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INFORMATION MEMORANDUM

TO : Protection and Advocacy Directors

SUBJECT : Summary Report of P&A Institutional Advocacy
Projects

LEGAL AND
RELATED
REFERENCES : The Developmental Disabilities Assistance and
Bill of Rights Act, Public Law 95-602, as
amended, Part D, Special Project Grants.

CONTENT : Attached is a report entitled "Summary Report
of Protection and Advocacy Organizations (P&As)
which Conducted Advocacy Projects for
Institutionalized Persons". This report
provides information on the experiences and
findings of three special projects awarded to
the New Hampshire, Oregon, and Idaho Protection
and Advocacy agencies to demonstrate differing
approaches to the provision of advocacy
services to residents of institutions who are
developmentally disabled. Also, included is
part of the survey conducted by Barry University
in Fiscal Year 1983 in which P&As give brief
descriptions of any activity which provided
advocacy for residents of institutions who are
developmentally disabled.

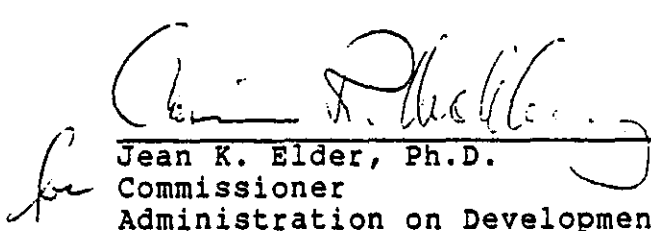
ATTACHMENT : "Summary Report of Protection and Advocacy
Organizations (P&As) which Conducted Advocacy
Projects for Institutionalized Persons".

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Summary Report of Protection and Advocacy
Organizations (P&As) which Conducted Advocacy
Projects for Institutionalized Persons

This report summarizes the experiences of the project conducted by three Developmental Disabilities P&As (New Hampshire, Oregon and Idaho) with grants under Projects of National Significance from the Administration on Developmental Disabilities during Fiscal Year 1982-83.

A summary of each project follows. Also included is a brief summary and conclusions based on a part of the survey of all P&As' experience with advocacy for institutionalized DD persons conducted in Fiscal Year 1983 by Barry University on prevention of abuse and neglect of DD persons in institutions.

NEW HAMPSHIRE

The Developmental Disabilities Advocacy Center, Inc., the New Hampshire P&A, utilizing grant funds from the Administration on Developmental Disabilities (ADD) conducted a one year demonstration of advocacy for institutionalized persons at the Laconia State School and Training Center. This model, called the Client Representative Project, involved a cooperative effort by the P&A, the University of New Hampshire's Graduate Program in Developmental Disabilities, and the New Hampshire Division of Mental Health and Developmental Services. There were several somewhat unusual conditions which worked together to provide incentives for each of the partners to cooperate:

- 1) a recent court order for deinstitutionalization of the Laconia State School and Training Center (LSS);
- 2) an unimplemented State law providing for the appointment of a "client representative" to advocate for and assist developmentally disabled persons in making decisions; and
- 3) the existence of a graduate program in developmental disabilities and its desire to provide clinical experience for its students.

In these conditions the P&A saw the opportunity to provide a stable and ongoing source of highly-motivated, well-trained and well-supervised advocates to work with the developmentally disabled population at LSS and their community-based counterparts who were at risk of being institutionalized, as well as an ongoing source of funding for this endeavor, after the completion of the one-year demonstrations.

The P&A received \$93,484 from ADD and provided an in-kind contribution of \$21,067 for a total cost of \$116,551. Staff for the project included:

- 1) Project Coordinator--providing overall coordination of planning, training, and case reviews;
- 2) attorney (part-time)--providing training and individual representation;
- 3) clinical coordinator (part-time)--supervised students' client experience, matched clients with students;
- 4) two faculty in graduate program--planned and presented classroom training;
- 5) secretaries (2 part-time);
- 6) graduate students--14 trained as client representatives; provided one-to-one advocacy and conducted community training seminars.

