

**NEXT STEPS:**

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**A NATIONAL  
FAMILY AGENDA  
FOR CHILDREN WHO HAVE  
EMOTIONAL DISORDERS**

**Family Support Services  
Access to Appropriate Educational Programs  
Coordination of Services: Case Management  
Relinquishing Custody to Obtain Services**



**Families as Allies Project**

**Research and Training Center on Family Support  
and Children's Mental Health  
Portland State University  
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## INTRODUCTION

This publication was developed as the result of a conference that brought together professionals and parents to discuss improvements needed in services for children with emotional disorders and their families.

The conference, entitled "Next Steps: A National Family Agenda for Children Who Have Emotional Disorders," was held in Washington, D.C. on December 10-11, 1988. The conference was sponsored by the Research and Training Center on Family Support and Children's Mental Health, with planning assistance from the National Alliance for the Mentally Ill, the National Institute on Disability and Rehabilitation Research (U.S. Department of Education), the National Institute for Mental Health (U.S. Department of Health and Human Services), and the National Mental Health Association.

Conference work groups developed recommendations regarding four issues:

- family support
- access to educational services
- coordination of services (case management)
- relinquishing custody to obtain services

Each section of this publication contains a brief discussion of the issue and the recommendations made by the work group. We hope this information will be useful in promoting change on behalf of these children and their families.

## Family Support

Family support is assistance provided to families to enhance their ability to cope with the special needs and demands of raising a child with an emotional disorder. This assistance addresses the needs of the entire family, as distinguished from the educational or therapeutic needs of the child. Many programs providing services to children with emotional disorders also offer a family support component.

Family support should be based on participation of all family members in deciding the types of services needed and the manner in which services are to be delivered. Because of the diversity of needs and circumstances among families, support services must be flexible and tailored to accommodate each family.

Family support encompasses a continuum of services, ranging from formal, professionally administered services to informal support networks. Examples of formal services are homemaker services, transportation, cash subsidies, and respite care. Informal services might include parent support groups, sibling support groups, emotional support from friends and relatives, and a variety of concrete services, such as babysitting and transportation.

In many instances, children with emotional disorders would not have to be placed out of their homes if support services were available to help their families meet and manage their special needs. Thus, a lack of support services may contribute to further disruption in the lives of children and families, further threatening their emotional health.

## Family Support

### *RECOMMENDATIONS*

For effective family support programs, the work group recommended that:

- A single point of entry be developed in each community;
- Flexible funding be provided for a variety of family support services in multiple settings;
- Boards and advisory groups include participation by parents;
- Financial incentives be created through legislation to integrate services creatively and effectively;
- A national family policy be developed; and
- Professional training be provided to parents for leadership skills development, knowledge of current technology, and advocacy.

The work group also made general recommendations that:

- State and national clearinghouses be established; and
- State policies be developed to assure high quality professional training.

## Access to Educational Services

Two federal laws establish the legal framework to guarantee access to free appropriate education for all children with handicapping conditions: Section 504 of the Rehabilitation Act of 1973 and the Education for All Handicapped Children Act of 1975 (Public Law 94-142).

However, the actual quality of education for children with emotional disorders varies greatly from community to community. Geographic location often determines the resources and types of services available to these children and their families.

Some communities do not place the same priority on emotional disorders as on physical or developmental disorders and therefore exclude or restrict these children from receiving special services.

Available services are often provided in a stigmatizing manner, requiring the child to demonstrate failure in a regular classroom in order to receive help. In some communities, special educational services for children who have serious emotional problems are provided only in segregated settings apart from other students.

Another complication arises from a lack of coordination between schools and treatment programs, thereby undermining the effectiveness of both systems in meeting the needs of children with emotional disorders.

