DOCUMENT RESUME

ED 475 886 CG 032 340

AUTHOR Koyanagi, Chris; Boudreaux, Ron

TITLE The Federal Government and Interagency Systems of Care for

Children with Serious Mental Disorders: Help or Hindrance?

INSTITUTION Bazelon Center for Mental Health Law, Washington, DC.

Daze of one of the second series of the second seri

PUB DATE 2003-00-00

NOTE 18p.

AVAILABLE FROM Bazelon Center for Mental Health Law, 1101 15th St, NW, Suite

1212, Washington, DC 20005. Tel: 202-467-5730; Fax: 202-223-

0409; Web site: www.bazelon.org. For full text:

http://bazelon.org/

issues/children/publications/helporhindrance/

helporhindrance.pdf.

PUB TYPE Reports - Descriptive (141)

EDRS PRICE EDRS Price MF01/PC01 Plus Postage.

DESCRIPTORS Access to Health Care; *Agency Cooperation; *Children;

*Delivery Systems; *Emotional Disturbances; Federal Programs;

*Mental Disorders

ABSTRACT

Children with serious mental or emotional disorders require a range of services and supports, as do their families. Yet fragmentation of services and conflicting program rules have long impeded children's and families' access to needed care. This issue brief examines how federal programs and rules have contributed to this fragmentation and explores ways to harmonize some of the differences between them so as to foster coordination of the services and supports needed by each child and family. In addition to funding a range of categorical programs, the federal government, through the Center on Mental Health Services, the Maternal and Child Health Bureau and other agencies, promotes a systems-of-care approach. Systems of care require the major child-serving agencies to collaborate in order to ensure that each child and family has a single plan of care detailing services to be provided and that these services are funded in a coordinated way. Target populations for these systems of care vary at the state and local level. Some focus on children with serious mental disorders and others on a broader group of children. This issue brief focuses on the needs of children with mental disorders within a system of care, regardless of the population of children included within that system. (GCP)

The Federal Government and Interagency Systems of Care for Children with Serious Mental Disorders: Help or Hindrance?

by

Chris Koyanagi

with Ron Boudreaux

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

- 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.

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL HAS BEEN GRANTED BY

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

The Federal Government and Interagency Systems of Care for Children with Serious Mental Disorders: Help or Hindrance?

CONTENTS

Introduction

The Bazelon Center's Study

Findings

Problems Identified as Facing State And Local Officials

Federal Program Barriers

- Eligibility
- Assessment
- Early intervention
- Family-focused sevices
- Data collection and reporting
- Collaboration
- Advisory groups
- Training

Recommended Federal Policy Improvements

- Mission and Goals
- Federal Innovations

Changing Current Federal Rules

- Eligibility and Assessment Rules
- Improving Early Intervention
- Expanding Family-Focused Care
- Ensuring Accountability Across Systems: Data and Reporting
- Eliminating Overlap in Planning and Advisory Groups
- Flexibility in Federal Training Funds
- Federal Technical Assistance

Conclusion

Notes

INTRODUCTION

Children with serious mental or emotional disorders require a range of services and supports, as do their families. Yet fragmentation of services and conflicting program rules have long impeded children's and families' access to needed care. This issue brief examines how federal programs and rules have contributed to this fragmentation and explores ways to harmonize some of the differences between them so as to foster coordination of the services and supports needed by each child and family.

All states have targeted these children and families under various programs run through a number of child-serving agencies, including mental health, education, child welfare, juvenile justice and substance abuse systems. States can receive aid to provide services to children through several different federal programs. Some of these programs target children with mental or emotional disorders and others address the needs of a wider group of children.

Federal support for these state and local initiatives is essential, but it comes with requirements and restrictions. The federal programs are based on a categorical approach that separates resources and targets them to specific purposes. Each system has its overall objective—e.g., child welfare, to protect, and school systems, to educate—and federal resources must be tied to this objective. Federal programs also have rules on eligibility, program management and allowable uses of funds, which differ from program to program.

State and local officials often complain that the result is unduly burdensome. Federal programs are not flexible enough, they say, to enable state and local governments to meet children's needs in a sensible way. However, federal policymakers and advocates point out that each federal program is designed to remedy the unmet needs of a specific population of children and certain rules are necessary to ensure that the funds are spent appropriately. They note that the federal government has a legitimate concern that states and localities be accountable for the taxpayer funds they receive.

