STAYING TOGETHER

Preventing Custody Relinquishment for Children's Access to Mental Health Services

A Guide for Family Advocates

Bazelon Center for Mental Health Law
and the
Federation of Families for Children's Mental Health

November 1999

THE BAZELON CENTER FOR MENTAL HEALTH LAW is the leading national legal advocate for adults and children with mental disabilities. Since its formation as a national nonprofit organization in 1972, the Bazelon Center has successfully challenged many of the barriers to dignity and choice that confront people with mental illness or mental retardation. Through precedent-setting litigation, in the public-policy arena and by assisting legal advocates across the country, the center works today to clarify and uphold the rights of adults and children with mental, emotional or behavioral disorders who rely on public services and ensure them equal access to health and mental health care, education, housing and employment.

THE FEDERATION OF FAMILIES FOR CHILDREN'S MENTAL HEALTH is a national parent-run organization focused on the needs of children and youth with emotional, behavioral or mental disorders and their families. The Federation's mission is to: provide leadership in the field of children's mental health; address the unique needs of children and youth with emotional, behavioral or mental disorders from birth through transition to adulthood; ensure the rights to full citizenship, support and access to community-based services for children with mental health needs and their families; and provide information and engage in advocacy regarding research, prevention, early intervention, family support, education, transition services and other supports needed by children and youth with emotional, behavioral or mental disorders and their families.

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FOREWORD AND ACKNOWLEDGMENTS

Many children in this country are uninsured or underinsured for mental health care, and those who have coverage often can't access the care they need. When private or public insurance will not pay for intensive mental health services, parents face a painful dilemma: If they want treatment for their children, they must relinquish custody to the child welfare system. We believe parents should never be asked to sever ties with their children to get help.

Recent studies confirm that the practice of requiring custody relinquishment is widespread, occurring in at least half of the states and affecting about one in five families of children with serious emotional disturbance, according to the National Alliance for the Mentally Ill. The Bazelon Center and the Federation of Families for Children's Mental Health urge family organizations and child advocates to join in a campaign, using this guide, to press for an end to custody relinquishment. In this booklet, we offer suggestions for making change happen, with examples of several types of programs used by states that have reduced the incidence of this egregious practice. A list of additional resources appears at the end.

Because many of the decisions with respect to children's services are made at the state level, we focus on state-based initiatives and advocacy. Excerpts from several state statutes are included in the appendix. However, recognizing that some advocates may also wish to work at a national level, a fact sheet on federal policy proposals is also included.

The guide was written by Mary Giliberti, director of the custody relinquishment project at the Bazelon Center, and Trina Osher, policy coordinator for the Federation of Families, in consultation with Chris Koyanagi, Bazelon Center policy director. It is based on research conducted by Ms. Giliberti and consultant Rhoda Schulzinger. We appreciate the legal support provided by intern Carolyn Frantz and the pro bono assistance of the law firm of Skadden, Arps, Slate, Meagher & Flom, as well as the administrative support of Gwen Ewing and Mark Wilger of the Bazelon Center staff. Lee Carty edited and designed the publication.

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Robert Bernstein, Executive Director
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A Guide for Family Advocates

WHAT IS THE PROBLEM?

Barbara's daughter Terry, 16, has severe attention deficit and hyperactivity disorder (ADHD). As she began having more and more serious problems at school, the school started calling Barbara almost every day to come and get her daughter. Sometimes Barbara was so frightened by Terry's violent behavior that she called the police.

Barbara sought mental health services for her daughter, but everywhere she turned she was told that nothing was available in her community. Over time, the situation got worse, until Terry had to be hospitalized for psychiatric care. Desperate, Barbara turned to the child welfare system. Reluctantly, she agreed to give the state custody of her daughter in hopes of finally getting the help the child needed.

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Terry's hospitalizations became increasingly frequent. But now Barbara wasn't allowed to make any decisions about her daughter's care or about where she lived or went to school. Yet she still had to attend all the meetings required by the child welfare system, taking so much time off from work for these that eventually she lost her job. Now Barbara and Terry are in dire straits, with no income and no health insurance—a plight they could have avoided if they had had access to mental health care and support early on.

Simply stated, the problem is that children with serious emotional disturbance do not have access to adequate mental health services and supports in their communities, and many families are forced to give up custody to the child welfare system to get help. Parents are then deprived of the authority to make medical, educational and other important decisions about their children's lives.

In several states, families who have relinquished custody of their children to get essential services and supports are even required to pay the state for the child's care—much like child support in a divorce. Furthermore, custody relinquishment makes

it much more difficult for families to bring up their children consistently with their values. Instead, the child may be raised by staff in a residential facility or by a foster parent who may have different cultural values or practice a different religion. Ironically, the foster parents get the very same services and supports denied the child's parents.

WHY DOES IT HAPPEN?

Custody transfer happens because children with mental health needs and their families cannot get the services and supports they need in their communities. This can occur for several reasons.

- Private health insurance plans often limit the number of hospitalizations and therapy visits they cover. Many don't cover intensive home-based services or residential treatment centers at all. As a result, a child's benefits are quickly exhausted.
- Publicly funded services are insufficient or unavailable. Although the Medicaid program requires states to provide any medically necessary Medicaid service, including any mental health service the child needs, some states do not fully implement the law, so low-income children who qualify still don't get help. And families with moderate and higher incomes are not eligible for Medicaid.
- Intensive treatment (whether at home or in hospitals and residential treatment centers) is very expensive. The vast majority of families can't afford it.