The students who were trained as the client representatives (CRs) had various backgrounds as professionals in delivering services to developmentally disabled persons, and thus were not new to the field. Training sessions took place weekly throughout the school year, with longer but less frequent sessions during the summer.

during the first quarter the training in class totaled 25 hours and included:

- 1) orientation to the project;
- 2) overview of legal authorities and issues;
- 3) New Hampshire service delivery system for DD persons;
- 4) mechanisms for service delivery (evaluations, client-centered conferences, IHPS);
- 5) guardianship/conservatorship;
- 6) the legal system;
- 7) the role of external advocates; and
- 8) ethical issues.

Second quarter training totalled 20 hours and included:

- 1) communication skills/group process;
- 2) P.A.S.S.--program evaluation;
- 3) psychiatric services;
- 4) financial entitlements;
- 5) housing;
- 6) interagency agreements; and
- 7) student research reports.

Third quarter training totalled 15 hours and included:

- 1) early intervention;
- 2) architectural barriers;
- 3) vocational skills training;
- 4) case termination;
- 5) parent concerns; and
- 6) citizen advocacy models.

During the summer quarter 5 sessions of training totalling 13 hours, included:

- 1) strategy/solution development;
- 2) systems advocacy;
- 3) evaluation; and
- 4) orientation for new students.

In addition, informal training with project staff averaged 55 hours per client.

Staff Training (at LSS)

As a result of the P&A's reputation with some of the LSS staff as "trouble-makers", the project adopted a less intense, more gradual approach, with the lead being taken initially by a member of the staff at LSS, the liaison person with the project. This was followed by informal sessions by the clinical coordinator with the LSS building coordinators and social workers, then with the project coordinator. Later the project coordinator and clinical coordinator met with the LSS

direct care staff. Finally, more formal sessions on external advocacy and the role of the client representative were conducted by the attorney and project coordinator.

Matching with LSS residents

The basic criterion for the residents selected was that they be "clinically incompetent", with additional consideration being given to their (target community) geographical location and distribution. They were matched with the students by matching the gender and location of client and student and the type of client needs with the background of the student. Of the 35 clients selected, the great majority were in the groups considered moderately or severely retarded. Nearly all were in the 22 to 60 year old range, and most had resided at LSS more than 20 years. The students spent time with the residents to get to know and to develop a relationship with them, explored community facilities with their clients, and went to their clients' planning meetings. The students as client representatives stressed in their relating to their client's service providers that they were advocates for their clients, not arbitrators or substitute decisionmakers.

Community Seminars

A secondary component of the New Hampshire project was the conducting of 3 one day training sessions around the State

to train persons who might wish to become client representatives for DD persons in their home communities. This part of the project had the least staff support, recruitment effort, and training preparation, and was the least successful in terms of numbers of participants. The recruitment procedure for the community seminars included:

- 1) working through a local host organization;
- 2) announcements in newsletters (reaching in the Manchester area alone over 2500 persons);
- 3) letters of invitation to persons on the host agency's and local advocacy organizations' mailing lists, civic groups, churches, and colleges, each tailored to the recipient;
- 4) public service announcements to news media statewide;
- 5) letters to the editors of each daily newspaper;
- 6) a memo from the N.H. D.D. agency to all regional area agencies encouraging participation;
- 7) fliers in appropriate local agencies; and
- 8) personal telephone and letter contacts.

In addition, continuing education credits were offered to participants through the University of New Hampshire. The training in these community seminars addressed:

- 1) normalization,
- 2) advocacy,
- 3) client rights,
- 4) ethics,

- 5) entitlements, and.
- 6) the service delivery system.

Goals and Results

- I. Demonstration of how a stable external advocacy mechanism can be established utilizing existing resources.

The key element for cooperation by all three principal parties was the desire to reach the same end, although for the differing reasons mentioned at the beginning of this section.

- II. Demonstration that internal advocacy is stimulated through external advocacy.

- a) The students judged that for 63% of the residents, increased internal advocacy was observed within client-centered conferences, LSS staff and administration case management in regional offices, the DD agency's client service section, community service providers and/or local SSA staff; and
- b) over 50% of the client representatives found that once they had advocated to an agency, that agency took additional steps with a second agency, an unusual occurrence.

