



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration on Developmental Disabilities

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6.	7.

PROGRAM INSTRUCTION

TO : Directors, State Protection and Advocacy Agencies

SUBJECT : Developmental Disabilities Protection and Advocacy Annual Program Performance Report Instructions

LEGAL AND RELATED REFERENCES :

Developmental Disabilities Assistance and Bill of Rights Act, as amended, 42 USC 6000, et. seq.

45 CFR Parts 1385 and 1386 amended November 20, 1989 (54 FR 47982)

CONTENT : Section 142 of the Developmental Disabilities Assistance and Bill of Rights Act requires that, in order for a State to receive an allotment under Part B, the State must have in effect a system to protect and advocate the rights of persons with developmental disabilities (P&A System). It further requires that the State submit to the Secretary an annual report describing the activities carried out by the system and any changes made in the system during the previous year.

A final draft of the Program Performance Report (PPR) was forwarded in March to provide P&A's with changes made to the PPR. Revisions were made as a result of discussions in the Advocacy Subcommittee of the Interagency Committee on Developmental Disabilities in order to have data collected be more comparable across programs of participating agencies (AOA, NIMH, RSA/CAP and ADD) and in order to report more fully to the Congress on aspects of the Developmental Disabilities Program of concern to the Congress.



Page 2 - Program Instruction

Please note the following changes:

Section II - Demographic Data on Clients Served:

- 1) an expansion of age brackets of clients
- 2) an addition of a listing of the ethnic background of client
- 3) an addition of the category "out of State" to the listing of the client's geographic location
- 4) an addition of the percentage of each county in the State's population served as clients
- 5) an addition of a "homeless" category to the listing of the client's living arrangement
- 6) an addition of the category "HIV" to the listing of the client's disabilities

Section V - Non-Case Directed Services:

- 7) an addition of a section on non-case directed services, including:
 - o number of I&R persons (other than supervised follow-up cases)
 - o number of training/education activities
 - o number of persons trained
- 8) an additional section on consumer involvement, including:
 - o number on staff
 - o number on governing board
 - o number on advisory board
 - o number of volunteers

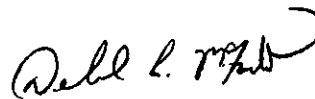
INSTRUCTION : The Program Performance Report (PPR) covers all activities during the Federal Fiscal Year, October 1 through September 30 (the reporting period). It must be submitted to the appropriate Regional Office within ninety days after the end of the Fiscal Year.

Page 3 - Program Instruction

ATTACHMENT : Developmental Disabilities Protection and
Advocacy Annual Program Performance Report
Instructions - OMB # 0980-0160.

EFFECTIVE
DATE : The report must be submitted within
ninety days following the close of the
Federal Fiscal Year, beginning with FY 1990.

INQUIRIES
TO : Regional Administrators, HDS



Deborah L. McFadden
Commissioner
Administration on Developmental
Disabilities

COPY TO : Regional Administrators, HDS
NAPAS

INSTRUCTION

INTRODUCTION

Section 113 of the Developmental Disabilities Assistance and Bill of Rights Act requires that, in order for a State to receive an allotment under Part C, the State must have in effect a system to protect and advocate for the rights of persons with developmental disabilities (P&A Systems). It further requires that the State submit to the Secretary, in a form prescribed by the Secretary in regulations, an annual report (or Program Performance Report) describing the activities carried out by the system and any changes made in the system during the previous year.

The purposes of the Program Performance Report (PPR) are to assist the Administration on Developmental Disabilities (ADD) to: (1) Determine whether the P&A system conforms to the requirements of the statute; and (2) inform ADD of program accomplishments.

Each section of the PPR is to be completed by the P&A office. If any section is not applicable, enter N/A.

The PPR is to cover all activities during the Federal Fiscal Year. October 1 through-September 30 (the reporting Period). It will be due to the Secretary within 90 days after the end of the Fiscal Year.

The PPR will require the following information:

- I. Clients Served
- II. Demographic Data on Clients Served
- III. Case Problem Areas of Clients Served
- IV. Remedies Used to Resolve Client Problems
- V. Non-Case Directed Services
- VI. Narrative Information

Please carefully read all of the instructions before using the reporting form.

Instructions

Section 1: Clients Served

For the purpose of this form, a client is defined as a person with a problem related to a developmental disability for whom the P&A System provides a service.