When services are not available from mental health centers or other local providers, or are unaffordable, families are advised to call the child welfare system to access residential care. At this point, parents are so desperate they seek residential services as the only way to get the specialized help their child and family need. But child welfare systems generally pay for services only for children and youth who are in their custody.

As a result, although the child welfare system could work out a voluntary agreement that would allow parents to remain involved in making decisions for their child, most child welfare agencies require parents who need services to relinquish custody of their child to the state. These officials mistakenly believe that they must take legal custody to qualify for the matching funds from the federal government that cover some of the costs of the child's room and board.

HOW WIDESPREAD IS THE PROBLEM?

The Bazelon Center for Mental Health Law has studied this problem in depth. We contacted advocates and affiliates of the Federation of Families, who reported that custody transfer is a problem in about half of the states. This may be an underestimate because we did not get responses from every state.

Custody relinquishment happens in at least half of the states and affects approximately one in four families of children with serious mental health needs

The states where families reported they are most often required to relinquish custody include Colorado, Indiana, Iowa, Nebraska, Tennessee and West Virginia. Families are also asked to relinquish custody in Arizona, southern California, Florida, Illinois, Kansas, Kentucky, Louisiana, Maryland, Michigan, Missouri, New York, Ohio, western Pennsylvania, Texas and Utah. Furthermore, families report they are asked to relinquish custody to get services for their children in Connecticut, Maine, Minnesota, North Dakota

and Oregon, even though these states have statutes to address the practice.

Recently, the National Alliance for the Mentally Ill released a report based on a survey of parents of children with serious emotional disturbance. Nearly one fourth of parents reported being advised to give up custody of their child to access mental health services, and one in five families did so. Other studies confirm the problem's nationwide scope.

WHAT IS THE SOLUTION?

The solution is both simple and complex. It is simple because there are two clear goals:

- to prohibit child welfare agencies from requiring custody relinquishment for families to get services and supports for children with significant mental health needs, and
- to prevent families from having to turn to the child welfare system for help by expanding access to home- and community-based mental health services and supports through the mental health care system.

The solution is complex because each state has its own laws and policies and because there are many ways to achieve the two goals. To fix the problem in any state, it is important to choose solutions that will accomplish *both* goals.

Prohibiting custody relinquishment without expanding mental health services and supports could result in more families' being directed to child welfare, and child welfare systems tend to place children out of their homes, often far from their communities. Similarly, focusing solely on expanding mental health services and supports will still force families who don't know where to access services or who don't meet the eligibility criteria for services to give up custody to get public assistance for their child's mental health care.

State policymakers and legislators need to be educated that a package of changes is needed to really fix the problem instead of just putting a Band-Aid on it.

Excerpts from state statutes appear later in this booklet, so advocates can pick and choose what meets their state's needs. Below are examples of the different approaches and issues to consider in evaluating what will best resolve the issue.

GOAL: Prohibit child welfare agencies from requiring parents to relinquish custody only for the purpose of getting necessary mental health services and supports for their child.

This goal is usually achieved through a state law prohibiting the child welfare system from requiring relinquishment as a condition for receiving mental health services. For example:

- Eleven states have passed laws specifically preventing parents from being forced to relinquish custody of their children solely to get treatment. They are: Connecticut, Colorado, Idaho, Iowa, Maine, Minnesota, North Dakota, Oregon, Rhode Island, Vermont and Wisconsin. The statutory language appears in a chart at the end of this booklet.
- Seven of these states use a "voluntary placement agreement." This is a written legal agreement that a parent signs. It allows the state to provide mental health treatment for children in out-of-home placements without the state's having legal custody. Although these laws prevent custody relinquishment, they may force families to place their children in out-of-home placements. For example: Rhode Island's statute specifies that:

"There shall be no requirement for the department to seek custody of any child with an emotional, behavioral, or mental disorder or developmental or physical disability if such a child is voluntarily placed with the department by a parent or guardian of the child for the purpose of accessing an out-of-home program for such child . . . "

- Iowa, Minnesota and Wisconsin have enacted laws giving the court power to order treatment for children both in and out of home, while prohibiting the child welfare agency from taking custody.

Iowa's statute, for example, requires that the petition for voluntary placement of a child with a disability describe the reasonable efforts that were made to keep the child in the home. The statute also gives the court the ability to order available services to the child and the child's family.

● Advocates in Pennsylvania have proposed a statute that would give the court power over all agencies that deal with children and ensure that children are served in their communities whenever possible. The draft language is very comprehensive; selected text appears in the chart on pages 20-21.

Advocates may want to combine some of the best ideas from these statutes and the others excerpted on lages 17-28. For example, Iowa's statute is exemplary because it specifies that all efforts should be made to keep children in their family home. Pennsylvania's draft statute would give courts authority to order all needed services from *all* of the agencies responsible for providing services to the child.

CAUTION! When modifying state laws that deal with custody transfers, don't forget to exempt these children from the new timelines in the Adoption and Safe Families Act. These timelines are designed to speed up adoptions by quickly terminating parents' rights. Minnesota is the only state with a law exempting children with disabilities from the strict timelines designed to move children into permanent placements. Minnesota requires termination of parental rights if a child has been in out-of-home care for 15 of the past 22 months for all children who are placed in out of home care—but only for reasons other than the care or treatment of the child's disability (see page 20).

