

## DOCUMENT RESUME

ED 321 443

EC 231 563

AUTHOR Petr, Christopher G.  
 TITLE Forging Alliances with Protection and Advocacy Systems: A Training Manual for Parents of Children with Emotional Disorders.  
 INSTITUTION Kansas Univ., Lawrence. Beach Center on Families and Disability.  
 SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.  
 PUB DATE Jan 89  
 NOTE 75p.  
 AVAILABLE FROM: Assistant Director, Beach Center on Families and Disability, 4138 Haworth Hall, Lawrence, KS 66045 (\$5.00).  
 PUB TYPE Guides - Non-Classroom Use (055)  
 EDRS PRICE MF01/PC03 Plus Postage.  
 DESCRIPTORS \*Agency Cooperation; Agency Role; \*Child Advocacy; Community Action; Delivery Systems; Elementary Secondary Education; \*Emotional Disturbances; History; \*Parent Participation; Program Evaluation; Services; Workshops  
 IDENTIFIERS \*Protection and Advocacy Mentally Ill Individ Act

## ABSTRACT

This manual is intended to be used in conjunction with a 1-day training workshop to help parents of children with emotional disorders establish working alliances with protection and advocacy agencies for people with mental illness (PAMIs). The workshop prepares parents for developing specific plans for forging alliances with the state PAMI. The first chapter reviews services for children with emotional disorders from 1850 to the present, concluding that community programs are more effective than institutional programs. The second chapter discusses Public Law 99-319, the Protection and Advocacy for Mentally Ill Individuals Act of 1986, including the role of the developmental assistance and protection and advocacy (DD-P&A) agencies, provisions and specific requirements of PL 99-319, and results of a survey investigating the potential impact of PL 99-319 on children. Chapter three provides an assessment of current P&E activity with six worksheets designed to help parents assess agency activities. Chapter four focuses on forging alliance with emphasis on P&A limitations and parent strategies including requesting direct services and forging organization-to-organization alliances. Appended is the text of PL 99-319 and names and addresses of four resources for parents. (DB)

\*\*\*\*\*  
 \* Reproductions supplied by EDRS are the best that can be made \*  
 \* from the original document. \*  
 \*\*\*\*\*

ED 321 443

U.S. DEPARTMENT OF EDUCATION  
Office of Educational Research and Improvement  
EDUCATIONAL RESOURCES INFORMATION  
CENTER (ERIC)

THE UNIVERSITY OF KANSAS



Beach Center on  
Families and Disability

- This document has been reproduced as received from the person or organization originating it.
- Minor changes have been made to improve reproduction quality.
- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

**Forging alliances with protection  
and advocacy systems:  
A training manual for parents of  
children with emotional disorders**

Christopher G. Petr, Ph.D.  
School of Social Welfare  
Lawrence, Kansas 66045

January, 1989

Bureau of Child Research  
4138 Haworth Hall  
Lawrence, Kansas 66045

(913) 864-7600

"PERMISSION TO REPRODUCE THIS  
MATERIAL HAS BEEN GRANTED BY

*Harriet*  
*Shaffer*

TO THE EDUCATIONAL RESOURCES  
INFORMATION CENTER (ERIC)."

TC 23/563



**Beach Center on  
Families and Disability**

**Forging alliances with protection  
and advocacy systems:  
A training manual for parents of  
children with emotional disorders**

**Christopher G. Petr, Ph.D.  
School of Social Welfare  
Lawrence, Kansas 66045**

**©January, 1989**

The Beach Center on Families and Disability, a rehabilitation research and training center at The University of Kansas, is funded by the National Institute of Disability and Rehabilitation Research, United States Department of Education, and the University to conduct research on families with members who have disabilities. A major focus of the Center's research is the families of children who are supported by technology.

**Bureau of Child Research  
4138 Haworth Hall  
Lawrence, Kansas 66045**

**(913) 864-7600**

<b>Introduction.....</b>	<b>1</b>
<b>How to Use this Manual.....</b>	<b>1</b>
<b>Goal.....</b>	<b>2</b>
<b>Chapter 1.....</b>	<b>3</b>
<b>Services for Children with Emotional Disorders: Historical Overview.....</b>	<b>3</b>
1850 - 1900.....	3
1900 - 1925.....	3
1925 - 1950.....	4
1950 - Present.....	4
<b>Institutional Responses.....</b>	<b>4</b>
<b>Community Responses.....</b>	<b>5</b>
<b>Today's Challenge.....</b>	<b>5</b>
<b>Chapter 2.....</b>	<b>7</b>
<b>The Protection and Advocacy for Mentally Ill Individuals Act of 1986.....</b>	<b>7</b>
<b>History of PL 99-319.....</b>	<b>7</b>
<b>Changes in Society's View of People with Severe Disabilities.....</b>	<b>7</b>
<b>Status of People with Mental Retardation Today.....</b>	<b>9</b>
<b>Success of Protection and Advocacy Agencies.....</b>	<b>9</b>
<b>Expansion of DD-P&amp;A's to Include People with Mental Illness.....</b>	<b>10</b>
<b>Events Leading to the Enactment of PL 99-319.....</b>	<b>10</b>
<b>Provisions of Public Law 99-319.....</b>	<b>11</b>
<b>Specific Requirements of PL 99-319.....</b>	<b>12</b>
<b>Potential of PL 99-319 to Meet Children's Needs.....</b>	<b>12</b>
<b>Exploratory Survey Investigating the Potential Impact of PL 99-319 on Children.....</b>	<b>13</b>
<b>Results of the survey:.....</b>	<b>13</b>

<b>CHAPTER 3.....</b>	<b>1 5</b>
<b>Assessing Current P&amp;A Activity.....</b>	<b>1 5</b>
Description:.....	1 5
Objectives:.....	1 5
Activities:.....	1 5
<b>Worksheet #1: Assessment of Purposes, Programs,     Projects, and Personnel.....</b>	<b>1 8</b>
<b>Worksheet #2A: Assessment of Children with Emotional     Disorders as Priority.....</b>	<b>2 0</b>
<b>Worksheet #2B: Agency intent Regarding Location of     Efforts.....</b>	<b>2 2</b>
<b>Worksheet #2C: Assessment of Agency Practice Re:     Children with Emotional Disorders as a Population.....</b>	<b>2 3</b>
<b>Worksheet #2D: Assessment of Agency Practice Re:     Location (Institutions or Community).....</b>	<b>2 4</b>
<b>Worksheet #3: Assessment of Decision Making Processes.....</b>	<b>2 6</b>
<b>CHAPTER 4.....</b>	<b>2 8</b>
<b>Forging Alliances.....</b>	<b>2 8</b>
Description:.....	2 8
Objectives:.....	2 8
Activities.....	2 9
<b>Forging Alliances.....</b>	<b>2 9</b>
1. Limited Funding:.....	3 0
2. Limited Staff:.....	3 0
3. Competing Requests from Other Groups:.....	3 0
4. Differing Interpretations of the Law:.....	3 1
5. Lack of Experience and Training in Children's Needs:.....	3 2
<b>Strategy 1: Requesting Direct Services.....</b>	<b>3 5</b>
<b>Worksheet #1: Requesting Direct Services.....</b>	<b>3 8</b>

Worksheet #1: Requesting Direct Services.....	3 8
Strategy 2: Forging Organization-to-Organization Alliances.....	3 9
Step 1:.....	3 9
Step 2:.....	4 0
Turn to Worksheets 2A, 2B, 2C, and 2D In UNIT 3.....	4 0
Step 3:.....	4 0
Step 4:.....	4 1
Step 5:.....	4 5
Making the Initial Contact.....	4 5
Step 6: Make Your Agenda Known.....	4 6
Step 7:.....	4 7
Help P&As be Successful.....	4 7
Step 8:.....	4 8
Continue Strategy 1.....	4 8
Summary.....	4 8
Worksheet #2: Forging Organization-to-Organization Alliances.....	4 9
APPENDIX I: P.L.99-319.....	50
APPENDIX II: Resources for Parents.....	61

## **INTRODUCTION**

### **How to Use this Manual**

Protection and Advocacy agencies for people with mental illness (PAMIs), have helped in some states to revolutionize the system of care for adults and children alike. The goal of the training is to help you as parents of children with emotional disorders establish working alliances with these agencies. In the course of the workshop, you will learn about what these agencies do and ways in which you can work together. Families acting alone can make a difference; acting together with PAMIs they can make an even bigger difference.

We want to emphasize that the purpose of this manual and our training is to help families work with Protection and Advocacy agencies for people with mental illness. We do not presume that PAMIs resist working with families on behalf of children with emotional disorders. Indeed, we presume exactly the opposite: PAMIs want to work with those families. This manual sets out systematic, precise, and research-validated ways for families to reciprocate. When families approach PAMIs recognizing that the agencies are part of the solution and when they use this manual and training, the result, we hope, will be that the natural alliance between PAMIs and families will become stronger.

One more word of introduction is necessary. Children with emotional disorders are served by two related programs within the Protection and Advocacy system as will be explained later in the manual. One program serves persons with developmental disabilities under legislation passed in 1975; the other program is the PAMI program which is the focus of this training. Even though children with emotional disabilities and their families can be served under both programs, this training pertains mainly to the PAMI program.

## Goal

This training manual is intended to be used in conjunction with one-day training workshops sponsored by The Beach Center on Families and Disability at The University of Kansas. Most of the workshop will focus on small-group activities related to Chapters 3 and 4. Chapters 1 and 2 provide important background information that should be read prior to the workshop.

In order to be fully prepared for the workshop, you should:

1. Read Chapter 1 and 2
2. Familiarize yourselves with the purposes and activities of Chapter 3 and 4.
3. Be prepared to discuss your opinions about the most important issues facing families of children with emotional disorders.

By the end of the workshop, you will have developed a specific plan to forge alliances with your state's Protection and Advocacy agency. This alliance can result in improved care and services for you as families and for your children.



## CHAPTER 1

### Services for Children with Emotional Disorders: Historical Overview

The question of whether children with emotional disorders are better served by institutions or by community-based responses has been a controversial issue among professionals over the years. This chapter will summarize their discussions to give you a better understanding of how children with emotional disorders have been viewed and treated in our history.

#### 1850 - 1900

In the latter half of the nineteenth century, people concerned with child welfare did not think in terms of children with emotional disorders. Rather, they focused their efforts on the plight of children they saw as neglected, dependent, or delinquent. Large institutions were established for these children to live in, where they were separated from parents or other adults and children seen as undesirable associates.

During this same time period, Charles Loring Brace and the New York Children's Aid Society championed their cause of "*placing out*." This controversial program placed dependent and delinquent children with rural farm families in western states. Between 1853 and 1878, the program placed 50,000 children in family situations. Because of the program's success, by 1900 professionals officially endorsed "*placing out*" as the preferred solution.

#### 1900 - 1925

Policies and programs during this period focused on "*deinstitutionalization*." "Mothers' pensions" subsidized children in their own homes, and juvenile courts tried to work with as many children as possible on probation as an alternative to institutional placement.

However, at the same time that professionals advocated these changes, the number of institutions increased. Institutions continued to thrive because of financial incentives provided by states, and because of difficulties in changing long-established patterns and beliefs of both professionals and families.

#### 1925 - 1950

It is important to remember that before this time children were not considered to have mental illness or emotional disorders, but to be dependent, neglected, or delinquent. Professionals first began to look at the *behavioral and emotional issues* of "problem children" in the 1920's. Child guidance clinics were established to provide outpatient treatment, usually in connection with juvenile courts, hospitals, schools, or other community agencies. Psychiatric hospitals for adults also began to serve children. Thus, by the 1950's, institutions were playing a larger role in serving children with emotional disorders.

#### 1950 - Present

##### Institutional Responses

Overall, this period has been a time of *transinstitutionalization* rather than deinstitutionalization.