In addition to funding a range of categorical programs, the federal government, through the Center on Mental Health Services, the Maternal and Child Health Bureau and other agencies, promotes a systems-of-care approach.





ABOUT THIS ISSUE BRIEF

© Judge David L. Bazelon Center for Mental Health Law, Washington D.C., February 2003. Reproduction of this issue brief all or in part is authorized for noncommercial advocacy or educational purposes with full attribution to the Bazelon Center for Mental Health Law.

The brief was written by policy director Chris Koyanagi with the assistance of Ron Boudreaux, Ph.D., consultant, and edited and designed by communications director Lee Carty. Its development and production were funded by the William T. Grant Foundation, with additional support provided through the Bazelon Center's general program by the John D. and Catherine T. MacArthur Foundation, the Evenor Armington Fund and the Public Welfare Foundation.

The Bazelon Center is the leading national legal advocate for adults and children with mental disabilities. Its mission is to protect these individuals' rights to exercise meaningful life choices and to enjoy the social, recreational, educational, economic, political and cultural benefits of community life. The staff uses a coordinated approach of litigation, policy analysis, coalition-building, public information and technical support for local advocates to end the segregation of children and adults with mental disabilities and assure them of the opportunity to access needed services and supports.

BAZELON CENTER FOR MENTAL HEALTH LAW 1101 15th Street NW, # 1212 Washington DC 20005 (202) 467-5730 Fax: (202) 223-0409 www.bazelon.org

Systems of care require the major child-serving agencies to collaborate in order to ensure that each child and family has a single plan of care detailing services to be provided and that these services are funded in a coordinated way. Target populations for these systems of care vary at the state and local level. Some focus on children with serious mental disorders and others on a broader group of children. This issue brief focuses on the needs of children with mental disorders within a system of care, regardless of the population of children included within that system.

THE BAZELON CENTER'S STUDY

In 2001-2002, the Bazelon Center for Mental Health Law examined the federal government's role from the perspective of state officials responsible for children's mental health programming. We asked these officials if they had found federal rules a significant barrier to their efforts at interagency system reform to address the needs of children with serious mental disorders. If so, we then asked which programs and which rules they had found most troublesome and why. While many federal programs could be improved in a number of ways, this study focused on specific problems raised by existing rules, not on omissions in federal policy. Broader improvements in federal programs are beyond the scope of this report. Here, we recommend changes that would both meet the federal policymakers' desire for accountability and assist states and localities as they strive to meet the needs of children with serious mental or emotional disorders.

State mental health officials in 16 states were asked for their views in preliminary conversations. We then held follow-up conversations in depth with six state directors of child mental health services and 12 other officials from child welfare, education and juvenile justice agencies in the same states who were responsible for policies relating to children with mental or emotional disorders and their families. All six of these states already had strong interagency collaborations to improve delivery of services to children with serious mental or emotional disorders. We expected that these individuals, as officials engaged in innovative policymaking in states that clearly prioritized these children's needs, would be especially knowledgeable about barriers in federal rules.

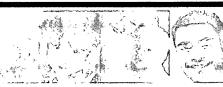
A few officials from the six states were then selected to participate in a twoday meeting to discuss their states' reforms and the impact of federal program rules on them. Officials from mental health, education, child welfare and juvenile justice agencies—the four core agencies that are normally part of system-of-care reforms for children's mental health - were invited. In all, nine state-agency officials participated in the meeting (five from child mental health, two each from child welfare and juvenile justice and one from education) along with two family advocates, one Medicaid representative and several national experts. This report

















is based primarily on this meeting, supplemented with information from the earlier phone conversations with officials from all 16 states.

FINDINGS

Overwhelmingly, the state officials reported, while barriers to strong and appropriate policies for children's mental health were many, only a few stemmed from federal program rules. A much more serious concern is the proliferation of programs—both federal and state—addressing the particular needs of subpopulations of children.

For policymakers, the creation of a wide variety of programs, each addressing a specific problem, makes eminent sense. Their constituents want government to address concrete problems, not the overall well-being of all children. They also want accountability for funds expended, and accountability is lost if programs become too broad in focus. However, this categorical approach means that each system deals with only some of a child's issues, while for each child and family the various issues are interrelated and inseparable. For example, a child with both a mental disorder and a substance abuse problem may be found eligible for services under either the mental health or the substance abuse block grant, but not for services through both. The failure of government programs to address the totality of a child's needs leads inevitably to complications that have to be overcome locally, when agencies attempt to coordinate the targeted federal programs to assist a group of children in need of mental health care.