Statutes dealing with the child welfare system work particularly well in states with well trained and knowledgeable juvenile court judges.

Advocates considering promotion of a statute dealing with the child welfare system should first evaluate the quality of their juvenile court because judges are important to the success of this scheme. These solutions work particularly well in a state with well trained and knowledgeable juvenile court judges. Where that is not the case, advocates may want to explore some of the options listed below.

GOAL: Expand home- and community-based mental health services for children and their families

Improving access to services and support through the mental health system is necessary so that families won't even have to come in contact with the child welfare system and juvenile courts, eliminating the possibility of relinquishment proceedings or court orders for services. Both child welfare agencies and courts are used to working with parents who have mistreated their children. As a result, they often view families as contributing to the problem. Furthermore, going to court is an intimidating and humiliating experience for families and children.

Expand Medicaid Coverage

Advocate for your state to take advantage of several ways Congress has allowed states to expand Medicaid coverage to families who would not normally qualify because of their income. States can adopt an "option" or apply for a "home- and community-based waiver."

An option gives states the opportunity to add certain groups of people to their Medicaid program beyond those they have to cover. One of the choices

is to cover children who would be eligible for Supplemental Security Income (SSI) because of their disability but who, under normal Medicaid rules, would have to live in an institution to get their medical care paid for by Medicaid. This is known as the "Katie Beckett" option.

Katie Beckett was a technology-dependent child (now a young adult) who was placed in an institution in order to qualify for Medicaid. While she lived in the institution, only her own income was counted, so she qualified for Medicaid. But when Katie lived at home, her parents' income was counted and she was not eligible for Medicaid benefits. Because her parents could not afford to pay to meet her extensive health care needs, Katie was forced to live in a residential care facility.

Congress passed a law allowing states to cover children like Katie under Medicaid without forcing them to live in an institution. The option is also called the TEFRA 134 option because it was enacted under section 134 of the Tax Equity and Fiscal Responsibility Act of 1982 (Pub.L. No. 97-248). The law covers all children with disabilities, including children with serious emotional disturbance.

According to 1996 data from the Health Care Financing Administration (HCFA), 21 states have elected to use this option: Alaska, Arkansas, Delaware, District of Columbia, Georgia, Idaho, Maine, Massachusetts, Michigan, Minnesota, Missouri, Nebraska, Nevada, New Hampshire, Pennsylvania, Rhode Island, South Carolina, South Dakota, Vermont, West Virginia and Wisconsin.

HCFA does not know how many children with mental health needs have Medicaid benefits under the Katie Beckett option. However, families report that it is rare for a child with an emotional, behavioral or mental disorder to be covered. If your state is on the list of those using the option, there are several things you can do to enable more children with such problems to get these benefits:

- Ask your state officials if children with serious emotional disorders are being served and, of so, how many.
- If your state's Medicaid program is not serving these children, advocate for the development of clear policies and procedures for children with serious emotional disturbance to qualify for the Katie Beckett option.
- Advocate for outreach to parents of children with mental health needs. Family-run organizations should consider partnering with state Medicaid or mental health agencies to get the word out.
- Check with families who are getting Medicaid through this option to see if they are getting enough services and whether they are getting home-based services.

If your state is not on the list, advocate with your state legislature, Medicaid office and mental health agency to get the Katie Beckett option. Work with them to establish eligibility rules for children and youth with significant mental health needs. Then follow the recommendations above regarding outreach to families and tracking quality of services. Although the Katie Beckett option can be very helpful in gaining access to funds to pay for necessary home- and community-based mental health services and supports, it is limited to children who need a level of care equivalent to that provided in a hospital. In addition, while the option gets children and youth access to Medicaid, the range of services and

Congress has given states several ways to expand Medicaid coverage to families who would not normally qualify because of their income.

supports available will be limited by what the state Medicaid program offers. If your state does not fully implement Medicaid, it may not provide necessary home- and community-based mental health services. In such cases, the option loses its effectiveness.

The Home- and Community-Based Waiver

Another possibility is the home- and community-based waiver, which allows the state to bypass or ignore normal Medicaid rules to cover people with disabilities and expand the array of services for which Medicaid will pay. This waiver is also known as Section 1915(c) waiver because it is authorized under Section 1915(c) of the Social Security Act. It is designed to cover the cost of home- and community-based services for individuals who, without such services, would require a hospital level of care that would be paid for by Medicaid.

Under the home- and community-based waiver, states can choose to help a particular group, can add some services that their normal plan doesn't cover, and can limit how many people they will help. States apply to HCFA for a waiver.

Waivers covering children with serious emotional disturbance have been approved for three states: Kansas, Vermont and New York. These states provide Medicaid to children who would normally be ineligible because of their parents' income. As a result, families who would have had to relinquish custody to child welfare can get help through the state mental health agency without going to court.

Advocates should work with their state mental health and Medicaid agencies to encourage them to apply for the waiver. It is very helpful if the state agencies and the advocates work together to get legislative support for funding the waiver and to draft the application for a waiver. However, if necessary, advocates can also ask the legislature to order the state agency to apply. The Maryland legislature, for example, recently passed a statute requiring that:

"The Department [of Health and Mental Hygiene] shall apply to the Health Care Financing Administration of the Federal Department of Health and Human Services for a Home and Community Based Services Waiver under Section 1915(c) of the federal Social Security Act in order to receive federal matching funds for seriously emotionally disturbed individuals."