In the 1950's forces combined to remove adults from psychiatric hospitals and to provide them with care in the community, mainly through community mental health centers established as a result of the Community Mental Health Center Act of 1963. Between 1955 and 1979, the number of long-term patients in psychiatric hospitals fell dramatically. However, the actual number of annual admissions to state and county hospitals consistently increased.

- During this same time period, the number of children in homes for the dependent and neglected was reduced by one-half, while the number of children in psychiatric hospitals and residential treatment centers tripled.

- Thus, for adults with mental illness, transinstitutionalization has involved movement away from psychiatric hospitals, while for children it has meant movement toward them. Furthermore, in the 1980's there is an accelerating trend toward private hospitalization for children with emotional disorders.

### Community Responses

Increasingly, communities have provided services to children with emotional disorders. Since 1975, *community mental health centers* have been required to provide specialized children's services. Also since 1975, public schools have been required to provide services for these children as well as for all children with disabilities. However, these children continue to be underserved.

In 1984, Congress established the Child and Adolescent Service System Program (CASSP) to address problems of lack of coordination of services and service deficiencies. However, even CASSP's national director has said that the program is a modest effort that cannot be considered curative of a system in such disarray.

### Today's Challenge

Today, at the end of the 1980's, *institutions* are still serving a large number of children, even though community programs are seen as more effective. In 1984, the U.S. Department of Education reported that a child with severe emotional disorders has a three times greater chance of being placed in a residential care program than does either a child with mental retardation or learning disabilities.

*Quality of institutional care varies widely*, and its effectiveness is still debated. Even if an institution provides decent, humane care, it still separates children from their families and removes them from a family atmosphere.

Child advocates have typically focused on problems of children with disabilities other than emotional. Recently, however, parents of children with emotional disorders have begun organizing. These parents need assistance in obtaining appropriate services for their individual children and in changing the system of care. The Protection and Advocacy for Mentally Ill Individuals Act of 1986 (PL 99-319) has the potential to provide this help. That law will be the focus of the next chapter.

## **CHAPTER 2**

### **The Protection and Advocacy for Mentally Ill Individuals Act of 1986 (Public Law 99-319)**

#### **History of PL 99-319**

This legislation creates protection and advocacy systems that will become part of existing systems established for people with developmental disabilities under PL 94-103, the Developmental Disabilities Assistance and Bill of Rights Act of 1975. Therefore, it is useful to begin by looking at the history of society's response to people with severe disabilities -- in particular, people with mental retardation.

#### **Changes in Society's View of People with Severe Disabilities**

There are four main historical periods in the care of people with severe mental retardation.

- (1) Mid-1800's to 1900. Society's goal was to restore people with mental retardation to the larger society to whatever degree possible. Training or "experimental" schools followed the model Dr. Samuel Howe established in Massachusetts in 1848. The schools admitted young clients, kept them a short time, and then discharged them into the community. Generally these schools avoided becoming custodial asylums.
- (2) 1900 to 1920 . Progressives saw people with mental retardation as a threat to society's well-being and to social improvement. They advocated institutionalization and segregation of people with mental retardation. Most superintendents of public institutions supported this view. Custodial care became the norm.
- (3) 1920 to 1960. The need for care and supervision of people with mental retardation in the community began to gain acceptance. A

major influence was the publication in 1919 of a highly favorable after-care study by Dr. Walter Fernald, a previously vocal advocate of institutionalization. New Jersey and New York pioneered the "colony plan" to form farm colonies for people with retardation. Other states developed foster family care options.

By the end of the 1930's most institutions were actively involved in getting residents back into the community. In 1946, California developed a plan under which social workers moved from institutions to the community to establish Family Care Homes for discharged residents. In the 1950's, parents organized into an effective pressure group, forming the National Association for Retarded Children (NARC) in 1951.

- (4) 1960 to today. Forces combined to bring about important federal legislation on behalf of people with mental retardation and other disorders. Various studies documented the negative effect of institutional life. The country as a whole became concerned with the human and civil rights of all dependent and disenfranchised groups.

President Kennedy, whose family had personally experienced mental retardation, initiated studies on mental retardation and mental illness. These studies led to the enactment of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, which allocated funds for training of professionals and for construction of research centers and clinical facilities for people with mental retardation.

Two federal laws passed in 1975 emphasized providing services in the least restrictive environment: (a) Public Law 94-142, the Education of the Handicapped Act, mandated a free public education for all persons with handicaps and; (b) Public Law 94-103, the Developmental Disabilities Assistance and Bill of Rights Act, mandated services in the setting least restrictive of the person's personal liberty, continued funding for research and

training, established a Bill of Rights, and required the establishment of protection and advocacy systems for the people with developmental disabilities.

### **Status of People with Mental Retardation Today**

Despite increased community services and a drop in residential census populations from 200,000 in the late 1960's to about 100,000 today, contemporary reformers continue to work for change.

- Current efforts focus on further reducing institutional populations, which now consist mainly of people with severe and profound mental retardation or multiple disabilities.
- Critics note that most states spend more money for institutions than for community services and that lack of services is a major barrier to deinstitutionalization.
- Reformers push to change the philosophy that views people with retardation as a vulnerable population in need of shelter and protection. They say this image of people with mental retardation as inferior has led normal people to patronize them and not allow them to grow up to become adults.

### **Success of Protection and Advocacy Agencies**

The 1975 law, PL 94-103 provided federal money so states could establish an independent agency in each state with the authority to protect the rights of persons receiving treatment, services or habilitation for conditions attributable to mental retardation, cerebral palsy, epilepsy or autism. The disorders had to have originated before age 18 and be expected to continue indefinitely.

These protection and advocacy agencies (DD-P&A's) have had an excellent track record. For example:

- In fiscal year 1985, DD-P&A's provided direct services to 52,000 clients and successfully resolved over 80% of these cases.

- Protection and advocacy agencies employ 171 attorneys. Two of the three disability cases before the U.S. Supreme Court in the 1985 term were argued by DD-P&A's.

### **Expansion of DD-P&A's to Include People with Mental Illness**

The Developmental Disorders Act of 1984 (PL 98-527) changed the definition of developmental disability to a functional one that opened eligibility to additional populations including people with mental illness. The new definition required only that the disabling condition be "attributable to a mental or physical impairment," manifested before age 22, likely to continue indefinitely, and resulting in substantial functional limitations in at least three of seven specified areas.

### **Events Leading to the Enactment of PL 99-319**

By 1985 an estimated 16% of DD-P&A clients had the primary diagnosis of mental illness, and concerted P&A efforts in at least two states had resulted in improved conditions in state psychiatric facilities. Nevertheless, concern for the plight of persons with mental illness continued.

In April, 1985, Senator Lowell Weicker chaired hearings on the care and treatment of institutionalized persons with mental disorders. The hearings, a culmination of a nine-month staff investigation of state-operated facilities for people with mental retardation and mental illness, described unsafe, unsanitary and dehumanizing conditions as well as extensive incidents of physical beatings, rapes and death. A 246-page report resulted, confirming serious and pervasive rights violations and analyzing the ineffectiveness of state and federal programs and laws in dealing with the problems.

That same month, Senator Weicker introduced legislation in the Senate. The House sponsored an amendment to broaden the scope of the bill to encompass services in the community for discharged patients.



A House and Senate Conference issued a joint Conference Report on May 5, 1986. It included the final compromise version of the bill enacted that same month (PL 99-319). The compromise included the addition of a clause that extended the Protection and Advocacy for Mentally Ill Individuals (PAMI) mandate to cover incidents of abuse and neglect that occur within 90 days of a patient's discharge.

Children were not specific targets of this legislation, but the law did not exclude them from its coverage. *It is important to note that the goals of deinstitutionalization of children and improving community-based services for them was never a specific goal of this legislation.* The intent of Congress centered on the abuse and neglect of adult, institutionalized persons with mental illness. Thus, the PAMI's are not mandated, nor even encouraged, to pursue the goal of deinstitutionalization of children.

#### Provisions of Public Law 99-319

The Protection and Advocacy for Mentally Ill Individuals Act of 1986 (PL 99-319) seeks to protect the rights of individuals with mental illness. The law does not specifically identify these rights, but it does encourage states to consider the Bill of Rights for Mental Health Patients, and specifically incorporates this Bill of Rights as Title 2 of PL 99-319. This Bill of Rights is extensive and includes such elements as:

- the right to appropriate treatment in an environment least restrictive of personal liberty;
- the right to an individual, written, updated treatment plan; and,
- the right to a humane treatment environment.

These rights are *suggested but not guaranteed* by PL 99-319.

## Specific Requirements of PL 99-319

The law covers people who have "a significant mental illness or emotional impairment" (determined by a mental health professional qualified under the laws and regulations of the state) and who are inpatients or residents in facilities rendering care or treatment. It also covers those who have been discharged for fewer than 90 days.

The law requires and provides that:

- incidents of abuse and neglect of persons with mental illness by employees of facilities rendering care or treatment must be investigated;
- state and federal statutes must be enforced;
- "abuse" includes the usual acts of violence as well as the use of excessive force while placing an individual in restraints;
- "neglect" includes failure to carry out an appropriate individual treatment plan and failure to provide adequate nutrition, clothing, health care, and a safe environment;
- the PAMI's must be independent of any agency providing treatment or service to individuals with mental illness;
- the PAMI's may conduct investigations, access facilities and records, and pursue administrative, legal, and other available remedies;
- each PAMI must establish a statewide advisory committee, composed of at least 50% consumers, to help establish policies and priorities for persons with mental illness;
- funding be provided to the states to carry out these activities (Initial authorization was \$10.5 million for fiscal year 1987 and \$11.025 million for fiscal year 1988, with no state receiving less than \$125,000.)

## Potential of PL 99-319 to Meet Children's Needs

Because of the law's broad provisions, each state is free to establish its own focus and priorities in executing it. Implementation may favor both adults and children equally or it may benefit one group disproportionately. *To avoid underserving children with emotional*

*disorders, parents and concerned professionals need to know how to realize the potential of the bill with respect to these children.*

### **Exploratory Survey Investigating the Potential Impact of PL 99-319 on Children**

In March, 1987, University of Kansas researchers conducted an exploratory study to investigate the impact of PL 99-319 on the lives of children with emotional disorders.

- Investigators telephoned the executive directors of a national sample of state PAMI agencies to get their answers to a questionnaire survey.
- The sample included 16 agencies, representing eight of the most highly populated states in the U.S. and eight less populated states.
- Agency directors were asked to rank the location of the most serious advocacy needs for children with mental illness in their state.
- Directors also ranked the types of abuse and neglect cited by the legislation according to relative severity for children with mental illness.
- Finally, they were invited to list other problems.

#### **Results of the survey:**

- All sixteen agencies reported that children will be eligible for services and that they will be served to some extent, but the extent varied widely from state to state.
- Based on the agencies' responses, the investigators estimated that between 15% and 30% of the PAMI resources will be spent to benefit children.
- Between 6,750 and 13,500 children with mental illness probably will be served in that period of time.
- Ten of the sixteen directors ranked the community as the location of the most critically need advocacy for children with mental illness. They ranked public institutions second and private institutions third.
- The directors' rankings of the severity of various types of abuse and neglect showed a focus on neglect in the form of inadequate

treatment. They rated lack of appropriate treatment and poor discharge planning as the most severe problems. Poor living conditions, physical abuse, and sexual abuse, in that order, ranked much lower.

The results of this survey show that, although the level of commitment varies from state to state, the PAMI's have not adopted a narrow focus on the rights of adults in institutions. The survey confirms that the law is *potentially a powerful resource for improving the lives of children with emotional disorders.*

*The task for parents is to see that the law's potential is realized in their own state and locality. The University of Kansas Beach Center on Families and Disability has sponsored a study to find out more about how to assess and influence agencies' decisions in implementing this law. The results have led to specific recommendations and guidelines for parents and professionals interested in forging working alliances with their own state's PAMI agency. The next chapter will include these guidelines.*

## **CHAPTER 3**

### **Assessing Current P&A Activity**

#### **Description:**

This chapter provides specific guidelines and instructions which enable you as parents to learn more about your own state's P&A activities. Your assessment is targeted on services and activities provided by (P & As) on behalf of children with emotional disorders. You will rate the level of agency performance as HIGH, MID, or LOW along two dimensions.