The federal government, through this categorical approach, has created barriers to systems of care that have nothing to do with the rules in any one program. The fundamental problem is that the federal government appears to have developed no coherent cross-agency policy of its own and has not considered how its programs can complement each other to help a particular child.

In addition to this overarching barrier, state officials said that several program-specific barriers in federal rules (described below) work against their goals of interagency collaboration and systems of care at the local level. Our informants cited flaws in the most important funding programs of major childserving systems, notably Medicaid, Part B of the Individuals with Disabilities Education Act and Title IV-E child welfare. Removing those barriers at the federal level would be a good start toward easing the problems of states and localities striving for interagency systems of care.

Finally, it was apparent that many of the barriers about which local officials complain are erected at the state level. State officials in one system sometimes blame the federal government for rules that were, in fact, created by other state agencies (for example, mental health authority personnel complain about





A BAZELON CENTER ISSUE BRIEF

Medicaid rules). This type of confusion arises when a federal program's rules are particularly complex. Misinformation about mental health coverage under Medicaid abounds and it usually stems from assumptions that barriers created by state rules are firm federal barriers. Ironically, the federal programs, such as Medicaid, that give states considerable flexibility can result in significant barriers locally if states fail to take advantage of this flexibility.

Other state barriers stem from state agencies' efforts to avoid costs by shifting children into other systems or from efforts to protect their own agency's role (or turf)—for example, by refusing to collaborate with other agencies or by undermining collaborations that do exist.

PROBLEMS IDENTIFIED AS FACING STATE AND LOCAL OFFICIALS

Officials contacted through this study cited as particular problems the following issues regarding federal policy:

- Federal rules are complex and require considerable knowledge by local staff. Turnover in staff at the state and local level further complicates this problem.
- Differing eligibility rules cause conflicts between systems when states or localities bring them together to collaborate. This is especially problematic for children who are not considered "high end" or significantly impaired because this group of children is harder to define and because there is concern about how to define the group of children who need mental health services without covering an expansive and overwhelming number of children.
- The states create additional burdens for localities by building their own restrictions into federal programs or by failing to take steps that make maximum use of federal flexibility.
- States and localities have a tendency to interpret federal rules very conservatively out of concern that the federal government will later disallow certain costs.
- Federal rules restricting allowable costs can cause conflicts among state and local agencies when they attempt to collaborate if important activities or support services cannot be funded. For example, if transportation cannot be covered by one agency, even though it is necessary to deliver a covered service such as inhome care, it must be picked up through some other budget.
- Misplaced emphasis in certain federal programs on out-of-home placements. With supports, most families want and could keep their children safe in their own home. It is frequently more effective and more efficient to work with parents and children in their own home rather than in an artificial environment. Youth with mental health issues have difficulty transferring skills to different environments and it is preferable for them to learn and practice new skills in the environment where they must apply them.





Some of these issues are endemic to a political system that targets certain children as worthy of services and places a limit on the level and type of services for which government is willing to pay. Others, however, could be addressed by rethinking federal policies to support collaborative, interagency systems of care.

FEDERAL PROGRAM BARRIERS

Participants at the meeting focused particularly on three key federal programs—Medicaid, special education and Title IV-E child welfare services—and identified rules in those programs that hamper their efforts to develop local systems of care. Medicaid is now the most important source of financing for public mental health systems and Medicaid rules are extremely lengthy and complex. Special education, supported by the Individuals with Disabilities Education Act (IDEA), is potentially an extremely important source of services for children targeted by interagency collaborations, but very few children with mental and emotional disorders are able to access it. Title IV-E provides the bulk of federal support for child welfare systems and funds out-ofhome care, but does not encourage keeping children at home or ensuring that they can be successfully reunited with their families.