Each client shall be counted only once during the reporting period, regardless of the number of times he or she returns for assistance. Clients carried over from the previous year because of unresolved problems will be included in this count.

- A. Enter the Number of Clients Served in each Age Group during the Reporting Period.
- B. Enter Number of Individuals Served Under Class Actions where number is known.
- C. Enter the Number of Eligible Clients that requested services from your P&A this year that you unable to serve.

D. Ethnic Background of Individual Clients

For those whose ethnic background cannot be determined, enter as an "unknown". For those whose background is known but not among those listed, enter as "other".

Section II: Demographic Data on Clients Served

A. Age of Clients

Enter the age of each client served during the reporting period. Examples:

"0-4" means from birth through age four.

"5-20" means from the fifth birthday through age 20.

B. Sex of Clients

Enter the number of males and females served.

C. Clients' Geographic Location

Enter the number of clients in each geographic location.

Urban - a city with a population of 50,000 or more, including the surrounding contiguous territory.

Rural - all other areas that have less than 50,000 population.

County - the county within your State in which the client resides.

Out of State - legal residence in a State other than the one in which the P&A is located includes (foreign countries).

D. Clients' Living Arrangements*

This is the living arrangements of each client. Count only one living arrangement per client. These living arrangements are not defined here; use each alternative as it most closely matches your own State's classification of living arrangement.

E. Clients' Disability

There are two parts for this count:

(1)

Client Impairments

Any one client may have more than one impairment; all major impairments identified for each client should be counted and listed. Example: for a person with mental retardation who also has epilepsy and cerebral palsy, all three impairments would be reported and counted on the list. Example: for a person who has cerebral palsy and diabetes, cerebral palsy could be counted on the list and diabetes could be counted as "other, specify."

(2)

Clients' Substantial Functional Limitations - count all functional limitations for each client.

Section III: Case Problem Areas of Clients Served*

These are the problems of P&A clients or of groups of clients addressed through client-directed services. Each problem area addressed by the P&A on behalf of a client or group during the reporting period should be entered at III.

*States may provide this information in the format of their choice.

Section IV: Remedies Used to Resolve Client Problems

- A. Indicate the approximate number of problems resolved in favor of the clients during the reporting period.
- B. Estimate the number of problems resolved in the clients' favor by each of the remedies listed.

"Supervised Referrals" are P&A agency-monitored referrals of clients to appropriate source of assistance.

"Counseling" pertains to discussions between P&A agency and client and/or client representative which lead to resolution of problem. No other intervention by P&A required.

"Administrative remedies" include the use of any systems for appeal within an agency or facility or between agencies which do not involve adjudication by a court of law.

"Legal remedies" pertain to legal representation of clients in litigation in court processes concerned with rights, grievances or appeals of such rights or grievances.

"Other appropriate remedies" include all actions, other than legal or administrative, taken on behalf of clients, (e.g., negotiation, participation in conciliation proceedings, public hearings, arbitration proceedings, etc.).

V. Non-Case Directed Services

Non-case directed services refer to those short-term services which are provided in connection with an individual, (e.g., calls for information and referrals to other agencies for assistance) as well as services which are provided but are not related to individual clients, i.e., public

information/education training activities. This section also requires that you report on the activities undertaken by your organization to involve consumers (e.g., using consumers on your staff, on your board, and/or in volunteer capacities).

Section VI. Narrative

Please provide information on the following subjects using the format of your choice:

- (1) Describe your P&A's outreach efforts to underserved developmentally disabled populations, such as minorities, migrants, and /or institutionalized persons. If your agency employs an Outreach Coordinator, please describe the activities and plans for reaching underserved populations.
- (2) Discuss the extent to which your system attained the goals and objectives set forth in your annual plan and describe any changes in the administration, organization or goals of the P&A system.
- (3) Provide any additional information which may be useful to other P&A systems in improving their programs or program administration (e.g., development of new funding sources, list all other funding sources and amounts, and discuss efforts to improve P&A system management and staff

performance, class actions and other actions resulting in systems changes on behalf of persons with DD).

- (4) Please describe to what extent your system's activities are evaluated, both externally and internally. Please furnish the date of your P&A's latest evaluation.
- (5) Please describe your system's relations with other agencies, and any inter-agency agreements you may have.