It is very helpful if state agencies and advocates work together to draft the application for a waiver and get legislative support for funding it.

The Maryland statute defined "seriously emotionally disturbed" as a condition that is

"1) manifest in an individual younger than 18 years of age or, if the individual is in a residential treatment center, younger than 21 years.

"2) diagnosed according to the current diagnostic classification system that is recognized by the secretary; and

"3) characterized by a functional impairment that substantially interferes with or limits the child's role or functioning in the family, school, or community activities."

In Kansas, families and advocates worked closely with the state mental health agency to get the funding for the home- and community-based services waiver program from the legislature. Families and advocates were part of a work group drafting the definitions of the services that would be provided to children on the waiver. The family advocacy group, Keys for Networking, also produced a booklet for outreach to families so they would know

about the waiver and the additional services.

The four services covered by Kansas' waiver are:
1) family training and support, which includes coaching and assisting the family to increase their knowledge and awareness of their child's needs, interpreting choices offered by service providers, explaining and interpreting policies, procedures and regulations that affect children living in the community.
2) wraparound facilitation/community support, which involves assessment of the child's and family's or caretaker's strengths and needs for community relationships and involvement This service also produces an individualized community-based plan to access and be part of informal community resources and develop relationships to help the child succeed in the community.
3) independent-living skills, which are designed to assist adolescents in acquiring, retaining and improving the self-help, socialization and adaptive skills they will need to reside successfully in community-based settings. This service includes budgeting, shopping and working, engaging in recreational activities with peers, peer-to-peer support and appropriate social and work skills.
4) respite care, which provides short-term and temporary direct care and supervision for children. The primary purpose is relief to families or caretakers of a child with a severe emotional disturbance. These activities include aid in the home, getting a child to school or program, and aid after school or at night, and/or any combination.

Although it is not perfect, the Kansas experience shows that the home- and community-based waiver can be an important tool in ending the practice of custody transfer to the state. School officials, family advocates in Kansas and others report that custody transfer has declined greatly since the waiver program started in January 1999. Advocates should be aware, however, that the waiver is limited to a specific number of slots. Also, for the waiver to succeed, services must be available in practice as well as on paper.

Create a system of care through legislation

Some states have passed a law creating local "systems of care" to provide community-based mental health services and supports for children and their families. These multi-agency systems often blend funding from several sources. Many of these statutes specify that custody relinquishment will not be required as a condition for receiving services. States that have used this approach include California, Georgia, Maine, Rhode Island, South Carolina, Vermont and Virginia.[1]

For example, Georgia has created the Multi-Agency Team for Children (MATCH) program. MATCH combines funds from child welfare, mental health and Medicaid to create a system of care for children with severe emotional problems. One of the goals of the legislation is to "preserve the sanctity of the family unit" and it specifically provides that "the receipt of services … is not intended to be conditioned upon placement of a child in the legal custody, protective supervision or protection of the Department of Human Resources [the child welfare agency]."

Many of the statutes creating systems of care specify that custody relinquishment will not be required as a condition for receiving services.

One of the problems with this approach in the few states that have tried it has been the need to fight each year for the dollars to support the program. Advocates for system-of-care solutions may

want to assess their ability to get funds appropriated by the legislature, both to start up the system and to sustain it over time. One possibility is to combine a system-of-care statute that has specific language against custody relinquishment with a requirement that the state apply for the home- and community-based waiver or, if the waiver has already been applied for, an appropriation of funds. The waiver will insure Medicaid reimbursement, giving the system more funds to serve children.

The main advantage of the system-of-care statute is that it avoids juvenile court and involves an interagency approach to the problem.

The main advantage of the system-of-care statute is that it avoids juvenile court and involves an interagency approach to the problem.

Enforce special education entitlements

The Individuals with Disabilities Education Act (IDEA) is a federal law guaranteeing all children with disabilities a free appropriate education. Children with mental health needs, however, are often not identified as requiring special education. And children who are identified often face great difficulty accessing services.

Any parent who is approaching the child welfare system for mental health treatment should be given information about the IDEA and how to request an assessment for services. Upon a parent's request, the school system must provide an assessment or request a due process hearing. A wide array of services should be available to children, including educational day treatment, in-school crisis and therapy services, vocational training, attendant care, a behavior-management program and other supports.

Advocates and school officials should work together to ensure that children with mental health needs are identified and have access to quality services because a good school program can help avoid the custody problem.

Enforce the Early Periodic Screening, Diagnosis and Treatment (EPSDT) mandate

Under EPSDT, Medicaid-eligible children are entitled to all medically necessary services to treat or ameliorate a health condition, including a mental disorder, even if the services would be optional for adults. A recent Bazelon Center study found that many states fail adequately to define their rehabilitation services, to educate providers about how to bill Medicaid for these services, or to make sure that Medicaid recipients know the array of services to which children are entitled.

In response to a federal class-action lawsuit, brought to stop the practice of custody relinquishment, Pennsylvania developed definitions and billing mechanisms for an extensive array of mental health services under Medicaid. The state issued bulletins describing the scope of the services, the provider qualifications and the payment procedures for residential treatment and community-based services. These help providers submit their bills and get payment for a wide array of rehabilitative services.