The various barriers in these and other federal programs cited during the meeting can be grouped into eight categories, as follows:

Eligibility

Eligibility in federal programs is based on financial standards, severity of the child's issues, age and sometimes other factors. Merging these different themes of eligibility locally is a challenge. For example, low-income children are eligible for Medicaid services and children with severe mental disorders (of any income level) for special education. Often, a child is eligible for one program but not the other. However, financing a comprehensive array of services is best accomplished by merging Medicaid and special education services and resources. Another significant barrier is that certain programs that purport to target the same or similar populations have widely varying eligibility requirements. For example, both schools and mental health systems use the term "serious emotional disturbance" but have very different definitions.

Assessment

Federal programs generally have specific requirements for assessments. While participants considered these requirements generally appropriate for each program, it is a problem when several federal programs all require a specific and additional assessment of the same issue - such as whether the child has a diagnosable serious mental disorder. Repeated assessments not only waste







resources, but they are administratively burdensome. Once a diagnosis is made, it should be acceptable across federal programs. Further problems arise when federal programs do not recognize the most appropriate instruments for making assessments and diagnosis of very young children.

Early intervention 3.

Across federal programs there is a general tendency to focus on children whose needs have become very high. Although the federal government has a few programs specifically for early intervention, the rules in the programs that provide by far the most significant funding do not encourage early intervention. Participants pointed out that even programs within the same system (Education) encourage early intervention at a young age (through Part C of IDEA), but leave the same children without services as they age (Part B of IDEA).

Family-focused services

Local programs address a child's broad needs in the context of the family. Some federal programs are specifically tailored to support this, particularly Part C of the IDEA. However, other federal programs, such as Medicaid, work directly against it by only funding services provided to the child (but not the family) when the parents are not themselves Medicaid-eligible.

Data collection and reporting 5.

All federal programs require reporting of certain data and each has its own rules on how to report. Individually, these data and reporting requirements may be quite reasonable and even helpful locally. However, when programs are brought together at the local level to serve a group of children, it can be very burdensome to meet the requirements for specialized data or to comply with different rules on how to report the same data in order to meet requirements in each of the federal programs. Data systems that states attempt to link include juvenile justice, child welfare, special education and Medicaid. These data systems, due to federal requirements in each program, do not have common identifiers and use different fields and definitions. It is therefore extremely hard, and often impossible, to pull them together to get the information necessary for effective interagency collaboration. Federal data reports also often focus more on individual children served or providers than on system results.

Collaboration

Cross-agency coordination has become a theme in federal categorical programs to such a degree that localities are now expected to devise special systems of care

















A BAZELON CENTER ISSUE BRIEF

led by various systems. Mental health, early education, substance abuse and Maternal and Child Health programs now all emphasize the development of systems of care. Federal rules for each of these systems are different and silos of systems of care may soon replace silos of categorical programs locally. Undermining true systems-of-care efforts are rules in the major federal funding programs, particularly Medicaid, that do not support collaboration. For example, Medicaid will not reimburse for team meetings regarding a child's service plan due to limitations on paying for consultation between providers when the patient is not present.

7. Advisory groups

Many federal programs require the creation of an advisory group to monitor or advise on program operations. For example: Part C of the IDEA mandates an interagency coordinating committee; the mental health block grant mandates a planning council; federal child care programs require a child care advisory committee; certain juvenile justice funds can only be obtained with a state advisory group. Federal requirements for all these groups are different with respect to membership and a balance between various interests, even though the groups' work often overlaps. At the local level, the number of individuals available to participate in advisory groups may be limited, but merging advisory groups is impossible due to the different requirements of each federal program, and so linkage between them, if it exists, is generally informal.

8. Training

Resources for training are a priority for local child-serving systems, and systems of care focus on cross-system and joint training for staff who work in various agencies. In contrast, federal rules on training are very categorical and preclude broad training initiatives that cross agencies or disciplines. For example, Title IV-E training funds are specifically linked to children in child welfare.

RECOMMENDED FEDERAL POLICY IMPROVEMENTS

If the federal government took steps to ensure that its rules were not acting as a barrier, participants at the meeting stated that this would greatly assist states and localities in building effective systems of care for children with mental health care needs. These steps are discussed below.