#### **Objectives:**

At the conclusion of this chapter, you will be able to:

1. Identify your P&A agency's 4"P"s--purposes, programs, projects, and personnel.
2. Assess and rate the P&A's priority on children with emotional disorders.
3. Describe the P&A agency's decision-making process.

#### **Activities:**

You will be divided into three small groups, one for each of the above objectives. The groups will use the information and the worksheets provided to complete their objective. The groups will then reform into the large group to share their results. The trainer will circulate from group to group to assist with problems, and will lead the large group sharing of results.

## Assessing Current P&A Activity

In order to have access to services and forge alliances with a particular Protection and Advocacy agency, you need to educate yourselves about the agency, its operations, and its commitment to children with emotional disorders. In other words, do your homework so that you can be better prepared to decide how, when, and where to begin your alliance-building efforts.

## Preliminary Assessment Objectives

The preliminary assessment has the following objectives.

1. To become familiar with the agency's purposes, programs, projects, and personnel. (The 4 "P"s)
2. To learn about the agency's priorities, specifically with respect to children with emotional disorders. (The 5th "P")
3. To begin to understand the agency's decision-making processes.
4. To develop a strategy for obtaining services and forging alliances.

Certain public agency documents are extremely useful sources of information in making the assessment. Your group was asked to obtain these documents in advance of this workshop:

1. Protection and Advocacy System Annual Program Performance Report (PPR) on Services to Mentally Ill Individuals. 2 reports: 1986-87 and 1987-88.

2. Protection and Advocacy System Annual Program Performance Report (PPR) on Services to the Developmentally Disabled, 1987-88.
3. Minutes of Governing Board Meetings for the last year.
4. Minutes of MI Advisory Board Meetings for the last year.
5. Brochures.
6. Newsletters for the last year or more.
7. Mission statement of organization.

Not only are the documents themselves useful, but the process of obtaining them can itself be enlightening. At this point, share your experiences in obtaining the documents as the trainer leads a discussion about what the group has already learned about your P&A agency through this process.

Discussion will focus on such questions as:

1. How open were the staff to your requests? Were some more cooperative than others?
2. Who needed to give permission to honor your requests?
3. Were certain documents harder to obtain than others?
4. Did anyone offer to make additional, unrequested documents available, or to meet with you about your concerns?

After this discussion, you will form into three small groups to examine the agency documents using the following assessment worksheets as guides. The three groups and worksheets correspond with the first three learning objectives above. The information obtained provides the basis for formulating a specific strategy, to be covered in the next chapter.

## **Worksheet #1: Assessment of Purposes, Programs, Projects, and Personnel**

In reviewing the documents (primarily newsletters, mission statements, brochures, and minutes), answer the following questions:

**I. Purposes:** How does the agency define its overall purpose? What values and philosophies does it espouse? What type of advocacy (legal or non-legal; individual or systemic) does it employ to carry out its purpose?

**II. Programs:** Does the agency sponsor specific programs? If so, which populations benefit? Which problems are addressed? Does the agency receive extra funding to support the program? If so, who supplies the funds and are contingencies ("strings") attached?

**III. Projects:** Is the agency planning for special projects? Describe them. What other groups and organizations are involved?



**IV. Personnel:**

**Position    Name    Occupation/Affiliation Yrs**

**Staff:**

1. Executive Director
2. Coordinator for MI
3. MI advocate(s)

4. Staff attorney
5. Others

**Governing Board:**

1. Chairperson
2. Vice-chair
3. Officers

4. Members

**Advisory Board:**

1. Chairperson
2. Vice-chair
3. Officers

4. Members

## Worksheet #2A: Assessment of Children with Emotional Disorders as Priority

Our research has verified the importance of assessing an agency's level of service along two dimensions: 1) intent, and 2) practice. The intent of an organization may or may not be actually translated into practice. Conversely, an agency's actual practice may or may not be reflected in official agency intent. This worksheet helps you to determine whether your agency's priority on children is HIGH, MID, or LOW on both the INTENT and PRACTICE dimensions. In the interest of time, it may be best for your small group to subdivide into two smaller groups--one to assess INTENT (Worksheet 2A and 2B), and one to assess PRACTICE (Worksheet 2C and 2D). As you will see in the next unit, this information is essential in planning the most effective alliance-building strategy.

The most important documents for assessing level of intent are brochures, newsletters, and mission statements. Minutes of Advisory Board and Governing Board meetings are also good sources of information. As you read these documents, use the following guidelines to assess whether the INTENT dimension is HIGH, MID, or LOW.

**HIGH level of intent:** The needs of children with emotional disorders are consistently and frequently mentioned in the documents, as one of the agency's priorities. The agency sees its mission and purpose as advocating for change in the system of care as well as protecting and advocating for individuals.

**MID level of intent:** The needs of children with emotional disorders are occasionally mentioned in documents, but inconsistently and without priority. Advocacy philosophy focuses on individual cases, with little or no systems change commitment.

LOW level of intent: The needs of children with emotional disorders are not addressed in any public documents, except in the briefest terms with emotional disorders.

NOTE:

Document

Key phrase, other "data"

YOUR ASSESSMENT RATING OF INTENT RE: CHILDREN WITH EMOTIONAL DISORDERS: (circle)

HIGH

MID

LOW

**Worksheet #2B: Agency Intent Regarding Location of Efforts  
(Institutions or Community)**

Since many parents and professionals believe that the needs of children with emotional disorders and their families center on developing and improving community-based services, the following guidelines can be used to assess agency intent in this area.

**HIGH level of intent:** Documents mention concepts such as "treatment in the least restrictive environment", "deinstitutionalization", and "improving services in the community". Advocacy within institutions is guided by concern for the problems of inappropriate placements and poor discharge planning.

**MID level of intent:** Documents may mention the above concepts and problems, but at least equal intent is demonstrated toward improving conditions within institutions and prioritizing problems such as physical abuse, sexual abuse and forced medications within institutions.

**LOW level of intent:** Documents reflect that agency intent focuses on institutional problems such as poor living conditions and other rights within institutions.

**NOTES:**

Document

Key phrases, other "data"

**YOUR ASSESSMENT OF INTENT RE: LOCATION OF EFFORTS (circle)**

HIGH

MID

LOW

**Worksheet #2C: Assessment of Agency Practice Re: Children with Emotional Disorders as a Population**

The best source of information regarding agency practice is the Annual Program Performance Report (PPR). This document reports the number of clients served by age category (0-20; 21-64; over 65). Its narrative section describes advocacy activities, including systems change efforts. Additional, more recent information about these activities can be obtained in newsletters and minutes of Board meetings.

Use the following guidelines to rank the level of actual agency practice with respect to this population.

HIGH level of practice: MI-PPR data (87-88) indicates that children represent more than 30% of the clients served.

Narrative section indicates systemic change efforts on behalf of children's needs, in collaboration with other groups and agencies.

MID level of practice: MI-PPR data (87-88)= 10-30% children. Systemic/collaborative child efforts being actively discussed and planned.

LOW level of practice: MI-PPR data (87-88)= 0-10% children. No systemic/collaborative child efforts.

**NOTES:**

	<u>%Children</u>	<u>Systemic/ Collaborative efforts</u>
MI-PPR (87-88)		
MI-PPR (86-87)		
DD-PPR (87-88)		
<b>YOUR ASSESSMENT OF AGENCY PRACTICE RE: CHILDREN WITH EMOTIONAL DISORDERS AS A POPULATION</b>		
	HIGH	MID
		LOW

**Worksheet #2D: Assessment of Agency Practice Re: Location (Institutions or Community)**

The MI-PPR report is an excellent source of information about the location of advocacy efforts and the types of problems addressed. In addition to the statistics, the narrative section, in conjunction with newsletters and minutes of Board meetings, offers insight into location of systemic/collaborative efforts.

In the statistical section, the first key category is "Client Living Arrangement". Compare the number of clients in the first four subcategories (Community Resident, Homeless, Independent, and Parental, Foster Care, or other Family Home) with the number in the next five subcategories (Nursing Homes, Prisons, Private Hospital, Public Hospital, State School). Compute the percentage of the total number of clients that live in the community (the number in the first four subcategories divided by the total number of clients). Record this percentage below.

Next, look at the category "Alleged/Reported Neglect"-- Part B under "Case Problem Areas of Individuals Served". The second, third, fifth, and sixth subcategories (Community Residential Placement, Community Services, Release from institution, and Discharge Planning) reflect community-oriented problems. Divide the number of problems in these four subcategories by the total number of Alleged/Reported Neglect problems to obtain the percentage of community-related problems. Record below.

Finally, read the narrative section of the MI-PPR report to assess whether the systemic/collaborative efforts focus on institutional reform or on improving community-based services.

HIGH level of practice: MI-PPR (87-88) report indicates 40% or more are living in community; 50% or more of neglect problems concern "community"; systemic/collaborative community efforts in place.

MID level of practice: MI-PPR (87-88)= 15-40% living in community; 25-50% of neglect problems concern "community"; systemic/community efforts planned.  
LOW level of practice: MI-PPR (87-88)= 0-15% living in community; 0-25% of neglect problems concern "community"; systemic/community efforts absent.

% Community under  
"Client Living  
Arrangement"

% Community under  
"Alleged/Reported  
Neglect"

YOUR ASSESSMENT OF PRACTICE RE: LOCATION (circle)

HIGH

MID

LOW

### **Worksheet #3: Assessment of Decision Making Processes**

The most informative documents about decision-making processes are the minutes of the Governing and Advisory Boards. A complete understanding of the decision-making processes is not possible from reading these documents, but initial and tentative insights can be obtained. Because the planning of the alliance-building strategy depends in part on this understanding, the following guidelines are recommended when reading the documents.

1. What appears to be the relationship between the Advisory and the Governing Boards? Is the Advisory Board strictly advisory, or does it appear to function with some autonomy? Is there a cooperative or antagonistic spirit between the two? What are typical agenda items on each Board?
  
2. How are Governing and Advisory Board members selected? If appointed, who does the appointing and from what pool of candidates? If elected, by whom and from what nomination process?
  
3. What is the attitude toward consumers? Are they fully represented on both Boards; among the officers of both Boards? Is there any outreach to clients; surveys of their concerns; satisfaction surveys?



4. How active and central is the Executive Director? Does he/she initiate and present information/ideas to the Boards, or does he/she respond to the direction of the Board(s)?
  
5. How involved are the "lower" levels of staff, especially the advocates themselves? Are they active in the meetings? Do they actively participate in establishing organizational goals? Does communication flow only from the top-down or in both directions?

## **CHAPTER 4**

### **Forging Alliances**

#### **Description:**

This chapter provides you with specific alliance-building guidelines. Initial topics include the constraints and limitations on the ability of P&As to respond, and tips on appropriate, assertive behaviors. Using the assessment from Chapter 3, you will go through a step-by-step procedure for developing a two-pronged strategy. The two strategies involve making direct requests for help with individual cases and forming organization-to-organization relationships.

#### **Objectives:**

At the conclusion of the chapter, you will be able to:

1. Enumerate 5 constraints and limitations of ability of P&As to respond to the needs of children with emotional disabilities.
2. Compare and contrast 4 qualities of assertive persons with those of passive and aggressive persons.
3. List three goals of Strategy 1: Requesting Direct Services.
4. Complete a 6-step procedure for developing an action plan related to Strategy 1.
5. Complete a 7-step procedure for formulating an action plan regarding Strategy 2: Forming Organization-to-Organization Alliances.

## Activities

You will be divided into two small groups--one for each strategy. After developing your plans, you will reform into a large group to share plans and begin to coordinate efforts.