Protection and Advocacy System Program
Performance Report

Reporting Period: October 1, 19__ Through September 30, 19__

State:

P&A Agency Name:

I. Clients Served

A. Number of Individuals Served _____

B. Number of Individuals Served Under Class _____

Actions (Where Number is Known) _____

C. Number of DD eligible Individuals requesting service
not served _____

II. Demographic Data on Clients Served

A. Age of Clients

0-4 _____

5-20 _____

21-59 _____

60-64 _____

65 and over _____

Total This Year _____

Protection and Advocacy System Program
Performance Report

B. Sex of Clients

Male _____

Female _____

Total This Year _____

C. Ethnic Background of Individual Clients

White/Caucasian _____

Black/African American _____

Hispanic _____

Asian/Pacific Islander _____

Native American _____

Other _____

Unknown _____

Total this Year _____

Protection and Advocacy System Program
Performance Report

D. Clients' Geographic Location

Urban - a city with a population of 50,000 or more, including the surrounding contiguous territory _____

Rural - all other areas that have less than 50,000 population _____

Out of State - legal residence in a State other than the one in which the P&A system is located (includes foreign countries) _____

Total this Year _____

Please furnish the population data of your State by County, and the percentage of the population in each county served as client cases by your P&A.

Protection and Advocacy System Program
Performance Report

E. Clients' Living Arrangements

Community residential home (supervised apartment,
semi-independent, halfway house, group home, etc.)

Foster Care

Independent

Nursing Home (includes ICF, SNF, ICF/MR, etc.)

Parental or other Family Home

Public Institution

Prison

State School

Private Educational Institution
or private physciatric hospital or
treatment facility

Homeless

Other

Total Client Cases by Living Arrangement

Protection and Advocacy System Program
Performance Report

F. Clients Disability

Client Impairments

Autism

Cerebral Palsy

HIV

Epilepsy

Mental Illness

Mental Retardation

Multiple Sclerosis

Physical/Orthopedic
(e.g., paraplegia, quadriplegic)

Spina Bifida

Traumatic Brain Injuries

Head Injuries

Tourette Syndrome

Visual Impairment

Hearing Impairment

Other, specify
(provide total of other impairments)

TOTAL Impairments This Year

Protection and Advocacy System Program
Performance Report

G. Clients' Substantial Functional Limitations

Self Care

Language

Learning

Mobility

Self-Direction

Independent Living

Economic Self-Sufficiency

Total Substantial Functional

Limitations This Year

Protection and Advocacy System Program
Performance Report

III. Case Problem Areas of Clients Served

Abuse/Neglect, Exploitation _____

Admission/Commitment to Institution _____

Architectural Barriers _____

Conditions in Facilities _____

Consent _____

Contracts/Ownership of Property _____

Criminal Justice Issues _____

Day Care _____

Education _____

Protection and Advocacy System Program
Performance Report

Employment _____

Financial Entitlements _____

Guardianship/Conservatorship _____

Habilitation Services _____

Housing _____

Insurance _____

Medical Services _____

Records (access to, confidentiality of, etc.) _____

Rehabilitation Services _____

Rights of Privacy _____

Sterilization _____

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Performance Report

Transportation (non-education related) _____

Voting _____

Wills and Estate Planning _____

Zoning _____

Other, specify _____

Total by Case Problem Area _____

This Year

Protection and Advocacy System Program
Performance Report

Section IV. Remedies Used to Resolve Client Problems

A. Number of Problems Resolved in Clients

Favor (estimated) _____

B. Number of Problems Resolved by Each
Remedy listed below (estimated)*: _____

1. Supervised Referrals _____

2. Counseling _____

3. Administrative Remedies _____

4. Negotiation/Mediation _____

5. Legal Remedies _____

6. Other Appropriate Remedies _____

*Total should equal 100%

Protection and Advocacy System Program
Performance Report

Section V: Non-Case Directed Services

A. Information and Referral Services

(Individual Non-Case I&R)

Total I&R this Year _____

B. Public Education and Training Activities

1. No. of Education/Training Activities

Undertaken _____

2. Total number of persons trained

(if known) _____

Protection and Advocacy System Program
Performance Report

C. Do you involve consumers in your organization?

Yes _____ No _____

How do you involve them?

1. Number on your staff _____

2. Number on your governing board _____

3. Number on your advisory board _____

4. Number who volunteer _____

*Total Should Equal 100%

Protection and Advocacy System Program
Performance Report

Section V. Narrative

(See
Instructions)

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