Mission and Goals

States are increasingly setting up interagency collaborations that focus on a shared mission, joint goals and integrated service delivery to children and





Example of State Interagency System of Care

The mission statement from the New Hampshire Children's Care Management Collaborative for Community Supports and Long-Term Care:

To ensure access to a full array of effective and efficient community-based services and supports for families with children and adolescents ages 0 to 21 who have or are at risk of serious emotional disturbance, developmental or educational disabilities, substance abuse issues or special health care needs. These services and supports will be culturally competent, family-centered, strength focused and available in the context of regional, multiagency systems of care bringing together both public and private providers with natural supports. Services and supports are designed to promote healthy growth and development, independence and active involvement of families as members of their chosen communities.

families across mental health, child welfare, juvenile justice and education systems. Such collaborations are at different stages in different states, but these joint approaches are uniformly the direction being taken by state child mental health policy.

There is considerable agreement across states on what these agencies' mission should be with respect to children's mental health needs, and the agencies are generally able to articulate goals across systems. For example, in most states child-serving agencies can agree that their mission is to ensure that children and youth live at home or in a placement in their own communities and receive services that meet their individual needs, maximize their strengths and use a collaborative team approach to care. Local systems of care established across the states seek to be child-, youth- and family-focused, culturally competent and outcome-oriented, and to provide comprehensive and individualized services through a single services plan with resources from any and all appropriate agencies. An example of a state mission statement on interagency collaboration for children is shown in the box.

At the federal level, however, each of the core agencies has its own mission. No collaborative process parallels the states' efforts, bringing these agencies together to forge a common federal mission and examine the goals of the different programs in light of this mission. Not only are program rules not designed to support such a common mission, they often work directly in opposition to each other, as illustrated above. It is important, though, to maintain the integrity of the specific programs, each of which arose to address particular unmet needs of certain subpopulations of children.

- The federal government should create a clear, all-encompassing mission and concrete goals and objectives that all of the major child-serving agencies can follow as they implement their programs. The population of children whose needs are addressed by such a mission should be those eligible for mental health services from federal programs. This target group allows for the inclusion of early identification and services, as well as efforts to address the needs of other children with serious mental disorders. The mission should focus on the outcomes desired for all children, such as: pregnant women and young children thrive; children are ready for school; children succeed in school; children live in stable, supported families; youth choose healthy behaviors and youth successfully transition to adulthood.
- Federal programs that encourage development of systems of care should suspend rules on payor of last resort, allowing greater flexibility in eligibility rules, provided the state has a jointly developed target population, and setting common measures of child and family outcomes.





Two Ways to Use Funds from Different Federal **Programs**

Blended funding pools have been used for many years; the concept of braiding funding is newer. Both approaches combine funds from different federal agencies or programs into a single funding stream so they can be used more easily at the point of service delivery.

- Blended funding: Funds are combined into a single pool from which they can be allocated to providers.
- Braided funding: Funds from various sources are used to pay for a service package for an individual child, but tracking and accountability for each pot of money is maintained at the administrative level. The funds remain in separate strands but are joined at the end of the "braid."

To local providers of care and for families, blended and braided funding streams should look the same. However, braiding avoids some potential difficulties with blended funding pools in that it recognizes the categorical nature of how we fund services in this country.

- The federal government should encourage blended and braided funding approaches and provide technical assistance to help states and localities implement them.
- Mandates for coordination at the state or local level should be uniform, so each locality can establish a single system of care and eliminate redundancy among the coordination plans and meetings required by each program. This would allow states to agree on a uniform structure and enable all agencies to work to accomplish common outcomes. It would also reduce agency staff meetings and the number of specific system of care plans while clarifying resource needs concepts.
- To support a mission of collaboration and systems of care, federal agencies should jointly review coverage of mental health services in the various federal programs and identify and adopt policies to close service gaps.

Federal Innovations

In addition to changing specific federal rules (see below), the federal government should create new interagency collaborations across federal agencies, similar to the interagency collaborations it so often mandates or encourages at the state and local level. This collaboration should foster greater blending or braiding of federal funds. While some fledgling interagency collaborations already exist, much more could be done.