III. Demonstration of clients becoming better self-advocates through their experience with the project. 30% of the clients were judged to have become better self-advocates by their client representative.

IV. Demonstration of an increase in deinstitutionalization from LSS and the improvement of the quality of services at LSS and in the community.

- a) 7% of the clients represented moved from L.S.S. to community-based placements.
- b) another 33% of the clients were somewhere in the process of moving to community-based placements where none had been at the beginning of the project.
- c) over 50% of the clients were receiving more appropriate/adequate services by the end of the year.
- d) none of the clients were receiving less appropriate/adequate services by the end of the year.

V. Demonstration of the enhancement of the quality of life for the clients.

This was judged to have taken place for half of the clients, based on, in addition to the above-mentioned criteria:

- a) new participation in activities in the community;
- b) having the involvement of a caring friend;
- c) having more adequate and new information on which to base their decisions.

Problems

- A) Discontinuity in representation—from students passing out of the program.

This was anticipated to present a problem, but did not, perhaps because, before one student resigned and before the rest graduated, their replacements were identified and oriented with the old student for a month before the turnover.

- B) Conflicts of Loyalty or of Interest—

There was occasional conflict between the student's role as client representative and as an employee of a service-providing agency serving that client. This sort of conflict demonstrates one of the seemingly inherent limitations of utilizing persons who have been and sometimes plan to continue to be employees to the agencies providing service to the clients, or, more generally, a limitation to having as an advocate a person who is not entirely external to the system.

C) Confusion About What Is The Role of the Client Representative

On a couple of occasions area agency directors refused to accept a client representative because they confused the role with that of a guardian, who serves as a substitute decision-maker.

D) The Limited Success in Attracting Participants to the Community Seminars

This is discussed above in the section on community seminars on pages 6 and 7.

Conclusions Drawn

- 1) the role of CR was not sufficiently clearly explained for potential participants;
- 2) the pool of potential participants in the community seminar was not sufficiently stable and ongoing;
- 3) the concept and goal of the endeavor was not generated from the participants or potential participants; and
- 4) the training and follow-up was too brief to be effective (the follow-up was left to the local agencies).

Continuation Beyond Grant Period

The N.H. D.D. agency agreed to supply funding to allow for the program to continue, and the University and the P&A agreed to continue their staff involvements.

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OREGON

The Oregon Developmental Disabilities Advocacy Center, the Oregon P&A, and the Oregon chapter of People First, Inc., a self-advocacy organization of mentally retarded persons, jointly conducted a project for a year and a quarter entitled "The Rights Network" with a grant of \$100,000 provided by ADD. The project had numerous facets contributing to two principal goals:

- 1) to stimulate an established but nonfunctional internal advocacy operation at Oregon's principal institution for DD persons, the Fairview Training Center; and
- 2) to establish a model for coordinated external advocacy linking volunteer community advocates with residents of Fairview.

The project developed three programs to achieve these goals:

- 1) an advocacy office at Fairview,
- 2) a community volunteer advocacy program and
- 3) systems advocacy for alternative service models for multi-handicapped groups chronically lacking services.

Institutional Advocacy Office

This program provided self-advocacy training in three substantive areas and provided assistance in advocacy in response to 26 requests from residents or parents. The target population was the physically handicapped and/or mild to moderately retarded residents of Fairview. The training was led by former residents of the institution who belonged to People First. Training was provided in the areas of:

- 1) understanding and participating in the planning of one's own plan of care;
- 2) asserting one's concerns through the grievance procedures; and
- 3) voting rights and procedures.

With the input of staff from Fairview, 56 residents from a total of 240 were chosen for the plan of care training. All but one completed the 12 week program, and all finishers achieved the level of competence set in the program objectives, as determined by pre- and post-tests.

Approximately 400 residents participated in the training

on utilizing the grievance procedure, while 63 participated in the voting rights workshops and followed up by actually voting. The objective of this office to handle at least 20 cases and resolve at least 5 favorably was exceeded. The issues identified through the plan of care process were used to stimulate redress through the administrative mechanisms at the institution.