## Access to Educational Services

### *RECOMMENDATIONS*

To improve educational services for children with emotional disorders, the work group recommended that:

- Parent education programs be established that address basic services, rights, and treatment models;
- State parent training centers be developed informational materials specific to emotional disorders and education for parents;
- National organizations develop and disseminate information to parents about educational issues, including a national newsletter;
- Boards and decision-making bodies governing education services include parents as members;
- A national workgroup be created to examine issues regarding "best practices" in education. Parents, teachers and children should participate in identifying "best practices";
- Local forums be held for parents and teachers to discuss important service issues;
- University curriculum and field service be improved so that professionals learn to provide appropriate treatment, education and service;
- A national parent training center be established to provide technical assistance and training about mental health issues; and
- Parent advocacy efforts be directed at influencing accreditation and certification requirements.

A general recommendation of the work group was to conduct public hearings in selecting research proposals.

## **Coordination of Services: Case Management**

## **Coordination of Services: Case Management**

### *RECOMMENDATIONS*

Case management provides coordination and continuity of services to address the specific needs of a child with an emotional disorder, which often extend across agency boundaries. Case management ensures that services are provided in a therapeutic manner and respond to the changing needs of children and their families.

Typically, case managers are specially trained individuals who provide continuity of care through identifying and locating services, referring the child and family to appropriate services, advocating within the service delivery system to respond to the child's and family's needs, and coordinating services among a variety of agencies, such as education and mental health. Because of the complex and fragmented nature of service delivery, a family may require assistance in obtaining the particular combination of services most effective in meeting their needs. The large number of agencies and variations in the types of service, eligibility criteria, specific conditions for providing services, and methods of service delivery often act as barriers to families in obtaining needed services.

Case management involves active participation by the family and child in identifying their needs and developing service plans. Effective case management considers the needs and resources of each family member and information is provided about alternative approaches so that the entire family can participate in treatment decisions. Family members are supported to strengthen the family unit and enable them to accommodate the needs of the child with an emotional disorder.

An understanding of family strengths, creativity, use of formal and informal resources, community education and outreach are crucial aspects of case management in effectively supporting and preserving the family.

To promote effective case management, the work group recommended that:

- Parents, professionals, and community leaders be encouraged to advocate for mandated case management services;
- Promotions and licensure of professionals be based at least in part on evidence of collaborative teamwork; and
- Community education be provided so that the public at large supports case management and other services for children who have emotional disorders.

The work group also established general recommendations that:

- A national political agenda be developed;
- A national clearinghouse be established; and
- Public education efforts regarding children's mental health issues be increased.

## Relinquishing Custody to Obtain Services

Many states require parents to relinquish legal custody of their children on a temporary basis to obtain special services, particularly residential treatment or other out-of-home care. This policy may require that parents state that they are unable to care for or control their child, although they may have endured considerable hardship in order to care for their child at home. Although practices vary from state to state, parents may be required to give up their rights and involvement in their own child's care to obtain needed services.

This practice may ultimately undermine the welfare of children by interfering with their support system and creating obstacles to parental participation in their treatment.

## Relinquishing Custody to Obtain Services

### *RECOMMENDATIONS*

In considering these issues, the work group recommended that:

- The value of family preservation be integrated into every law, policy, and action developed and implemented on behalf of children in need of mental health services;
- Education be offered to parents about the way the system operates, the nature and effect of treatment, their rights and options for treating mental and emotional disorders;
- Multidisciplinary research be conducted regarding the attitudes of professionals toward custody, statutory provisions governing custody relinquishment, scope of the problem, model statutes and programs, and the impact of relinquishing custody on the child and family;
- Funding mechanisms be created that are contingent upon appropriate use of custody relinquishment;
- Awareness of custody issues be included in funding patterns, child welfare laws, and professional education; and
- Funding be established for research regarding custody issues.

A general recommendation of the work group was to create a national policy to provide needed services for children and families, regardless of categories of service or diagnostic labels.

***FOR MORE INFORMATION***

For a copy of the full proceedings of the "Next Steps" conference or for additional information about issues affecting children with emotional disorders and their families, please contact:

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