- Federal agencies should come together to pool resources from their demonstration program funds and make them available to state and local collaborations that target children involved with more than one system. For example, the Department of Education and the Center for Mental Health Services (CMHS) might collaborate to test new and improved school-based mental health services for children, including services for children who have serious mental disorders.
- Federal agencies should come together to establish common indicators for the set of outcomes delineated in the new federal mission statement (see above). These measures would cross federal agency responsibilities. For example, to measure whether children live in stable supported families, indicators might include: Percentage of children living in families receiving food stamps; rate of child abuse and neglect; out-of-home placement rate; percentage of child support paid and average median family income. Greater emphasis on outcomes should coupled with relaxation of the level of detail required in federal reporting. This would enable states to capitalize on their unique strengths and assets to reach desired outcomes.
- A federal approach should be created to encourage and fund case managers to operate in and across the various systems. Families often find themselves with several case managers, each responsible for coordinating their child's care in a





different context. A single approach to training, standard-setting and casemanager certification across systems, together with a way to pool existing funds that pay for case management, could help to eliminate this.

- A new federal Systems Collaboration Reward Grant should be established, funded with appropriations from the four core federal agencies. Grant funds should be provided to states that have memoranda of understanding between their own four core agencies and can show that substantial resources (cash and/or in-kind staff time) have been committed by each agency to address children's mental health care needs (as defined by the state) through a coordinated system
- The Substance Abuse and Mental Health Services Administration (SAMHSA) should provide clear guidelines to states and localities on how funds from both the mental health and the substance abuse block grants can be braided to meet the needs of individuals who are eligible for services from both block grants.

CHANGING CURRENT FEDERAL RULES

Eligibility and Assessment Rules

Common terminology and greater compatibility are needed across eligibility rules and assessment requirements. Medicaid covers any child with a diagnosable mental disorder; the federal mental health block grant can be used for children with "serious emotional disorders"; and special education funds services for children with "emotional disturbance" who cannot benefit from their education. These are very different groupings of children.

It may not be possible for all federal programs to have the same eligibility criteria because to do so may de-emphasize the necessity of targeting particular at-risk groups. Nevertheless, the term "emotional disturbance" should have the same meaning regardless of the federal agency that uses it. Children who need mental health services should be a single, identifiable group at the local level, not a group of varying size depending upon which federal program rule is in play. Children with serious mental or emotional disorders should, similarly, be an identifiable group and inclusion in that group should open the door to the level or type of services needed by a child whose mental health problem has a major impact on his or her ability to function and succeed.

State officials contacted through this study recommended changes to several federal programs in order to improve eligibility determinations across systems and programs:

 Review federal programs and develop, to the extent feasible, a common dictionary of terms across programs. Terms that particularly need to be more consistent are "emotional disturbance" and "case management."







BAZELON CENTER ISSUE BRIEF

- Change the definition of "emotional disturbance" in the IDEA so it more appropriately aligns with the definition of mental disorders used in mental health systems. This change would address the large and growing gap between prevalence estimates of children with serious mental disorders and extreme or significant functional impairment and the number of children identified for special education and related services under Part B of the IDEA. Although some states have significantly higher identification rates than others—rates range from 0.10% to 1.92%— even the states with the highest rates identify less than a third of the 5% of children estimated to have an extreme functional limitation. Two thirds of the children with extreme functional impairments and serious mental disorders are now expected to succeed in school without access to the IDEA's services. Changes need to be made to the inappropriate federal definition of emotional disturbance by dropping the language that excludes children based on the undefined and unscientific term "social maladjustment" and making other changes to the definition that have been recommended by professional groups.²
- Amend Medicaid rules to allow infants, toddlers and very young children to qualify for mental health services through an assessment appropriate to their age. State Medicaid systems (primarily due to reporting requirements) now must use either the ICD or DSM diagnostic systems. Very young children can be far more accurately assessed in terms of developmental delay. Other more flexible and appropriate diagnostic systems for very young children have been established or are under development that would identify infants and toddlers who need (and whose families need) mental health services.3
- Consider as having a mental disorder the children in all systems who are assessed as having a disorder that meets the criteria for a DSM diagnosis. A child should not have to be assessed by numerous other agencies to establish the existence of the disorder. Further assessment should focus exclusively on determining other eligibility factors, such as, for education systems, the impact of the disorder on the child's ability to succeed in school and, for the Medicaid program, low-income status.

Improving Early Intervention

The Surgeon General has highlighted the growing importance of early intervention to address mental disorders in children. States, too, are focusing on identifying children who exhibit problems early and addressing their needs. In addition to more appropriate assessments of very young children, services are needed by children of all ages before their disorder escalates into crisis. Years of neglect are hard to overcome as children fall behind in school, fail to develop appropriate social skills and develop behaviors that become ingrained.