The services and supports most often provided include mobile therapy, therapeutic staff support, and the services of a behavior specialist. A 1994 state bulletin describes these services:

- **"Mobile therapy**, by definition, provides intensive therapeutic services to a child and family in setting other than a provider agency or office. Settings include the child's home, in particular,... the school, the church, the community center, a

neighbor's or extended family member's home, and other community settings....Core services include ... assessment of strengths and therapeutic needs of child and family... [and] provision of child-centered, family-focused, individual and family psychotherapy.

- **"Therapeutic staff support** services provide one-on-one interventions to a child or adolescent at home, school, day care, YMCA, emergency room or other community-based program or community setting when the behavior without this intervention would require a more restrictive treatment or educational setting.
- "The **behavioral specialist consultant**, in collaboration with other members of the treatment team, designs and directs the implementation of a behavior modification intervention plan....The behavioral specialist consultant identifies behavioral goals and intervention techniques, and recommends non-aversive behavioral change methods."

Advocates should work with state Medicaid and mental health agencies to get clear definitions and information on accessing and billing for services. A wide array of intensive community-based services should be available and the information should be widely distributed to providers and families. In Philadelphia, the managed care entity contracted with a family advocacy group, Parents Involved Network, to produce a guide describing the services available to families and how to access them.[2]

This solution is limited because it applies only to children with access to Medicaid. However, it's worth pursuing because that is a large group.

Ensure adequate children's mental health treatment under the Children's Health Insurance Program (CHIP)

The Balanced Budget Act of 1997 includes new federal funding for a child health block grant to the states. States may use these funds to expand coverage to children under the Medicaid program, to create or expand separate child health programs or to use a combination of the two approaches. According to the Health Care Financing Administration (HCFA), 49 states and territories have had their Children's Health Insurance Plans approved. As of June 1999, 23 states and territories have CHIP Medicaid expansion programs,[3] 15 states have separate state-designed CHIP programs[4] and 13 have a combination of Medicaid expansion and a state-designed program.[5]

Advocacy groups recommend that states adopt the Medicaid expansion because it offers the most comprehensive package of mental health services. However, of those who have created separate plans, California and Pennsylvania are covering a wide range of services and supports. For example, if a child meets clinical criteria in California, the plan covers "acute psychiatric inpatient hospital services; administrative day, residential treatment; crisis residential treatment; crisis intervention and stabilization; day rehabilitation and treatment; medication support; and case management."[6] If your state has a separate plan, advocate for a wide array of mental health services.

Clear definitions and billing procedures for EPSDT services can ensure availability of a wide array of services so that parents of Medicaid-eligible children won't have to relinquish custody.

CHIP can assist families who qualify so they do not have to relinquish custody to get services. However, even though the family-income limits are higher for CHIP than for Medicaid, many children still will not qualify because their family has too much income. A home- and community-based waiver or a Katie Beckett option would be needed for these children to qualify for Medicaid.

WHAT DOES IT TAKE TO MAKE THE SYSTEM CHANGE?

National efforts to fix the custody problem

National advocates for children's mental health have been trying to end the practice of requiring families to relinquish custody of their children in order to get the mental health services and supports their children desperately need. The advocates are calling for a comprehensive solution that help children and families early by expanding the services and supports they can access in their communities.

The Federation of Families and the Bazelon Center have begun discussions with supportive members of Congress about changing several federal laws to put such a comprehensive solution in place: Title IV-B (child welfare and family preservation), Title XIX (Medicaid) and Title XXI (child health insurance program) of the Social Security Act, Title XIX of the Public Health Services Act (mental health state block grant), and the Adoption and Safe Families Act. They are also seeking a requirement that HCFA establish mechanisms for counting children with mental and emotional disorders who participate in selected Medicaid programs and provide states with technical assistance and encouragement to use Section 1915(c) waivers to provide services and supports for children with serious emotional disturbances. A fact sheet used by the Federation of Families for Children's Mental Health to explain this approach is on pages 29-30.

Making change in your state

While these national efforts are important and the changes achieved through them will make a significant difference, many of the policy decisions about which children are eligible for certain services are made by state legislatures and state agencies. Therefore, state and local family-run organizations need to work on solving the custody problem in their state.

Becuse so many of the policy decisions are made by state legislatures and state agencies, local family-run organizations need to work on solving the custody problem in their state.

Many family members and advocates for children have a passionate desire to spare other children and families the same kinds of pain, disappointment and poor outcomes they experienced. Harnessing the power of this passion and dedicating the energy it generates to effective strategies for influencing public policy requires four steps:
1) getting clear about the problem and its solution; 2) mobilizing a network of supporters; 3) getting policymakers' and legislators' support; and 4) educating the public and the media.

1) Be clear about the problem and its solution.

Take a look at the general problem first, then get specific. Talk to others who have faced custody relinquishment and see what they have in common and where they have had different experiences. This will help you be as specific as possible about the nature of the problem and describe it accurately.

Next get copies of existing laws, regulations, and policies and analyze them to find out just how they contribute to the problem. For example, is there a state law that requires families to relinquish custody to access certain services? Or does the state child welfare agency insist on having custody of all children for whom they provide or pay for services? It could be that no law or state-agency policy requires families to relinquish custody but that the practice of social workers in local child-serving agencies is simply out of date. Understanding where the breakdown is will help you focus your efforts to find a solution.