## Forging Alliances

Organized parents can be extremely effective advocates for their children. You can be even more effective when you work together with Protection and Advocacy Systems, because P&As bring additional "ammunition" in the form of political, financial, legal, and professional advocacy staff resources. Since P&As can mobilize these helpful resources, they warrant serious alliance-building efforts, but these efforts should never consume a majority of parents' time and resources. You also can be effective voices in your own right and should maintain your own autonomy. If you spend too much time and energy focusing on P&As themselves, there is a danger that the P&A itself would be mistakenly viewed as the problem, rather than as part of the solution.

In developing alliances with P&As, you are basically taking an "advocacy for advocacy" stance. That is, you are advocating to the P&A system for more advocacy from the P&A on behalf of your children. Generally, you can expect that P&As will be responsive to their issues and concerns, because the P&A mandate is to protect and advocate for the rights of "mentally ill" individuals.

Still, you as parents must understand that P&As face real limits and constraints. These include limited funding, limited staff, competing requests from other groups, differing interpretations of the law itself, and lack of experience and training in the needs of children with emotional disorders. You as parents need not accept any of these limits as "excuses" for inaction, but the more you understand the

realities, the more readily you can develop alliances based on realistic expectations and goals.

### **1. Limited Funding:**

The new federal minimum allotment is \$140,000, and larger states can receive more than double this amount. The federal allotment represents the total (100%) budget for serving persons with mental illness many P&As, but others receive additional funding from state government or private grants.

Remember, too, that the total budget of the P&A is this federal allotment plus allotments (usually greater) to serve persons with Developmental Disabilities under the earlier DD-P&A legislation.

#### **Recommended Parent Position:**

*No matter what the funding level, it should only constrain and limit activities, never prohibit them altogether. Thus, you can acknowledge and empathize and agree that there are some legitimate funding limits to the P&As ability to respond, while reasonably asserting your requests for some level of service.*

### **2. Limited Staff:**

This constraint often derives from limited funding. The number of front-line advocates who can be supported on a given amount of money is clearly limited. Also, advocates' job responsibilities of advocates can be quite complex and far-reaching, so that they are "spread thin".

#### **Recommended Parent Position:**

*As with funding, the number of staff only constrains and limits activities, it should not prohibit them. The issue is not really the number of staff, but how the staff spend their time. Some proportion of their time can be targeted to the needs of children with emotional disorders.*

### **3. Competing Requests from Other Groups:**

Many other groups are potentially underserved by this legislation, including the elderly, ethnic minorities, and the rural poor. Even groups representing adults within institutions can feel poorly served. The P&A may be receiving requests for additional advocacy efforts from any or all of these groups.

#### **Recommended Parent Position:**

*Avoid competition and confrontation with these other groups. Promote a cooperative, "we're all in this together" atmosphere. By working together to meet each other's goals, the agency as a whole is strengthened, if for no other reason than that time and energy are devoted to achieving goals rather than being drained off into competitive battles. Basically, all of the groups have equally legitimate needs, so that trying to prove that children are more needy than others is a futile and divisive struggle. Make it clear to all concerned that you are not asking for special treatment, only a fair share, and support others' rights to the same.*

### **4. Differing Interpretations of the Law:**

Recent national data confirm that each P&A is implementing the law differently--different problems and populations are emphasized from state to state. A narrow interpretation of the law's mandate usually results in a narrow focus on the rights' violations of adults within institutions. However, it is clear that Congress intended, wide discretion so that states themselves can implement the law to meet the local needs as identified and defined by the P&A itself.

#### **Recommended Parent Position:**

*Acknowledge that there are many legitimate ways to interpret and implement the act, but assert that a narrow interpretation is unduly restrictive. To bolster your argument, the Beach Center research and*

*national PPR data confirm that some states have managed to find a way to devote significant (even a majority of ) agency resources to children with emotional problems in the community. Nationally, 14% of the P&A clients were children, so this "average" #figure could serve as an initial, minimal goal. The percentage ranged for 0% (in three states) to 65% (one state). The percentage was 51% in one other state and was in the 30-50% range in several others. Clearly, some states have already reached the criteria for our HIGH level of practice with regard to children as a population. Similarly, with respect to location, ten states (20%) reported that more than 50% of their clients lived outside of an institution. (Fiscal Year 1987 Report, 1988).*

#### **5. Lack of Experience and Training in Children's Needs:**

It may be a fact that the executive director and/or staff do not know a lot about the issues for children with emotional disorders and their families. Yet, it is clear that professional and personal experiences (especially the latter) can make a difference.

#### **Recommended Parent Position:**

*Don't take it personally! Just because they don't know doesn't mean they don't (or can't) care. If they are willing, educate them! Give them some experiences! Send them articles (brief only), news clippings, written accounts of your experiences. Let them know about workshops, resources in the community, sympathetic professionals, etc. When staff positions become available, be sure that experienced and sympathetic persons apply. Above all, recognize achievements and accomplishments by writing letters of thanks to individual staff, supervisors, and board members. Along this line, consider establishing official awards of recognition given by your group for outstanding contributions and efforts.*

The above considerations help set the stage and the context for the your efforts. Knowledge of the legitimate realities under which P&As operate helps you be sensitive while anticipating potential barriers.

We now move to consideration of specific strategies that can build successful alliances.

We recommend a two-pronged approach to this alliance-building effort. The first is focused on requesting help with specific, individual rights violations in the role of client of the P&A. The second approach focuses on building organization-to-organization links that promote change in the system of care for children and their families.

Remember that our suggestions reflect an "ideal" approach--your strategies will depend on the amount of time and energy that you can commit. The rest of the training consists of small groups using guidelines to develop specific strategies in each area.

Remember:

- 1) P&As are part of the solution, not part of the problem.
- 2) Be assertive, not passive or aggressive
- 3) Focus on positives and recognize achievements.

Before presenting those guidelines, it is important to remember and incorporate certain attitudes about yourselves as advocates. The goal is to be assertive, not passive or aggressive. An assertive style will be the most successful in both parts of the two-pronged alliance building effort.

#### A PASSIVE PERSON:

Hopes for favors  
Views others as superior  
Defers to others  
Avoids problems and conflicts

#### AN AGGRESSIVE PERSON:

Attacks persons, rather than problems  
Demands respect, but lacks respect for others  
Views own rights as superior to others  
Demands favors and services

**AN ASSERTIVE PERSON:**

Attacks problems, not people

Claims legitimate rights, while recognizing rights of others

Works toward goals

Requests favors and services

(Adapted from Kelker, 1987)



## Strategy 1: Requesting Direct Services

Introduction: One of the findings of our research is that many P&A agencies develop their priorities based on the problems that clients themselves ask help with. In other words, most P&As report being sensitive to the needs and problems of their clients, as judged by "whatever problems come in the door". Thus, requesting direct services serves three goals:

1. Obtaining help for the individual client.
2. Educating the P&A about the needs of children with emotional disorders, as seen in actual cases.
3. Developing working relationships with front-line advocacy staff.

### STEPS

#### Step 1:

**Choose one or two current individual cases which need some advocacy assistance.**

Your group probably is aware of several individual families whose rights are somehow being violated. Remember, the law basically ensures for humane treatment in the least restrictive environment, so this covers a lot of ground. The choice of the "best" case or two to take to the P&A for assistance may be a difficult one, so the following guidelines may help.

- A. First and foremost, since the best advocate for children is the child's parent, it may be important for the parent himself or herself to be a willing and assertive spokesperson.
- B. Second, you may want to choose an individual case which is an example of a larger issue that your group has targeted for change. In this way your two-pronged strategy would be highly coordinated. For example, if your group is concerned about the way your public school system refers too many children with emotional disorders for residential treatment, it may be most effective to request help

from them for an individual child currently in residential care or being threatened with that possibility.

- C. Third, Some P&A's have decided--as they are permitted to do under the law--to focus on adults with mental illness and even on children with emotional disorders. But not all children meet the definition of those who are targeted under the PAMI legislation. Thus, it is important that your first case be one that clearly meets the eligibility guidelines; that is, a child who is currently placed in a public or private facility, or one that was discharged within the last 90 days.

Take a few minutes (15-20) to discuss various individual cases and write your tentative choice (it can be changed later) on WORKSHEET 1.

**Step 2:**

**Decide who will call the P&A to request help.**

Ideally, this is one of the parents, but if both are involved, which one? In addition to parents, should others, such as concerned professionals involved in the case, also call to inform the P&A of the situation? Maybe it would be best for the professional to call first and then the parent.

Discuss the options and write your choice on WORKSHEET 1.

**Step 3:**

**Decide which person in the P&A agency to seek help from.**

Generally, it is best to begin at the bottom (with front-line advocacy staff) and "work up" if there are problems. But, rather than talking to whomever answers the phone, you may want to request to speak to a certain member of the advocacy staff, perhaps one with particular experience or duties regarding children. Or, there may be a sympathetic ear among the staff of Board membership who could advise you on the best way to proceed.

Discuss the possibilities and write your choice(s) on WORKSHEET 1.

**Step 4:**

**Establish a timetable, set rough guidelines for when you hope to complete various tasks. Ask for follow-up meetings with P&A staff within a certain, specified time period.**

Record these on WORKSHEET 1.

**Step 5:**

**Sketch out a PLAN B, to pursue if your initial attempts to get help are unsuccessful.**

This will generally involve "working up the ladder" of the organization until help is obtained. This plan will ultimately depend on special circumstances that can't be anticipated now, but you can develop a tentative plan now.

**Step 6:**

**Finally, decide upon a committee of persons to meet periodically to make ongoing decisions about what to do next.**

In other words, form a working group that can be supportive of the efforts of the primary spokesperson and help plan strategy.

## Worksheet #1: Requesting Direct Services

### STEP 1:

Identifying the case. Write the one or two situations that you have decided to ask the P&A to help with.

### STEP 2:

Who will make the initial contact with the P&A to explain the situation?

### STEP 3:

Which person(s) in the P&A is to be contacted?

### STEP 4:

Timetable:

- A. The initial contact will be made before: (date)
- B. We will request a follow-up meeting/report by: (date)
- C. Our committee will meet again to discuss the next steps to be taken on: (date)

### STEP 5:

If our efforts to obtain help are unsuccessful, we will make a new contact with which person or which level of the P&A organization?

### STEP 6:

Names of ongoing working committee.

## Strategy 2: Forging Organization-to-Organization Alliances

Introduction: The second strategy aims to build alliances between your organization and the P&A that can result in better services to children with emotional disorders and their families. Rather than direct request for service on individual cases, this approach supplements these direct requests by establishing relationships at the organizational level. The assessment of your P&As activities yields guidelines on how to pursue this alliance-building effort.

### STEPS

#### Step 1:

The first thing to do in your group is to discuss the problems that you as parents see with the system of services for you and your children. These problems usually fall into three areas: 1) educational school systems, 2) community mental health programs, and 3) hospital and institutional care.

For example, in some states, the problems in the educational/school system involve mainstreaming of children with emotional disorders into regular classrooms. In others, the school problems have to do with getting good self contained classrooms, or well qualified teachers, or preventing unnecessary expulsions. In the area of community mental health programs, the problems may relate to the need for in-home family counseling, or parent training, or day treatment programs. Regarding hospitalizations, the problem may be too much hospitalization or too little, too much or not enough use of medication, or sending children out-of-state.

Use your worksheet #2 at the end of this section to list the issues you see in each area.

**Step 2:**

Now that you have decided what your issues are, you want to figure out the best way to forge an alliance with your P&A to work together on these system problems.

**Turn to Worksheets 2A, 2B, 2C, and 2D in UNIT 3.**

Record the assessment rating for each worksheet below.