Early intervention is encouraged in Part C of the IDEA but in many other federal programs it is actively discouraged. For example, mental health block







grant funds must be targeted to children whose disorders are already serious. Too often, even children with serious disorders are not served until the situation reaches crisis level. Among changes that would facilitate earlier intervention:

- Permit Title IV-E child welfare funds to be used to provide services to children who are still at home but who are at imminent risk of out-of-home placement. Currently, the federal government spends nearly \$5 billion on services for children in child welfare out-of-home placements, but only \$300 million to keep children with their families. No state has been able to use the waiver authority to readjust these priorities. Moreover, it is becoming more difficult and more expensive to find sufficient numbers of skilled foster parents for larger numbers of youth with increasingly severe mental health problems.
- Encourage the provision of mental health services in schools before a child's disorder becomes so serious that he or she qualifies for special education. It is easier, less expensive and more effective to help a child succeed in school when the problem is first noticed than to wait for months or years until the child has repeatedly failed, as is often the case.
- Improve identification and assessment of children who qualify for special education due to mental disorders at an early age. While these children are identified by their families and often by other child-serving systems prior to or soon after they enter kindergarten, schools do not identify them, on average, until age 10. By then, negative school experiences have often undermined children's belief in their ability to succeed. These delays create frustration for the child, teachers, parents and often other classmates and increases the likelihood of the child dropping out of school. It also can result in lowering a school's performance rating.

Expanding Family-Focused Care

Best practice in children's mental health recognizes that children are part of a family, and that the family's functioning is key to the ability to improve the mental health status of a child with a serious mental disorder. However, few federal programs recognize this and, as a result, these programs work against the efforts of local systems of care to furnish family-focused care. For example, while the 1997 reauthorization of the IDEA emphasized family partnerships and family participation under Part B, this is not the family focus emphasized in Part C. Participants in the meeting particularly recommended:

- Clarification of Medicaid rules regarding family education and training when a child has a serious mental disorder so that families can have access to some of the same supports offered to therapeutic foster families.
- Changing Medicaid rules for services to very young children (0-6) to permit mental health and substance abuse services for the caregiver as well as the child,

THE FEDERAL GOVERNMENT: HELP OR HINDRANCE TO SYSTEMS OF CARE





provided that such services are expected to have a beneficial effect on outcomes for the child.

- Amending Part B of the IDEA to allow continuation of family services furnished to children who have been eligible under Part C at least until the child reaches a more mature age—perhaps until leaving grade school. Better results are more likely if services operate on the basis of a functional/developmental reality rather than on the basis of a calendar. Allowing for the possible continuation of family services could increase the likelihood of better outcomes.
- Amending the federal mental health block grant to make it explicit that children's services can be furnished to the "child and family."

Ensuring Accountability Across Systems: Data and Reporting

Federal agencies should work together to develop a unified approach to accountability, data needs and data reporting for state and local systems providing mental health services to children.

- Federal programs should all encourage the provision of evidence-based services and best practices in mental health services delivery. No federal program should deny payment for evidence-based care; reimbursement schemes should discourage provision of ineffective care.
- Federal data-reporting systems should focus more on outcomes of federally funded programs and less on measuring minutiae of service delivery. Federal agencies should collaborate to provide more assistance to states and localities on appropriate performance and outcome measures and how they can be measured across systems.
- Federal funds for developing management information systems should permit the blending of resources locally so that a single cross-agency MIS can be developed in place of categorical data systems.
- While much data may be needed for particular federal programs, uniformity in terms and formats for data collection and data reporting should be developed. This would greatly aid state and local systems of care.

Eliminating Overlap in Planning and Advisory Groups

Many federal programs now require interagency planning groups and ask for evidence of local or state coordination. While well-intentioned, too many such requirements simply result in multiple coordinating bodies. Furthermore, while federal agencies should not reduce the number of advisory groups or alter their purposes, more flexibility with respect to participating individuals would be of great assistance to local systems of care.

• Federal programs that require interagency planning and collaboration need to take into account other similar federal requirements. Local applicants should have the flexibility to demonstrate that an existing interagency collaborating body

THE FEDERAL GOVERNMENT: HELP OR HINDRANCE TO SYSTEMS OF CARE





can fulfill (or be adapted to fulfill) the purposes of the federal program, even though its composition may differ somewhat from the requirements in that particular program. Similarly, in submitting its plan for a federal program, a local interagency collaboration should have flexibility to justify approaching the federal planning mandate in an alternative manner.