Community Volunteer Advocacy

The Rights Networks achieved the goal of having a substantial level of volunteers recruited and trained (75 total) in part on account of the thoroughness of their recruitment and screening process. An initial mailing list of 1200 was compiled from parents, professionals in the field, local consumer organizations, past clients of the P&A, and volunteers in other programs. In addition, ads were placed in newspapers. Of those mailed to, over 25% responded and submitted applications. They were then interviewed by telephone and agreed to complete 10 hours of training. Of these, 57 became certified as volunteer advocates.

The volunteers were used to handle the paraprofessional tasks formerly handled by the P&A's paid staff, thus stretching staff resources. They worked under the direction of two case managers, while the volunteer program was developed and managed overall by a volunteer advocacy coordinator. Each volunteer

was required to participate in at least 10 hours of training in client interviewing, investigation, and facilitating communication with service providers, and at least one additional workshop on legal rights or substantive programming issues. 57 advocates were considered fully trained of the number who received some training (lay advocacy skills and other for a total of at least ten hours of training). As of this June, 54 cases had been assigned to these advocates. The number of volunteers trained in each of the four substantive areas offered varied widely:

Volunteer Advocacy Skills - 48

Special Education Advocacy - 128

Institutional Advocacy - 8

Behavior Programming - 12

The greatest number were trained in community-based rather than institution based skills, and a disproportionally large number trained in that area of historically heavy involvement, i.e., community-based operations.

Systems Advocacy for Alternative Service Models

For multi-handicapped Populations Chronically Lacking Institutional or Community Services. The 3 multi-handicapped populations targeted were: deaf-blind persons, mentally retarded-emotionally disturbed persons, and mentally retarded

persons with maladaptive behaviors. The approach employed was:

- 1) identification of the barriers to the provision of appropriate services to these groups,
- 2) researching models suitable for the delivery of such appropriate services,
- 3) developing and presenting at least five legislative or administrative proposals to address these barriers, and
- 4) providing legal advocacy in 20 or more individual cases which would impact these barriers.

The project, working with an existing Deaf-Blind Advisory Committee to the Oregon Department of Education, presented to the relevant Oregon legislative committee their study and a legislative bill to designate a State agency to be responsible for lifetime planning and co-ordination of services for deaf-blind adults. This effort resulted in a legislative mandate for such action in the budget for the Department of Human Resources. Additionally, the project staff through comments to the DD Council on the development of its 10 Year Plan for services succeeded in having included the development of specialized community services for low-incidence populations, including the deaf-blind. Through its monitoring of the implementation of the decree in a Federal court case

involving institutional services provided to a deaf-blind retarded woman, the project was able to get a new program for deaf-blind persons included in the Governor's budget recommendations. (This was the only expanded area of institutional programming in the Governor's recommendations).

The project addressed the special needs of the other two targeted multi-handicapped populations through the development of a coalition of some 20 persons from advocacy groups, service providers, and academicians. This coalition accomplished three objectives:

- 1) generated adequate data to describe this MR/MED population through 55 questions asked to 300 persons across the State. (The coalition is still analyzing the data received from this survey);
- 2) generated \$6,000 from two foundations to purchase counselling services for this population; and
- 3) conducted a workshop to enhance public awareness of the special needs of the MR/MED population. The response to this workshop exceeded all expectations: 90 persons submitted registrations for the 40 places available.

Co-ordination of the Institutional and Community Components of the Project

The objective of this component was to link 20 or more residents of an institution with advocacy teams in their

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Co-ordination of the Institutional and Community Components of the Project

The objective of this component was to link 20 or more residents of an institution with advocacy teams in their

community in order to stimulate the movement from institutional to community residences. However, on account of barriers to getting access to the residents of the institution and apparent reluctance by some parents to confront the deficiencies in the care provided, most of the project's effort in this area involved addressing these 2 points of resistance. Formal procedures were negotiated for access to clients and to records. The institution agreed to allow access to the records and the plan of care meetings and to allow the P&A to receive referrals from the staff of the institution. If the resident did not have a guardian and was judged competent to give informal consent, then the request for assistance would be forwarded to the P&A. If the resident had a guardian, the request would be sent to that guardian who would decide whether the P&A would proceed with the case. If the guardian refused and the resident still wanted assistance, an appeal could be made to the superintendant of the institution. If there were no guardian for a resident who was judged by an interdisciplinarian team not to be competent to give informed consent, then an appeal could be made to the superintendant.