**Worksheet #Rating**

2A: INTENT re: children with emotional disorders

2B: INTENT re: Location of efforts

2C: PRACTICE re: children with emotional disorders

2D: PRACTICE re: Location of efforts

**Step 3:**

*Since the goal of serving children with emotional disorders as a population is a "bottom-line" objective, we first look at the assessment of INTENT and PRACTICE with respect to this goal above, 2A and 2C. (Later, you can repeat these steps for 2B and 2D). Place an "X" in the appropriate box.*

**INTENT (2A)**

	<b>HIGH</b>	<b>MID OR LOW</b>
<b>HIGH</b>	BOX 1	BOX 3
<b>MID OR LOW</b>	BOX 2	BOX 4

**PRACTICE (2C)**

**Step 4:**

*The focus of your initial alliance-building efforts are determined by which box your "X" is in in Step 2. Guidelines for each box (each result) follow.*

**BOX 1: HIGH INTENT/HIGH PRACTICE.**

No Problem!!! Your P&A has stated intentions of serving children with emotional disorders and it is doing just that! Probably this means that you have already established alliances with the P&A and you didn't need this workshop! Look now at the INTENT and PRACTICE ratings for LOCATION (2B and 2D). If they are both HIGH also, then your P&A is an exemplary one indeed, and your efforts can focus on enhancing and supporting its work, in whatever ways you mutually agree to. If they are not both HIGH, then find the appropriate box below for alliance-building guidelines on this issue.

**BOX 2: HIGH INTENT/LOW PRACTICE.**

Here you have uncovered a problem in the way the P&A agency is translating its intent into practice. You have clarified that the intent of the organization is not the problem--it sees and recognizes the needs of children with emotional disorders at the higher organizational levels. The problem is that its good intentions are not yet reflected in its actual caseload. Since this involves internal organizational issues, your efforts can be targeted accordingly. Organizational literature and the Beach Center study confirm that there are four areas of internal functioning that need to be examined--any one, or all four, may be contributing to the poor-translation of intent into practice.

These are:

1. Lack of participation by front-line advocacy staff in the organization's goal setting. In effect, it may be that the advocates are being asked to implement goals that they have had no say in formulating.
2. Lack of agreement by front-line staff with the goal of serving needs of children with emotional disorders. The staff may have participated in the organization's goal-setting but not agreed with the result. Perhaps they believe that other issues and problems are more pressing.
3. Lack of advocacy staff training and experience in the problems of children with emotional disorders and their families. Staff may agree that there are problems, but lack sufficient training and experience to deal with them.
4. Poor overall job satisfaction. No matter how much the advocacy staff participate, agree, and are trained, if they don't like their jobs and there is poor morale, all of the organization's goals are in jeopardy.

These are not the only internal factors affecting translation of goals into practice, but they are excellent places to examine to begin the problem-solving. Unfortunately for parents' groups, internal organizational problems are somewhat private matters, not open to public scrutiny. Thus, you are in a better position to investigate the problems if you are already involved in the Governing Advisory Boards. If not, until you are more officially sanctioned in the agency, the best you can probably do is to inform the agency, starting with the executive director, of the discrepancy you have found and express your concerns. You might also point out the problem to sympathetic persons on the two Boards. Suggesting solutions, or insisting that they look at the above four areas may be overstepping your bounds. Your job is to get them to see and recognize the problem. Once they do so, it is



their job to solve it, and unless they invite you to help in that effort, it would be intrusive to suggest how they might better run their organization. A better plan would be to respect their ability to solve the problem, volunteer to be on a committee or whatever to help, and ask for a progress report in a specified time frame. This approach communicates respect, assumes good-will intentions, and promotes cooperation.

### BOX 3: LOW INTENT/HIGH PRACTICE

Although an unlikely possibility, this result occurs when the "bottom" of the organization is responding to problems and issues that are not yet officially recognized by the organization as a whole. For example, advocates may be responding to client requests and needs that the "higher" levels of the organization are unaware of. Or, because an advocate is experienced, trained and interested in the needs of children with emotional disorders, he/she may be spending more time and energy on those cases even though the agency hasn't required, or even encouraged this.

Your group has two options in this case. Since the agency PRACTICE is HIGH, and that is what you want, should you 1) leave well enough alone, or 2) attempt to formalize the child focus in the mission statements, brochures, etc.? Even though there is a risk either way, we believe the second choice is best in most cases. Leaving things alone may be fine in the short-run, but without official agency support, what assurances are there that children will continue to be a priority? The better choice seems to be to try to improve the internal communications and decision-making processes so that the official intent matches the practice. The risk is that the higher levels may reject children as a priority and instruct the advocates to spend more time on other issues and populations, but it is usually a risk worth taking.

Even though the issues here involve "bottom-up" rather than "top-down" communication issues, they are still internal, organizational issues that are not very open to public scrutiny. If a member of your group is on one of the Boards, you have sanction to go beyond identifying the problem to trying to solve it. If not, as in BOX 2, the best strategy is to help the agency, through its executive director, to identify the problem, volunteer to help by being on a task force or committee if one is formed, but respect the good-will intentions of the agency. You may have to talk or write to Board members and others in order to get them to recognize the organizational problem; but once they do so, your job is to let them do their job of solving it, asking for periodic progress reports.

#### BOX 4: LOW INTENT/LOW PRACTICE

This result will take the most time and effort to build effective alliances. If one of the dimensions is MID instead of low, there is some interest and experience to build on, but if both are LOW, you are basically starting from scratch. Our research suggests three main approaches to the alliance building, but the ones you choose to emphasize depends on your assessment of the organization's decision-making processes. The three general approaches are:

##### 1. MAKE ASSERTIVE REQUESTS FOR SERVICE

This targets the lower levels of the organization and impacts the PRACTICE dimension. Guidelines for this approach were presented in the section "Strategy 1: Requesting Direct Services".

##### 2. COMMUNICATE WITH THE EXECUTIVE DIRECTOR

In many organizations, the executive is the central decision-maker and the key to impacting both the INTENT and PRACTICE dimensions.

##### 3. JOIN ADVISORY AND /OR GOVERNING BOARDS

This targets the higher levels of the organization and impacts the INTENT dimension the most.

Where to begin and what to emphasize depends on your assessment of the P&As decision-making processes. Your efforts to influence the INTENT dimension will be most successful if you recognize and "go with" the decision-making processes in your P&A agency, rather than trying to change how it makes decisions. For example, even though an Advisory Board is mandated to "advise the system on priorities and policies", in some P&As it may not be very active, assertive, or influential. If that is the case in your P&A, you may want to bypass participation on this group in favor of directing your time and energy at the decision-makers. If you do join the Advisory Board, you could easily become embroiled in an internal battle to try to get the Advisory Board more power, trying to change the organization rather than focusing on the needs of children--it may seem that the first is necessary to accomplish the second, but that isn't necessarily so. In other P&As, the Advisory Board may be functioning almost as a Governing Board, with the official Governing Board delegating many of its functions to them. In this case, you clearly would want to join the Advisory Board.

In still other P&As, the executive director may be the principal decision-maker. Executive directors are always key actors, but their styles differ markedly. Some view their role as building consensus among various groups and carrying out the wishes of the Governing and/or Advisory Boards. Others have their own goals and objectives which they present to Boards for advice and approval maintaining more control of the Boards and the organization.

The relationship between the executive director, Advisory Board and the governing board is the most important factor in determining agency INTENT. Other factors include the "strings" attached to non-federal funding, the history of the agency's response to children under the DD-P&A legislation, the influence of political and governmental officials who are not members of the Boards, and the decrees resulting from lawsuits. You will gain knowledge about these latter factors as you get more involved in the organization. The place to start is trying

to assess the decision-making process of the organization, then targeting your alliance-building to the most influential aspect.

Use Worksheet 3 in Chapter 3 and your experiences with the P&A to date to assess the decision-making process in your P&A.

**Step 5:  
Making the Initial Contact**

Regardless of which result you identify in Steps 2 and 3, there are some general guidelines for initiating your efforts.

1. Write an introductory letter to the executive director. The letter should be cordial and cooperative in tone. Begin by informing the director of the general goals and purposes of your organization. Then express your desire to meet with the executive director to explore ways in which your two organizations could identify and work on common goals. (Wait until the meeting to share your specific ideas and concerns about the P&A and how you can work together). Close by saying that you will be calling in about a week to set up an appointment.
2. Meet with the executive director. It is a good idea for two or three persons from your organization to attend the first meeting. This is not a meeting to challenge or criticize, but to find common ground. You also want to express your interest in participating in the Advisory or Governing Boards, if you have decided that, in the context of exploring ways to work together. Once you have established that the director is interested in inter-organizational cooperation, ask "What would be ways that we could get more involved--would participation on the Advisory or Governing Board be appropriate?" If it's not awkward, you might ask how members on these Boards are selected, although it would also be fine to have this information ahead of time.

Your minimal goal for this meeting is to set a time to continue discussions--with the executive director, and/or with influential persons on the Boards, and/or with advocacy staff. Don't expect too much too early.

### **Step 6: Make Your Agenda Known**

After the first meeting with the executive director, you will be meeting again with him/her and you may be meeting other staff or Board members. You need to begin to share your issues and goals for children with emotional disorders and their parents, without asking for special treatment. You want to be able to articulate what you think needs to be changed in the system of care--the system issues that you believe the P&A can help with. In other words, you probably want the P&A to do more than just serve more kids in its caseload, you want them to focus on one or two specific issues. Take time (10-15 minutes) during your small group to identify the most important system of care issues in your state/region. What needs to be done for children and their families?

However, depending on where you are beginning, these larger systemic issues may need to wait until the staff gain more sensitivity and experience in handling the individual cases. In either case, educate the staff and board members about the needs of children. Talk about experiences, circulate copies of news clippings, mail summaries of government reports and studies.

### **Step 7: Help P&As be Successful**

As you get more involved as a participant in P&A activity, there are several strategies to pursue to help the P&A advocacy efforts be most successful.

1. Cultivate and recruit Board members with political influence - - legislators, government officials, politicians. Your P&A will be most effective when it has broad-based support from influential officials.

2. **Champion consumer involvement.** Help the P&A find ways to involve consumers in all aspects of the organization - - program development, helping consumers build organizations, conducting consumer satisfaction surveys.
3. Encourage the P&A to consider sponsoring (or co-sponsoring with other groups) a statewide study of the needs of children with emotional disorders. Use the study to educator legislators, politicians, and the general public about the issues.
4. When P&A advocacy efforts are being frustrated and resisted, encourage the P&A to consider a class-action lawsuit. Premature legal actions can unnecessarily polarize situations, but when other advocacy efforts fail, class-action suits can result in dramatic changes. P&As have initiated such suits in some states, with the result being not only improved care, but improved cooperation between the P&A and the state agencies.

**Step 8:  
Continue Strategy 1**

This strategy can have immediate effects on the PRACTICE dimension, and as the problems become known, concerns can filter up to higher levels, impacting the INTENT dimension as well.

**Summary**

By engaging in a two-pronged strategy, you can forge effective alliances with P&A agencies. These alliances can significantly affect the system of care and quality of life for children with emotional disorders. Each of the two strategies requires a working group (3-5 persons) that meets regularly to discuss progress and make decisions. The two efforts also need to be coordinated, but not so coordinated that the same people are doing everything. Finally, remember the danger of targeting the P&A as the problem. This could occur when you become frustrated in your efforts to obtain help. Remember that P&As are

potentially a part of the solution, they are not the problem. Your group and others can also work independently, on other fronts, on other parts of the solution.

## Worksheet #2: Forging Organization-to-Organization Alliances

1. What are the major problems that your parents see in the system of care?

A. Educational/school systems

B. Community mental health programs

C. Hospitalization/Residential treatment

2. Who from your agency will contact the P&A?

3. Whom will they contact?

4. What are the one or two system-of-care issues that you want the P&A to help with?

5. What, specifically, do you want to change about the P&A itself--its INTENT, PRACTICE, or both dimensions?

6. Who will be the members of your working group? How often will you meet?

How will you coordinate with the Strategy 1 group?



*Appendix I*

**Public Law 99-319 (1986)**

**Amendment Public Law 100-509 (1988)**

Public Law 100-509  
100th Congress

An Act

To amend the Protection and Advocacy for Mentally Ill Individuals Act of 1986 to reauthorize such Act, and for other purposes.