- Requirements that percentages of advisory groups be drawn from particular constituencies should have flexibility. A single group at the local level would then sometimes be able to fulfill a similar role for two different federal agencies. Percentages of families, youth or advocates for children and families should not be weakened, but there could be flexibility with respect to representation of providers or agency personnel.
- Federal program rules should be relaxed so as to permit funds to be used to compensate families for participating in advisory groups.

Flexibility in Federal Training Funds

Very few federal programs support training of workers in systems of care for children with mental health care needs. One is the Title IV-E training program. However, this program's rules tie its funding to the number of children in foster care to be served. This restricts its usefulness when services are furnished through an interagency system of care instead of in a categorical manner.

 Title IV-E should be amended to permit the training of interagency and interdisciplinary teams.

Federal Technical Assistance

The federal government should give more attention to state and local officials' need for technical assistance when they use the funds made available through various federal programs. Specifically:

- The federal agencies should develop technical assistance materials that address how funds from particular programs can be used. The myths that spring up at the state and local level on perceived, but unreal, barriers in federal rules need to be dispelled.
- Federal agencies should designate a point person for each federal program, who can be available to answer questions by state and local officials who are working together to develop a systems of care approach across agencies.
- Technical assistance materials should be developed on how states and localities can use multiple federal resources in a collaborative and coordinated way. For example, a recent manual from the Centers for Medicare and Medicaid Services (CMS) described home- and community-based services for individuals with disabilities under Medicaid. The inclusion of home- and community-based service rules for other child-serving systems might illustrate to states and

THE FEDERAL GOVERNMENT: HELP OR HINDRANCE TO SYSTEMS OF CARE









BAZELON CENTER ISSUE BRIEF

localities how to build systems of care for children that make the most effective and efficient use of federal funds.

CONCLUSION

The many complaints from states and localities that federal programs are a barrier to their efforts are not always accurate. Some barriers are erected at the state or local level, for various reasons; others exist because officials do not understand the extremely complex federal rules. However, as described in this brief, several major barriers result from the federal rules themselves in programs that provide significant funding for services to children with mental health disorders. Since these programs are critical to the effective financing of interagency systems of care, even a few barriers here have a serious impact.

Perhaps more important than specific rules that are problematic, however, are the conflicts between federal programs. Issues that run counter to state and local objectives and the ability to provide effective care with good outcomes include differing eligibility rules in programs that purportedly target the same population of children, duplicative assessment requirements, multiple interagency system-planning bodies with similar (but not quite the same) assignments, complex and overlapping data-reporting requirements and programs that focus narrowly on the child, ignoring the family's issues.

Resolving such issues is not an easy task, but a start could be made by adoption of the suggestions outlined above. According to state officials contacted for this study, such changes would be very well received at the state and local level.

THE FEDERAL GOVERNMENT: HELP OR HINDRANCE TO SYSTEMS OF CARE





NOTES

- 1. In the Department of Health and Human Services: Substance Abuse and Mental Health Services Administration and Administration on Children, Youth and Families. In the Department of Education: Office of Special Education and Rehabilitative Services. In the Justice Department, the Office of Juvenile Justice and Delinquency Prevention.
- 2. Bazelon Center for Mental Health Law, Failing to Quality: The First Step to Failure in School?, A Bazelon Center Issue Brief, January 2003.
- 3. The DSM-IV is currently being adapted for very young children and an alternative diagnostic system, Zero to Three, is already available.
- 4. U.S. Department of Health and Human Services. Mental Health: A Report of the Surgeon General. Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.
- 5. The appropriation for Title IV-E of the Social Security Act for children in foster care was \$4.885 billion in FY 2002 while appropriations for Title IV-B for the Promoting Safe and Stable Families Program that funds services so children can remain with their families was only \$305 million for FY 2002.

THE FEDERAL GOVERNMENT: HELP OR HINDRANCE TO SYSTEMS OF CARE















U.S. Department of Education



Office of Educational Research and Improvement (OERI)

National Library of Education (NLE)

Educational Resources Information Center (ERIC)

NOTICE

Reproduction Basis

X	This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.
	This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").