Once you are clear about the problem and its source, you need to figure out what is necessary to correct the situation:

- Does a law have to be changed or is a new law needed?
- Should the state take steps to implement options or apply for a waiver to increase the pool of children eligible for Medicaid or expand services Medicaid will pay for?
- Does a state agency need to change its regulations to conform with the law?
- Or does a state agency need to better monitor implementation of the law or better educate providers and staff about their responsibilities?

Advocates may find the statutes and policies at the end of the guide helpful in generating ideas.

As the solution becomes clear, be mindful of its impact. Look for and evaluate unintended consequences of any proposal you consider. For example, prohibiting a state from taking custody for a child who needs residential treatment for a mental health problem is likely to prevent the destruction of families. But unless the mental health system is, at the same time, strengthened and given responsibility for providing these services, children who need mental health services will still be forced into the child welfare system when they should be getting help from the mental health system.

As the solution becomes clear, be mindful of its impact. Look for and evaluate unintended consequences of any proposal you consider.

Other states' experience can reveal potential pitfalls. The Federation of Families can help you connect with family-run organizations and advocates in other states (see the resource list on page 14).

Anticipate opposition and develop counter proposals. For every position from which someone benefits, there is likely to be someone or some group concerned about being harmed by the same policy. For example, in advocating for more home- and community-based children's mental health services, some providers of adult services may fear loss of funds for their programs. Advocates need to anticipate who is likely to oppose their proposals and understand what their objections will be.

2) Mobilize a network of supporters.

You can't change the system alone. It takes large numbers of advocates and coalitions of advocacy groups and other stakeholders—such as service providers—to generate support for a new policy. In

building a network, tap into existing support and information networks before re-inventing the wheel. For example, in addition to local affiliates of the national associations listed on page 14, get groups like the Learning Disabilities Association, the Chamber of Commerce and the Parent-Teachers Association to join you in a coalition. Use their networks to distribute information, locate families who are affected by the problem and create a telephone tree for contacting policymakers and legislators quickly when it is time to vote on a bill.

Seek support from individuals and service providers who will be affected by the policy change you are proposing. It is difficult to get legislative support for change when those who have to implement the change don't understand or support it. Even if the new policy is established, resistance by front-line staff who provide services could prevent the policy from having the desired effect.

Seek support from key agency heads who will be responsible for implementing the policy. Create opportunities to talk with state agency heads about the custody problem, explain your solution, and how it will help them do their job better as well. Ask them to give their support when they testify before the legislature. For example, if the policy you are proposing would prevent the child welfare system from taking custody of children who need mental health services and also require the mental health system to provide those services, the child welfare director is relieved of a burden (as long as the welfare budget remains intact) and the mental health director has an appropriately expanded sphere of responsibility and funding to do the job. Help agency heads see how this improves the situation and gives responsibility to those who have the most expertise.

3) Get policymakers' and legislators' support.

A new law needs a sponsor, and so do amendments to an existing law. Examine the records of your state legislators and find those—preferably in both houses—who will support your policy position. Meet with them, or their children's policy staff, to explain what you want to accomplish. Offer to help draft a bill and get support for legislation. Support their efforts to get other legislators on board by using your network to link key committee members with constituents in your coalition. And, remember to thank them *publicly* for taking the right position.

Change takes time and is usually incremental. Consider even small achievements to be victories and celebrate them.

Seek widespread bipartisan support. Offer to help organize and promote a public hearing sponsored by a legislator—and remember to gets lots of families and supporters to attend.

Hold a briefing for key committee members and the press. Find families and youth to testify and coach them to be effective. Use your most eloquent speakers to present your proposed solution.

4) Educate the public and the media.

Every politician pays close attention to public opinion. Generating broad public support for your proposal from people who are not directly affected but who are likely to believe in your cause will help a great deal. To draw attention to the problem, hold marches and vigils. To educate people about the problem and its potential solution, hold information fairs, arrange to make short presentations at luncheons for the garden club, the chamber of com-

merce, Rotary Club and other organizations. Consider discussing the issue at a brown-bag lunch at the local factory or ask the high school principal for a few minutes to talk at the next staff meeting.

If you don't already know them, get acquainted with local newspaper editors and TV newscasters. Ask them to feature personal stories that illustrate the problem and gain compassion for the victims of bad policy. Make sure to balance these "bad news" stories with other accounts that will illustrate the success of the proposed solution and get good press for the sponsoring legislators.

Gather good statistics about the problem and present solid facts in clear, straightforward graphics. Remember: a picture is worth a thousand words.

Make a poster that will get attention and put it all over town; include a number to call for more information. Show the data, state the problem and present the solution—linking it all with a concise human interest story.

Above all, keep your public messages simple. Make a case for the broad impact of change , such as how your proposal will ultimately result in less taxpayer expense for residential care and will return resources to the local community.

Closing advice about making change

Change takes time and is usually incremental. Policies are rarely changed on the first try. Stick with it, take change on as a mission, be patient, and expect setbacks. Know when to accept a compromise even if it falls short of your goal. Consider even small achievements to be victories and celebrate them. There is always another opportunity to move your agenda forward.