Oct. 20, 1988  
[S. 2393]

*Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,*

Protection and  
Advocacy for  
Mentally Ill  
Individuals  
Amendments  
Act of 1988.  
42 USC 10801  
note.

SECTION 1. SHORT TITLE.

This Act may be cited as the "Protection and Advocacy for Mentally Ill Individuals Amendments Act of 1988".

SEC. 2. REFERENCES.

Except as otherwise specifically provided, whenever in this Act an amendment or repeal is expressed in terms of an amendment to, or a repeal of, a section or other provision, the reference shall be considered to be made to a section or other provision of the Protection and Advocacy for Mentally Ill Individuals Act of 1986 (42 U.S.C. 10801 et seq.).

SEC. 3. SCOPE OF COVERAGE.

Section 102 (42 U.S.C. 10802) is amended—

(1) in paragraph (1), by inserting "or death" after "caused, injury";

(2) in paragraph (3)—

(A) by inserting "(i)" after the subparagraph designation in subparagraph (B);

(B) by striking out the period at the end of subparagraph (B) and inserting in lieu thereof the following: " , even if the whereabouts of such inpatient or resident are unknown;"; and

(C) by adding at the end thereof the following new clauses:

"(ii) who is in the process of being admitted to a facility rendering care or treatment, including persons being transported to such a facility; or";

"(iii) who is involuntarily confined in a municipal detention facility for reasons other than serving a sentence resulting from conviction for a criminal offense."; and

(3) in paragraph (4)—

(A) by inserting "or death" after "injury" each place such word occurs; and

(B) by inserting before the period at the end thereof the following: " , including the failure to maintain adequate numbers of appropriately trained staff".

Health care  
facilities.

SEC. 4. ESTABLISHMENT OF A GOVERNING AUTHORITY.

Section 105 (42 U.S.C. 10805) is amended—

(1) in subsection (a)(6), by striking out "a board" and inserting in lieu thereof "an advisory council"; and

(2) by adding at the end thereof the following new subsection:

State and local  
governments.

"(c)(1)(A) Each system established in a State, through allotments received under section 103, to protect and advocate the rights of mentally ill individuals shall have a governing authority.

"(B) In States in which the governing authority is organized as a private non-profit entity with a multi-member governing board, or a public system with a multi-member governing board, such governing board shall be selected according to the policies and procedures of the system. The governing board shall be composed of—

"(i) members (to be selected no later than October 1, 1990) who broadly represent or are knowledgeable about the needs of the clients served by the system; and

"(ii) in the case of a governing authority organized as a private non-profit entity, members who broadly represent or are knowledgeable about the needs of the clients served by the system including the chairperson of the advisory council of such system.

"(2) The governing authority established under paragraph (1) shall—

"(A) be responsible for the planning, design, implementation, and functioning of the system; and

"(B) consistent with subparagraph (A), jointly develop the annual priorities of the system with the advisory council."

#### SEC. 5. ADVISORY COUNCIL REPORT.

Section 105(a)(7) (42 U.S.C. 10805(a)(7)) is amended by striking out the period and inserting in lieu thereof the following: ", including a section prepared by the advisory council that describes the activities of the council and its assessment of the operations of the system;".

#### SEC. 6. ACCESS TO RECORDS.

(a) SYSTEM REQUIREMENT.—Section 105(a)(4)(B) (42 U.S.C. 10805(a)(4)(B)) is amended by striking out "any individual" and inserting in lieu thereof "any individual (including an individual who has died or whose whereabouts are unknown)".

(b) DEFINITION OF RECORDS.—Section 106(b) (42 U.S.C. 10806(b)) is amended by adding at the end thereof the following new paragraph:

"(3)(A) As used in this section, the term 'records' includes reports prepared by any staff of a facility rendering care and treatment or reports prepared by an agency charged with investigating reports of incidents of abuse, neglect, and injury occurring at such facility that describe incidents of abuse, neglect, and injury occurring at such facility and the steps taken to investigate such incidents, and discharge planning records.

"(B) An eligible system shall have access to the type of records described in subparagraph (A) in accordance with the provisions of subsection (a) and paragraphs (1) and (2) of subsection (b)."

#### SEC. 7. MISCELLANEOUS PROVISIONS.

Health and  
medical care.

(a) SUBCONTRACTING.—Section 104(a)(2) (42 U.S.C. 10804(a)(2)) is amended by striking out "which, on the date of enactment of this Act" and inserting in lieu thereof "including, in particular, groups run by individuals who have received or are receiving mental health services, or the family members of such individuals, which".

(b) TECHNICAL ASSISTANCE LIMITATIONS.—

(1) STATE ASSISTANCE.—Section 104(b)(2) (42 U.S.C. 10804(b)(2)) is amended by striking out "5 percent" and inserting in lieu thereof "10 percent".

(2) ASSISTANCE BY THE SECRETARY.—Section 10 (42 U.S.C. 10825) is amended to read as follows:

“TECHNICAL ASSISTANCE

“SEC. 115. The Secretary shall use not more than 2 percent of the amounts appropriated under section 117 to provide technical assistance to eligible systems with respect to activities carried out under this title, consistent with requests by such systems for such assistance.”

(c) ADDITIONAL SYSTEM REQUIREMENTS.—Section 105(a) (42 U.S.C. 10805(a)) (as amended by section 5), is further amended by adding at the end thereof the following new paragraphs:

“(8) on an annual basis, provide the public with an opportunity to comment on the priorities established by, and the activities of, the system; and

“(9) establish a grievance procedure for clients or prospective clients of the system to assure that mentally ill individuals have full access to the services of the system.”

(d) APPLICATIONS.—Section 111 (42 U.S.C. 10821) is amended—

(1) by inserting “(a)” after the section designation; and

(2) by adding at the end thereof the following new subsection:

“(b) Applications submitted under this section shall remain in effect for a 3-year period, and the assurances required under this section shall be for the same 3-year period.”

(e) ALLOTMENT FORMULA.—Section 112(a) (42 U.S.C. 10822(a)) is amended—

(1) in paragraph (2) to read as follows:

“(2) Notwithstanding paragraph (1) and subject to the availability of appropriations under section 117—

“(A) if the total amount appropriated in a fiscal year is at least \$13,000,000—

“(i) the amount of the allotment of the eligible system of each of the several States, the District of Columbia, and the Commonwealth of Puerto Rico shall be the greater of—

District of  
Columbia.  
Puerto Rico.

“(I) \$140,000; or

“(II) \$125,000 in addition to the amount determined under paragraph (3); and

“(ii) the amount of the allotment of the eligible system of Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Trust Territory of the Pacific Islands, and the Virgin Islands shall be the greater of—

Territories, U.S.

“(I) \$75,000; or

“(II) \$67,000 in addition to the amount determined under paragraph (3); and

“(B) if the total amount appropriated in a fiscal year is less than \$13,000,000, the amount of the allotment of the eligible system—

“(i) of each of the several States, the District of Columbia, and the Commonwealth of Puerto Rico shall not be less than \$125,000 in addition to the amount determined under paragraph (3); and

District of  
Columbia.  
Puerto Rico.

“(ii) of Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Trust Territory of the Pacific Islands, and the Virgin Islands shall not be less than \$67,000 in addition to the amount determined under paragraph (3).”; and

Territories, U.S.

(2) by adding at the end thereof the following new paragraph:  
 “(3) In any case in which the total amount appropriated under section 117 for a fiscal year exceeds the total amount appropriated under such section, as in effect on the day before the date of enactment of this paragraph, for the preceding fiscal year by a percentage greater than the most recent percentage change in the Consumer Price Index published by the Secretary of Labor under section 100(c)(1) of the Rehabilitation Act of 1973, the Secretary shall increase each of the allotments under clauses (i)(II) and (ii)(II) of subparagraph (A) and clauses (i) and (ii) of subparagraph (B) of paragraph (2) by an amount which bears the same ratio to the amount of such minimum allotment (including any increases in such minimum allotment under this paragraph for prior fiscal years) as the amount which is equal to the difference between—

“(A) the total amount appropriated under section 117 for the fiscal year for which the increase in minimum allotment is made, minus;

“(B) the total amount appropriated under section 117 for the immediately preceding fiscal year,  
 bears to the total amount appropriated under section 117 for such preceding fiscal year.”

(f) **AUTHORIZATION OF APPROPRIATIONS.**—Section 117 (42 U.S.C. 10827) is amended to read as follows:

“**AUTHORIZATION OF APPROPRIATIONS**

“Sec. 117. For allotments under this title, there are authorized to be appropriated \$14,300,000 for fiscal year 1989, and such sums as may be necessary for fiscal year 1990 and fiscal year 1991.”

42 USC 10827  
 note.

**SEC. 8. EFFECTIVE DATE.**

(a) **IN GENERAL.**—The amendments made by this Act, other than the amendment made by section 7(f), shall become effective on the date of the enactment of this Act.

(b) **AUTHORIZATION OF APPROPRIATIONS.**—The amendment made by section 7(f) shall become effective on October 1, 1988.

Approved October 20, 1988.

**LEGISLATIVE HISTORY—S. 2393 (H.R. 5155):**

**HOUSE REPORTS:** No. 100-903 accompanying H.R. 5155 (Comm. on Energy and Commerce).

**SENATE REPORTS:** No. 100-454 (Comm. on Labor and Human Resources).

**CONGRESSIONAL RECORD,** Vol. 134 (1988):

Aug. 9, considered and passed Senate.

Sept. 20, H.R. 5155 considered and passed House; proceedings vacated and S. 2393, amended, passed in lieu.

Oct. 4, Senate concurred in certain House amendment with an amendment and disagreed to another.

Oct. 5, House receded and concurred in Senate amendment.

○

Public Law 99-319  
99th Congress

An Act

May 23, 1986 To provide for protection and advocacy for mentally ill individuals, and for other  
[S. 974] purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Protection and Advocacy for Mentally Ill Individuals Act of 1986".

Protection and  
Advocacy for  
Mentally Ill  
Individuals Act  
of 1986.  
42 USC 10801  
note.

TITLE I—PROTECTION AND ADVOCACY SYSTEMS

PART A—ESTABLISHMENT OF SYSTEMS

FINDINGS AND PURPOSE

42 USC 10801. SEC. 101. (a) The Congress finds that—

- (1) mentally ill individuals are vulnerable to abuse and serious injury;
- (2) mentally ill individuals are subject to neglect, including lack of treatment, adequate nutrition, clothing, health care, and adequate discharge planning; and
- (3) State systems for monitoring compliance with respect to the rights of mentally ill individuals vary widely and are frequently inadequate.

(b) The purposes of this Act are—

- (1) to ensure that the rights of mentally ill individuals are protected; and
- (2) to assist States to establish and operate a protection and advocacy system for mentally ill individuals which will—
  - (A) protect and advocate the rights of such individuals through activities to ensure the enforcement of the Constitution and Federal and State statutes; and
  - (B) investigate incidents of abuse and neglect of mentally ill individuals if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred.

DEFINITIONS

42 USC 10802. SEC. 102. For purposes of this title:

- (1) The term "abuse" means any act or failure to act by an employee of a facility rendering care or treatment which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury to a mentally ill individual, and includes acts such as—
  - (A) the rape or sexual assault of a mentally ill individual;
  - (B) the striking of a mentally ill individual;
  - (C) the use of excessive force when placing a mentally ill individual in bodily restraints; and

(D) the use of bodily or chemical restraints on a mentally ill individual which is not in compliance with Federal and State laws and regulations.

(2) The term "eligible system" means the system established in a State to protect and advocate the rights of persons with developmental disabilities under part C of the Developmental Disabilities Assistance and Bill of Rights Act.

(3) The term "mentally ill individual" means an individual—

- (A) who has a significant mental illness or emotional impairment, as determined by a mental health professional qualified under the laws and regulations of the State; and
- (B) who is an inpatient or resident in a facility rendering care or treatment.