These procedures did not solve the problem fully, however, and access remained a problem at the end of the grant period. The problem of reluctance on the part of the parents was addressed by holding a day-long conference attended by 90 parents, guardians or relatives on the rights of institutionalized persons. This conference resulted in a

number of referrals and allowed the P&A to continue to have contact with the parents through regular mailings.

Among the products developed were:

- a) a plan of care manual,
- b) trainer and curriculum information and interview forms for using to plan of care manual, and
- c) a brochure describing the Rights Network.

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IDAHO .

The Coalition of Advocates for the Disabled, Inc., the Idaho P&A, received an award of \$77,434 to conduct a model project providing advocacy to institutional residents through resident representatives. This project focused more on the continuum of deinstitutionalization, from preparing the community services for a persons moving out of the institution to the community to preventing persons at risk from being institutionalized, rather than actually providing advocacy to persons residing in an institution. The project intentionally focused on individual needs rather than on class action or systemic reform. The project utilized "resident representatives" (RRs) (created by State regulation), a sort of volunteer citizen advocate. The project attempted to emphasize the use of remedies in State and local law, rather than relying on Federal laws and Federally guaranteed rights.

The project began by trying to survey at least 80% of the discharged population and all of the currently institutionalized population to assess whether appropriate services were being provided and what was the effectiveness of various forms of advocacy. After the grant for this project was awarded, the process of negotiating the terms of access to the residents of the State institution and to their records, which had been underway with considerable promise for some time, took a negative turn which was to prove decisive for the success of the overall project. The P&A and the Director of

the institution had almost concluded an agreement to allow the P&A to use anything in the resident's records that would be useful to conduct this survey, limited only by a provision that would allow the institution a veto on the use of outdated material in any public release of information. Just before the last meeting to make final that agreement, the Idaho Attorney General's office ruled that the P&A could not have access to records of any resident or former resident whom it did not formally represent. Thus, during the entire period of the project, the P&A has had to rely on fall-back strategies for the implementation of both this key first step of conducting a survey and all following steps of its plans.

Those fall-back strategies included:

- 1) obtaining records of residents and former residents through RRs, guardians, and family members;
- 2) contacts with community service providers, who were usually quite willing to help;
- 3) development of a newsletter (mailed by institution) to all family members and guardians and a request for permission to have access to their relative's or ward's records;
- 4) a consideration by the P&A's Board of Directors to bring legal action (ultimately rejected by the Board, the majority of whose members are parents of residents at the institution); and

- 5) a news media blitz requesting information and help in locating former residents.

Overall, the P&A concluded that a survey of this type cannot be really successful without access to records of the institution.

The second objective of the project was to provide RRs or guardians for at least 75% of the residents of the institution and for at least 90% of the residents of community-based ICF/MRs, to provide the RR's with written training materials, and to provide training in workshops to at least half of them. During the course of the project, of the 351 residents at the institution, RRs were appointed for 104 and guardians for another 53. RRs were appointed for 90% of the residents in community-based facilities. The record as to how these RRs for the residents in community-based facilities and guardians were appointed is not clear (the P&A did not choose them). It was reported that some came from the staff's speaking to ARCs and other disability groups, but that no responses came from requests through news media, speaking in college classes or recruitment efforts through churches.

All RRs were supplied with written training material and all were offered workshop training; of these, 2 of the community-based RRs and 26 of the institution-based RRs and guardians actually participated in the workshop training.

The principal shortfall for the Idaho project was the very limited success it has had in gaining access to resident records and facilities. Those which they have accessed seem to be those of the residents who are least likely to have been abused or neglected. This shortfall caused the principal action in the project to be in the more accessible community-based settings, which were not intended to have been the principal focus of these demonstration projects. The P&A concluded that its strategy of relying solely on State and local law and remedies was not adequate to secure the rights of the institutionalized residents.