Once the policy proposal becomes law, follow through to make sure legislation is implemented. And make sure everyone gets credit for the success achieved.

WHAT HAPPENS WHEN SOLUTIONS ARE COMPREHENSIVE?

Two examples of change already achieved document the value of comprehensive solutions to the problem of custody relinquishment:

- Georgia adopted a comprehensive statute setting up an interagency system of care and prohibiting custody relinquishment to get services under the Act. Advocates report a significant decline in custody transfer as a result of the state's MATCH program.
- Kansas began a home- and community-based waiver program for children with serious emotional disturbance. The state tracked outcome measures, including the percentage of children who 1) remain in a permanent home; 2) have no contact with law enforcement; 3) have improved behavior as measured by clinically significant child behavior checklist (CBCL) scores; and 4) obtain A, B, or C grades in school. School attendance is also followed.

The children on the Kansas waiver were compared to children with mental health needs who received only case management. Although more of the waiver children had more severe illnesses, they generally had better outcomes than children who were receiving only case management services. Children served by the home- and community-based waiver did better on all other measures than their comparison group on all measures except the CBCL score and contact with law enforcement. The difference between groups on the law enforcement measure was only a few percentage points. The differences in CBCL scores reflected the fact that these children's problems were more severe.

In addition, Kansas stakeholders reported that the waiver was having a positive effect on outcomes for children. One special education director credited the waiver with decreasing the number of expulsions in his middle school by 50 percent. Families were generally very happy with the waiver services and reported that the services prevented custody transfers.

CONCLUSION

No family should ever be asked to give up custody of a child in order to get treatment for a mental health condition. Such a policy destroys families and adds to children's mental health problems. The solutions described above demonstrate that family advocates and state policymakers do not have to accept such inhumane practices as inevitable.

Several approaches are readily available, although, of course, the only complete solution is universal access to mental health treatment. The suggestions above are designed to help move toward that goal while significantly reducing the tragic and shameful incidence of custody relinquishment.

NOTES

1. Because this type of legislation involves many statutory provisions, only two examples (Georgia and Virginia)are excerpted in this booklet.
2. The guide can be obtained by contacting Parents Involved Network, Mental Health Association of Southeastern Pennsylvania, 1211 Chestnut Street, 11th floor, Philadelphia PA 19107 (215) 751-1800.
3. Alaska, Arkansas (plan not yet submitted, using a Medicaid waiver), District of Columbia, Hawaii, Idaho, Indiana, Iowa, Louisiana, Maryland, Minnesota, Missouri, Nebraska, New Mexico, North Dakota, Ohio, Oklahoma, Rhode Island, South Carolina, South Dakota, Tennessee, Virginia, Virgin Islands and Puerto Rico.
4. Arizona, Colorado, Delaware, Georgia, Kansas, Mississippi, Montana, North Carolina, New York, Nevada, Oregon, Pennsylvania, Utah, Vermont and Wyoming.
5. Alabama, California, Connecticut, Florida, Illinois, Kentucky, Massachusetts, Maine, Michigan, New Hampshire, New Jersey, Texas and West Virginia.
6. National Mental Health Association, The State Children's Health Insurance Program (1999).

Judge David L.
BAZELON CENTER
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www.bazelon.org

Update on Medicaid for Children

Since this publication was produced significant changes have been made to the Medicaid program by two laws: the Deficit Reduction Act (DRA, P.L. 109-171), signed into law in 2006, and the Affordable Care Act (health reform, P.L. 111-148), enacted in 2010. The Bazelon Center has produced summaries of the impact of both on children with mental health issues. The DRA summary can be accessed at http://www.bazelon.org/LinkClick.aspx?fileticket=C5qWWjIo20E%3d&tabid=242 and the health reform summaries at http://www.bazelon.org/Where-We-Stand/Access-to-Services/Health-Care-Reform/Final-Law-and-Implementation-.aspx.

These laws will affect children with mental health issues in the following ways:

- ***Eligibility***

  - ✓ Medicaid eligibility is expanded to require coverage of all children with family incomes at or below 133% of the federal poverty level (as of 2010, $29,400 for a family of 4, or $14,400 for an individual). States must maintain Medicaid eligibility rules for children that were in place early in 2010 for children until 2019. (Affordable Care Act).

  - ✓ At the state's option, certain families of children with disabilities may buy into the Medicaid program (this provision is from the Family Opportunity Act). Specifically, Medicaid coverage can be purchased by parents with family incomes of up to 300% of the federal poverty level for children under age 19 whose disabilities meet Supplemental Security Income (SSI) eligibility standards (Deficit Reduction Act).

  - ✓ States will have the option starting in 2014 to extend Medicaid coverage—including all benefits and EPSDT—to former foster children who have aged out of the system, up to age 26 (Affordable Care Act).

  - ✓ Eligibility for Medicaid is now available only to U.S. citizens, and applicants must be able to prove their citizenship (Deficit Reduction Act).

- ***Benefits***

  - ✓ States have new authority to limit benefits for certain groups of children on Medicaid by enrolling them in a "benchmark" plan modeled on private insurance benefit packages. However, all children up to age 19 are still entitled to any necessary Medicaid-covered service because the Early and Periodic Screening, Diagnosis and Treatment provision (EPSDT) still applies to them. However, in states that take this option, the Medicaid

benefit is bifurcated —children have certain benefits under their benchmark plan and only if they seek additional services based on the EPSDT mandate will those services be furnished. Very few states chose this option, and not all of those that initially used it still do. There are significant limits on which groups of children states may *require* to enroll in a benchmark plan. However, states may *offer* these benefits to any child enrolled on Medicaid (Deficit Reduction Act).