(4) The term "neglect" means a negligent act or omission by any individual responsible for providing services in a facility rendering care or treatment which caused or may have caused injury to a mentally ill individual or which placed a mentally ill individual at risk of injury, and includes an act or omission such as the failure to establish or carry out an appropriate individual program plan or treatment plan for a mentally ill individual, the failure to provide adequate nutrition, clothing, or health care to a mentally ill individual, or the failure to provide a safe environment for a mentally ill individual.

(5) The term "Secretary" means the Secretary of Health and Human Services.

(6) The term "State" means each of the several States, the District of Columbia, the Commonwealth of Puerto Rico, Guam, the Commonwealth of the Northern Mariana Islands, American Samoa, the Virgin Islands, and the Trust Territory of the Pacific Islands.

ALLOTMENTS

SEC. 103. The Secretary shall make allotments under this title to eligible systems to establish and administer systems—

- (1) which meet the requirements of section 105; and
- (2) which are designed to—

- (A) protect and advocate the rights of mentally ill individuals; and
- (B) investigate incidents of abuse and neglect of mentally ill individuals if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred.

USE OF ALLOTMENTS

SEC. 104. (a)(1) An eligible system may use its allotment under this title to enter into contracts with State agencies and nonprofit organizations which operate throughout the State. In order to be eligible for a contract under this paragraph—

(A) such an agency shall be independent of any agency which provides treatment or services (other than advocacy services) to mentally ill individuals; and

(B) such an agency or organization shall have the capacity to protect and advocate the rights of mentally ill individuals.

(2) In carrying out paragraph (1), an eligible system should consider entering into contracts with organizations which, on the date of enactment of this Act, provide protection or advocacy services to mentally ill individuals.

42 USC 6061.

42 USC 10803.

Contracts,  
State and local  
governments.  
42 USC 10804.





(b)(1) If an eligible system is a public entity, the government of the State in which the system is located may not require the system to obligate more than 5 percent of its allotment under this title in any fiscal year for administrative expenses.

(2) An eligible system may not use more than 5 percent of any allotment under this title for any fiscal year for the costs of providing technical assistance and training to carry out this title.

SYSTEM REQUIREMENTS

SEC. 105. (a) A system established in a State under section 103 to protect and advocate the rights of mentally ill individuals shall—

(1) have the authority to—

(A) investigate incidents of abuse and neglect of mentally ill individuals if the incidents are reported to the system or if there is probable cause to believe that the incidents occurred;

(B) pursue administrative, legal, and other appropriate remedies to ensure the protection of mentally ill individuals who are receiving care or treatment in the State; and

(C) pursue administrative, legal, and other remedies on behalf of an individual who—

(i) was a mentally ill individual; and

(ii) is a resident of the State,

but only with respect to matters which occur within 90 days after the date of the discharge of such individual from a facility providing care or treatment;

(2) be independent of any agency in the State which provides treatment or services (other than advocacy services) to mentally ill individuals;

(3) have access to facilities in the State providing care or treatment;

(4) in accordance with section 106, have access to all records of—

(A) any individual who is a client of the system if such individual, or the legal guardian, conservator, or other legal representative of such individual, has authorized the system to have such access; and

(B) any individual—

(i) who by reason of the mental or physical condition of such individual is unable to authorize the system to have such access;

(ii) who does not have a legal guardian, conservator, or other legal representative, or for whom the legal guardian is the State; and

(iii) with respect to whom a complaint has been received by the system or with respect to whom there is probable cause to believe that such individual has been subject to abuse or neglect;

(5) have an arrangement with the Secretary and the agency of the State which administers the State plan under title XIX of the Social Security Act for the furnishing of the information required by subsection (b);

(6) establish a board—

(A) which will advise the system on policies and priorities to be carried out in protecting and advocating the rights of mentally ill individuals; and

(B) which shall include attorneys, mental health professionals, individuals from the public who are knowledgeable about mental illness, a provider of mental health services, individuals who have received or are receiving mental health services, and family members of such individuals, and at least one-half the membership of which shall be comprised of individuals who have received or are receiving mental health services or who are family members of such individuals; and

(7) on January 1, 1987, and January 1 of each succeeding year, prepare and transmit to the Secretary and the head of the State mental health agency of the State in which the system is located a report describing the activities, accomplishments, and expenditures of the system during the most recently completed fiscal year.

(b) The Secretary and the agency of a State which administers its State plan under title XIX of the Social Security Act shall provide the eligible system of the State with a copy of each annual survey report and plan of corrections for cited deficiencies made pursuant to titles XVIII and XIX of the Social Security Act with respect to any facility rendering care or treatment to mentally ill individuals in the State in which such system is located. A report or plan shall be made available within 90 days after the completion of the report or plan.

ACCESS TO RECORDS

SEC. 106. (a) An eligible system which, pursuant to section 105(a)(4), has access to records which, under Federal or State law, are required to be maintained in a confidential manner by a provider of mental health services, shall, except as provided in subsection (b), maintain the confidentiality of such records to the same extent as is required of the provider of such services.

(b)(1) Except as provided in paragraph (2), an eligible system which has access to records pursuant to section 105(a)(4) may not disclose information from such records to the individual who is the subject of the information if the mental health professional responsible for supervising the provision of mental health services to such individual has provided the system with a written determination that disclosure of such information to such individual would be detrimental to such individual's health.

(2)(A) If disclosure of information has been denied under paragraph (1) to an individual—

(i) such individual;

(ii) the legal guardian, conservator, or other legal representative of such individual; or

(iii) an eligible system, acting on behalf of an individual described in subparagraph (B),

may select another mental health professional to review such information and to determine if disclosure of such information would be detrimental to such individual's health. If such mental health professional determines, based on professional judgment, that disclosure of such information would not be detrimental to the health of such individual, the system may disclose such information to such individual.

(B) An eligible system may select a mental health professional under subparagraph (A)(iii) on behalf of—

(i) an individual whose legal guardian is the State; or

Reports.

42 USC 139c.

42 USC 1395.

Reports.

State and local governments. Classified information. 42 USC 10806.

to and local governments. USC 10805.

USC 1395.



(ii) an individual who has a legal guardian, conservator, or other legal representative other than the State if such guardian, conservator, or representative does not, within a reasonable time after such individual is denied access to information under paragraph (1), select a mental health professional under subparagraph (A) to review such information.

(C) If the laws of a State prohibit an eligible system from obtaining access to the records of mentally ill individuals in accordance with section 105(a)(4) and this section, section 105(a)(4) and this section shall not apply to such system before—

(i) the date such system is no longer subject to such a prohibition; or

(ii) the expiration of the 2-year period beginning on the date of the enactment of this Act, whichever occurs first.

LEGAL ACTIONS

Sec. 107. (a) Prior to instituting any legal action in a Federal or State court on behalf of a mentally ill individual, an eligible system, or a State agency or nonprofit organization which entered into a contract with an eligible system under section 104(a), shall exhaust in a timely manner all administrative remedies where appropriate. If, in pursuing administrative remedies, the system, agency, or organization determines that any matter with respect to such individual will not be resolved within a reasonable time, the system, agency, or organization may pursue alternative remedies, including the initiation of a legal action.

(b) Subsection (a) does not apply to any legal action instituted to prevent or eliminate imminent serious harm to a mentally ill individual.

PART B—ADMINISTRATIVE PROVISIONS

APPLICATIONS

Sec. 111. No allotment may be made under this title to an eligible system unless an application therefor is submitted to the Secretary. Each such application shall contain—

(1) assurances that amounts paid to such system from an allotment under this title will be used to supplement and not to supplant the level of non-Federal funds available in the State in which such system is established to protect and advocate the rights of mentally ill individuals;

(2) assurances that such system will have a staff which is trained or being trained to provide advocacy services to mentally ill individuals;

(3) assurances that such system, and any State agency or nonprofit organization with which such system may enter into a contract under section 104(a), will not, in the case of any individual who has a legal guardian, conservator, or representative other than the State, take actions which are duplicative of actions taken on behalf of such individual by such guardian, conservator, or representative unless such guardian, conservator, or representative requests the assistance of such system; and

(4) such other information as the Secretary may by regulation prescribe

ALLOTMENT FORMULA AND REALLOTMENTS

Sec. 112. (a)(1)(A) Except as provided in paragraph (2) and subject to the availability of appropriations under section 117, the Secretary shall make allotments under section 103 from amounts appropriated under section 117 for a fiscal year to eligible systems on the basis of a formula prescribed by the Secretary which is based equally—

(i) on the population of each State in which there is an eligible system; and

(ii) on the population of each such State weighted by its relative per capita income.

(B) For purposes of subparagraph (A)(ii), the term "relative per capita income" means the quotient of the per capita income of the United States and the per capita income of the State, except that if the State is Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Trust Territory of the Pacific Islands, or the Virgin Islands, the quotient shall be considered to be one.

(2) Notwithstanding paragraph (1) and subject to the availability of appropriations under section 117—

(A) the amount of the allotment of the eligible system of each of the several States, the District of Columbia, and the Commonwealth of Puerto Rico shall not be less than \$125,000; and

(B) the amount of the allotment of the eligible system of Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, the Trust Territory of the Pacific Islands, and the Virgin Islands shall not be less than \$67,000.

(b)(1) To the extent that all the amounts appropriated under section 117 for a fiscal year are not allotted to eligible systems because—

(A) one or more eligible systems have not submitted an application for an allotment for such fiscal year; or

(B) one or more eligible systems have notified the Secretary that they do not intend to use the full amount of their allotment,

the amount which is not so allotted shall be reallocated among the remaining eligible systems.

(2) The amount of an allotment to an eligible system for a fiscal year which the Secretary determines will not be required by the system during the period for which it is available shall be available for reallocation by the Secretary to other eligible systems with respect to which such a determination has not been made.

(3) The Secretary shall make reallocations under paragraphs (1) and (2) on such date or dates as the Secretary may fix (but not earlier than 30 days after the Secretary has published notice of the intention of the Secretary to make such reallocation in the Federal Register). A reallocation to an eligible system shall be made in proportion to the original allotment of such system for such fiscal year, but with such proportionate amount for such system being reduced to the extent it exceeds the sum the Secretary estimates such system needs and will be able to use during such period. The total of such reductions shall be similarly reallocated among eligible systems whose proportionate amounts were not so reduced. Any amount so reallocated to an eligible system for a fiscal year shall be deemed to be a part of its allotment under subsection (a) for such

42 USC 10822.

District of Columbia. Puerto Rico.

Guam. American Samoa. Northern Mariana Islands. Trust Territory of the Pacific Islands. Virgin Islands.

Federal Register, publication.

State and local governments. contracts. 2 USC 10807.

42 USC 10821.

State and local governments.

State and local governments. contracts.



## PAYMENTS UNDER ALLOTMENTS

42 USC 10823. **SEC. 113.** For each fiscal year, the Secretary shall make payments to each eligible system from its allotment under this title. Any amount paid to an eligible system for a fiscal year and remaining unobligated at the end of such year shall remain available to such system for the next fiscal year for the purposes for which it was made.

## REPORTS BY THE SECRETARY

42 USC 10924. **SEC. 114.** (a) The Secretary shall include in each report required under section 107(c) of the Developmental Disabilities Assistance and Bill of Rights Act a separate statement which contains—

42 USC 6006. (1) a description of the activities, accomplishments, and expenditures of systems to protect and advocate the rights of mentally ill individuals supported with payments from allotments under this title, including—

(A) a specification of the total number of mentally ill individuals served by such systems;

(B) a description of the types of activities undertaken by such systems;

(C) a description of the types of facilities providing care or treatment with respect to which such activities are undertaken;

(D) a description of the manner in which such activities are initiated; and

(E) a description of the accomplishments resulting from such activities;

(2) a description of—

(A) systems to protect and advocate the rights of mentally ill individuals supported with payments from allotments under this title;

(B) activities conducted by States to protect and advocate such rights;

(C) mechanisms established by residential facilities for mentally ill individuals to protect and advocate such rights; and

(D) the coordination among such systems, activities, and mechanisms;

(3) a specification of the number of systems established with allotments under this title and of whether each such system was established by a public or nonprofit private entity; and

(4) recommendations for activities and services to improve the protection and advocacy of the rights of mentally ill individuals and a description of needs for such activities and services which have not been met by systems established under this title.

