independence (for DD Councils).**

The DD Act requires that states not interfere with either the Councils or the P&As in their operations as federal grantees under the DD Act. For Councils, designated state agencies are no longer required to sign off on a Council's state plan. Councils will be required to show that they did show their state plan to the DSA, but the state does not approve it.