Most of the other activities of the project were focused around prevention of institutionalization of at-risk persons or recently deinstitutionalized persons living in the community, many of the kinds of things that P&As around the country have focused on.

Among the more innovative resources developed by the Idaho project was a computerized resource directory which allowed a very specialized reading of resources most applicable in a given geographical region to any specific set of needs which a given type of handicapped person might have.

The overall experience of the Idaho P&A is most completely discussed in a manual for P&As for institutionalized persons covering the techniques utilized and lessons learned from their experience with this project. The manual had not been completed at the time of this report, but was expected to be completed sometime this fall.

For further information contact:

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OTHER STATE P&AS ACTIVITIES IN PROVIDING ADVOCACY IN
INSTITUTIONS

The brief survey conducted by the Barry University School of Social Work's Abuse and Neglect Project as a part of a current grant co-funded by ADD and the Administration on Children, Youth, and Families indicates that the majority of P&As have no type of program providing external advocacy services within institutions. Most of those that provide some such services do so on a very limited scale. The following is a brief summary (alphabetically) of the type of program provided by those who indicated on the Barry survey more than a minimal presence to provide external advocacy to residents of institutions (from among the 43 P&As who responded).

Connecticut--has a contract with a private advocacy group to provide an on-site advocate at one institution one day per week;

D.C.--has advocates working within the institution; advocates have access to residents and records, are operating under a court-ordered deinstitutionalization decree, are monitoring residents constantly, and are under the supervision of the Deputy Clerk of the Court;

Florida (not the P&A)--the DD administering agency employs attorneys through "Patient Legal Services, Inc." to provide advocacy services at institutions (unclear whether this should be considered internal or external advocacy) except at N.E. Florida State Hospital, where the Jacksonville Area Legal Services provides advocacy services.

Hawaii--has two full time institutional advocacy employees and volunteer citizen advocates and provides in-service training on rights of residents to the staff of the institution;

Indiana--has trained volunteers in institutions for fact-finding;

Michigan--has an extensive program providing advocacy services within institutions. The P&A has a staff person based at each of the State's Centers for Developmental Disabilities who has statutory authority to provide P&A services to residents. The usual procedure is for a complaint to be filed by the P&A, investigated by the DD agency's office of Recipient Rights, and action taken. The P&A can appeal the response to the head of the agency (or in case of a community-based program, to the community service director), and if still not satisfied, can take legal action;

South Carolina--has one advocate operating at each of four DD regional centers one day per week who oversees

IHPs and informally investigates abuse and neglect allegations for referral to appropriate agency.

Tennessee--the old P&A had a memorandum of agreement recently negotiated with the DD agency and the Clover Bottom Developmental Center to provide advocacy services for adult residents. The P&A was guaranteed access to residential and program areas.

Washington--a presence utilizing VISTA workers.

Conclusions

Elements or Characteristics Indicated for Success in Providing Advocacy Services to Institutionalized DD Persons (as evidenced in those demonstration grants):

- A) a general, cooperation or absence of opposition (at least regarding access to records and to residents), if not outright support by staff and administration of the institution (this seems more critical than support from the ranking officials of the State agency which has charge of services and administration at the institution);
- B) a court order to deinstitutionalize and/or a requirement by law or regulation that there be a resident representative or client representative for all residents of an institution;
- C) a stable and ongoing body of highly motivated and committed persons from which to draw representatives or advocates for the residents of the institution, and
- D) a formalized arrangement for ongoing support of the institutional advocacy effort from an organized group providing the representatives or advocates, preferably made prior to the beginning of the endeavor;
- E) some means to provide for an ongoing peer support group for the representatives or advocates;

- F) an emphasis on the development of self-advocacy skills by the handicapped client or person being advocated for; and
- G) for development of other community-based support there should be:
 - 1) a local organization sponsoring, and the more local, the more grass-roots the initiative, the higher the likelihood for success; and
 - 2) the use of personalized invitations.

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REGION VII

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1) For DD Program ONLY, OFO contact through Regions III, VI,
VII and IV

2) Currently not participating in DD Program