(b) In preparing each statement required by subsection (a), the Secretary shall use and include information submitted to the Secretary in the reports required under section 105(a)(7).

## TECHNICAL ASSISTANCE

42 USC 10825. **SEC. 115.** The Secretary shall provide technical assistance to eligible systems with respect to activities carried out under this title.

## ADMINISTRATION

**SEC. 116.** The Secretary shall carry out this title through the Administrator of the Alcohol, Drug Abuse, and Mental Health Administration. 42 USC 101

## AUTHORIZATION OF APPROPRIATIONS

**SEC. 117.** For allotments under this title, there are authorized to be appropriated \$10,000,000 for fiscal year 1986, \$10,500,000 for fiscal year 1987, and \$11,025,000 for fiscal year 1988. 42 USC 108

## TITLE II—RESTATEMENT OF BILL OF RIGHTS FOR MENTAL HEALTH PATIENTS

## RESTATEMENT OF BILL OF RIGHTS

**SEC. 201.** It is the sense of the Congress that, as previously stated in title V of the Mental Health Systems Act, each State should review and revise, if necessary, its laws to ensure that mental health patients receive the protection and services they require, and that in making such review and revision, States should take into account the recommendations of the President's Commission on Mental Health and the following: State and I government 42 USC 101 42 USC 954

(1) A person admitted to a program or facility for the purpose of receiving mental health services should be accorded the following:

(A) The right to appropriate treatment and related services in a setting and under conditions that—

(i) are the most supportive of such person's personal liberty; and

(ii) restrict such liberty only to the extent necessary consistent with such person's treatment needs, applicable requirements of law, and applicable judicial orders.

(B) The right to an individualized, written, treatment or service plan (such plan to be developed promptly after admission of such person), the right to treatment based on such plan, the right to periodic review and reassessment of treatment and related service needs, and the right to appropriate revision of such plan, including any revision necessary to provide a description of mental health services that may be needed after such person is discharged from such program or facility.

(C) The right to ongoing participation, in a manner appropriate to such person's capabilities, in the planning of mental health services to be provided such person (including the right to participate in the development and periodic revision of the plan described in subparagraph (B)), and, in connection with such participation, the right to be provided with a reasonable explanation, in terms and language appropriate to such person's condition and ability to understand, of—

(i) such person's general mental condition and, if such program or facility has provided a physical examination, such person's general physical condition;

(ii) the objectives of treatment;

(iii) the nature and significant possible adverse effects of recommended treatments;

(iv) the reasons why a particular treatment is considered appropriate;

(v) the reasons why access to certain visitors may not be appropriate; and

(vi) any appropriate and available alternative treatments, services, and types of providers of mental health services.

(D) The right not to receive a mode or course of treatment, established pursuant to the treatment plan, in the absence of such person's informed, voluntary, written consent to such mode or course of treatment, except treatment—

(i) during an emergency situation if such treatment is pursuant to or documented contemporaneously by the written order of a responsible mental health professional; or

(ii) as permitted under applicable law in the case of a person committed by a court to a treatment program or facility.

(E) The right not to participate in experimentation in the absence of such person's informed, voluntary, written consent, the right to appropriate protections in connection with such participation, including the right to a reasonable explanation of the procedure to be followed, the benefits to be expected, the relative advantages of alternative treatments, and the potential discomforts and risks, and the right and opportunity to revoke such consent.

(F) The right to freedom from restraint or seclusion, other than as a mode or course of treatment or restraint or seclusion during an emergency situation if such restraint or seclusion is pursuant to or documented contemporaneously by the written order of a responsible mental health professional.

(G) The right to a humane treatment environment that affords reasonable protection from harm and appropriate privacy to such person with regard to personal needs.

(H) The right to confidentiality of such person's records.

(I) The right to access, upon request, to such person's mental health care records, except such person may be refused access to—

(i) information in such records provided by a third party under assurance that such information shall remain confidential; and

(ii) specific material in such records if the health professional responsible for the mental health services concerned has made a determination in writing that such access would be detrimental to such person's health, except that such material may be made available to a similarly licensed health professional selected by such person and such health professional may, in the exercise of professional judgment, provide such person with access to any or all parts of such material or otherwise disclose the information contained in such material to such person.

(J) The right, in the case of a person admitted on a residential or inpatient care basis, to converse with others privately, to have convenient and reasonable access to the telephone and mails, and to see visitors during regularly scheduled hours, except that, if a mental health professional treating such person determines that denial of access to a particular visitor is necessary for treatment purposes, such mental health professional may, for a specific, limited, and reasonable period of time, deny such access if such mental health professional has ordered such denial in writing and such order has been incorporated in the treatment plan for such person. An order denying such access should include the reasons for such denial.

(K) The right to be informed promptly at the time of admission and periodically thereafter, in language and terms appropriate to such person's condition and ability to understand, of the rights described in this section.

(L) The right to assert grievances with respect to infringement of the rights described in this section, including the right to have such grievances considered in a fair, timely, and impartial grievance procedure provided for or by the program or facility.

(M) Notwithstanding subparagraph (J), the right of access to (including the opportunities and facilities for private communication with) any available—

(i) rights protection service within the program or facility;

(ii) rights protection service within the State mental health system designed to be available to such person;

(iii) system established under title I to protect and advocate the rights of mentally ill individuals; and

(iv) qualified advocate;

for the purpose of receiving assistance to understand, exercise, and protect the rights described in this section and in other provisions of law.

(N) The right to exercise the rights described in this section without reprisal, including reprisal in the form of denial of any appropriate, available treatment.

(O) The right to referral as appropriate to other providers of mental health services upon discharge.

(2)(A) The rights described in this section should be in addition to and not in derogation of any other statutory or constitutional rights.

(B) The rights to confidentiality and access to records as provided in subparagraphs (H) and (I) of paragraph (1) should remain applicable to records pertaining to a person after such person's discharge from a program or facility.

(3)(A) No otherwise eligible person should be denied admission to a program or facility for mental health services as a reprisal for the exercise of the rights described in this section.

(B) Nothing in this section should—

(i) obligate an individual mental health or health professional to administer treatment contrary to such professional's clinical judgment;

(ii) prevent any program or facility from discharging any person for whom the provision of appropriate treatment, consistent with the clinical judgment of the mental health

Ante, p. 478.

Classified information.

Classified information.  
Classified information.

70

71

professional primarily responsible for such person's treatment, is or has become impossible as a result of such person's refusal to consent to such treatment;

(iii) require a program or facility to admit any person who, while admitted on prior occasions to such program or facility, has repeatedly frustrated the purposes of such admission by withholding consent to proposed treatment; or

(iv) obligate a program or facility to provide treatment services to any person who is admitted to such program or facility solely for diagnostic or evaluative purposes.

(C) In order to assist a person admitted to a program or facility in the exercise or protection of such person's rights, such person's attorney or legal representatives should have reasonable access to—

(i) such person;

(ii) the areas of the program or facility where such person has received treatment, resided, or had access; and

(iii) pursuant to the written authorization of such person, the records and information pertaining to such person's diagnosis, treatment, and related services described in paragraph (1)(I).

(D) Each program and facility should post a notice listing and describing, in language and terms appropriate to the ability of the persons to whom such notice is addressed to understand, the rights described in this section of all persons admitted to such program or facility. Each such notice should conform to the format and content for such notices, and should be posted in all appropriate locations.

(4)(A) In the case of a person adjudicated by a court of competent jurisdiction as being incompetent to exercise the right to consent to treatment or experimentation described in subparagraph (D) or (E) of paragraph (1), or the right to confidentiality of or access to records described in subparagraph (H) or (I) of such paragraph, or to provide authorization as described in paragraph (3)(C)(iii), such right may be exercised or such authorization may be provided by the individual appointed by such court as such person's guardian or representative for the purpose of exercising such right or such authorization.

(B) In the case of a person who lacks capacity to exercise the right to consent to treatment or experimentation under subparagraph (D) or (E) of paragraph (1), or the right to confidentiality of or access to records described in subparagraph (H) or (I) of such paragraph, or to provide authorization as described in paragraph (3)(C)(iii), because such person has not attained an age considered sufficiently advanced under State law to permit the exercise of such right or such authorization to be legally binding, such right may be exercised or such authorization may be provided on behalf of such person by a parent or legal guardian of such person.

(C) Notwithstanding subparagraphs (A) and (B), in the case of a person admitted to a program or facility for the purpose of receiving mental health services, no individual employed by or receiving any remuneration from such program or facility should act as such person's guardian or representative.

TITLE III—CONSTRUCTION

CONSTRUCTION

SEC. 301. (a) Titles I and II shall not be construed as establishing any new rights for mentally ill individuals. 42 USC 10851.

(b) For purposes of this section, the term "mentally ill individual" has the same meaning as in section 102(3).

TITLE IV—OTHER PROGRAMS

ALZHEIMER'S DISEASE

SEC. 401. Part B of title III of the Public Health Service Act is amended by inserting before section 317 the following: 42 USC 243.

"FAMILY SUPPORT GROUPS FOR ALZHEIMER'S DISEASE PATIENTS

"SEC. 316. (a) Subject to available appropriations, the Secretary, acting through the National Institute of Mental Health, the National Institutes of Health, and the Administration on Aging, shall promote the establishment of family support groups to provide, without charge, educational, emotional, and practical support to assist individuals with Alzheimer's disease or a related memory disorder and members of the families of such individuals. In promoting the establishment of such groups, the Secretary shall give priority to— 42 USC 247a.

(1) university medical centers and other appropriate health care facilities which receive Federal funds from the Secretary and which conduct research on Alzheimer's disease or provide services to individuals with such disease; and

(2) community-based programs which receive funds from the Secretary, acting through the Administration on Aging.

"(b) The Secretary shall promote the establishment of a national network to coordinate the family support groups described in subsection (a).

"(c) The Secretary shall report to Congress, not later than one year after the date of the enactment of this section, on family support groups and the network of such groups established pursuant to this section." Report.

BALANCED BUDGET PROVISION

SEC. 402. This Act shall not be construed as superseding any of the balanced budget provisions set forth in section 3(7) of the Congressional Budget and Impoundment Control Act of 1974. 42 USC 10801 note. 2 USC 622.

Approved May 23, 1986.

LEGISLATIVE HISTORY—S. 974 (H.R. 3492) (H.R. 4055):

HOUSE REPORTS: No. 99-401 accompanying H.R. 3492 (Comm. on Energy and Commerce) and No. 99-676 (Comm. of Conference).

SENATE REPORT No. 99-103 (Comm. on Labor and Human Resources).

69

Classified Information.

72



73

## **Appendix II**

### **Resources for Parents of Children with Emotional Disorders**

1. Natalie Reatig, Coordinator  
Protection & Advocacy Program  
Division of Education and Service Systems Liaisons  
National Institute of Mental Health  
Room 11-C-27  
5600 Fisher's Lane  
Rockville, Maryland 20857  
(301) 443-3667
  
2. Curt Decker  
Executive Director  
NAPAS  
220 Eye St., N.E., Suite 150  
Washington, C.C. 20001  
(202)546-8202
  
3. Two national research and training centers focus on the needs of children with emotional disorders and families. Both publish informative, no-cost newsletters describing their activities and new developments in the field. Contact:

Barbara J. Friesen, Ph.D.  
Director, Research and Training Center  
Regional Research Institute for Human Services  
Portland State University  
P.O. Box 751  
Portland, OR 97007-0751  
(503) 464-0440

Robert M. Friedman, Ph.D.

Director, Florida Research and Training Center for  
Improved Services for Seriously Emotionally Disturbed  
Children

University of South Florida  
Florida Mental Health Institute  
13301 N. 30th Street  
Tampa, FL 33612  
(813) 974-4500

6275