- ✓ The definition of targeted case management is clarified, as is when other programs must pay for case management because Medicaid is the last payer. The new legislative definition is essentially the same as the definition that has been in regulation for some years. The clarification regarding other programs' responsibility for case management focuses particularly on child welfare systems and also is not significantly different from prior administrative rules. General language about other programs' responsibility is of concern, but has not been clarified in the final federal regulations (Deficit Reduction Act).

- ✓ The two laws create a new state plan option for home- and community-based services under Section 1915(i) of the Medicaid law. Eligibility and services covered are the same as for home- and community-based waivers under Section 1915(c). Unlike under a waiver, however, children do not need to be either in or at risk of placement in a Medicaid-covered institution in order to qualify. Also, states may not limit the number of people eligible for services under the state plan option. States may target specific populations, such as children with mental disorders, although to date states have used this provision primarily for adults. (Originally enacted under the Deficit Reduction Act but important improvements were made by the Affordable Care Act.)

- ***Demonstration Projects***

  - ✓ A five-year demonstration project has been established to test the feasibility and cost of home- and community-based waivers (1915(c)) for children who would otherwise be placed in psychiatric residential treatment centers. Ten states were selected for participation and the project is authorized until FY 2011. Under Medicaid law, to be eligible for a home- and community-based waiver, the child would otherwise need to be placed in a hospital, nursing home or ICF-MR (Deficit Reduction Act).

- ***Premiums and Cost-Sharing***

  - ✓ States may now impose premiums, deductions and co-payments for groups of Medicaid-covered individuals. Medicaid beneficiaries can also now be denied coverage for failure to pay their premium within 60 days and denied a service if they fail to pay co-payments. Allowable levels for state-imposed premiums and cost-sharing vary by family income. Although most children are exempt, those in families with incomes between 100% and 150% of poverty who qualify through a Medicaid optional eligibility group can be charged. Children whose family income is above 150% of FPL are also not exempt. There are limits on total cost-sharing, by service and/or income (Deficit Reduction Act).

- ***Other Provisions***

  - ✓ To simplify the enrollment process, states must establish a state-administered website through which all individuals may apply for and enroll in Medicaid, CHIP (see description below) or the new state health care Exchanges set up as a result of the health reform law (Affordable Care Act).

  - ✓ To assist states with the increased costs of the Medicaid expansion, the Affordable Care Act provides for an increase in the federal share of Medicaid costs for the newly enrolled children and adults (Affordable Care Act).

Children's Health Insurance Program (CHIP)

In addition to changes to Medicaid, Congress has continued the State Children's Health Insurance Program (CHIP) and extended the current authorization (through FY 2013) for two additional years (to 2015), providing funding through September 2015 with an increase in the federal share.

States must maintain current CHIP eligibility standards at least until September 30, 2019 (Affordable Care Act). Another law enacted in 2009 amended the rules on benefits to require parity for mental health benefits so that they are comparable to benefits for medical/surgical services (Children's Health Insurance Program Reauthorization Act of 2009, P.L. 111-3).

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WHERE DO I GET MORE INFORMATION?

Bazelon Center for Mental Health Law
1101 Fifteenth Street NW, Suite 1212
Washington D.C. 20005
(202) 467-5730; TDD (202) 467-4232
www.bazelon.org

For a copy of the full 1999 report *Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs*, order online or send $20 (check or Visa/MasterCard authorization) to the publications desk (add an administrative surcharge of $4.50 for billing). The Bazelon Center has many publications on children's mental health issues, including managed care and Medicaid; call for a brochure or visit the bookstore at www.bazelon.org. The Bazelon Center can also provide technical assistance to state-based advocates seeking policy change. Call, write or e-mail to the attention of Director, Custody Relinquishment Project. Unfortunately, because of resource limitations, the Bazelon Center is *not* able to provide individual advice or representation to families facing custody relinquishment.

Federation of Families for Children's Mental Health
1021 Prince Street
Alexandria, Virginia 22314
(703) 684-7710
www.ffcmh.org

The Federation of Families for Children's Mental Health is a national family-run advocacy group with state-based affiliates throughout the country. The Federation can help you get in contact with other families concerned about children's mental health issues and can provide advice on advocacy strategies. The Federation has publications for families to help them with schools, managed care and systems of care.

The National Alliance for the Mentally Ill
200 N. Glebe Road
Arlington, VA 22203-3754
(703)524-7600
www.nami.org

NAMI has recently released a report: *Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness*, discussing the results of a survey of parents of children with serious mental health disorders. The report offers recommendations for improving access to mental health services for children.

The National Mental Health Association (NMHA)
1021 Prince Street
Alexandria VA 22314-2971
(703) 684-7722
www.nmha.org

The NMHA has a national office and affiliates nationwide who advocate for improving the mental health of all individuals. You can call the number above or visit NMHA's website to get in contact with your local mental health association. NMHA has produced numerous publications about children's mental health, including *The State Children's Health Insurance Program: An Analysis of the Mental Health/Substance Abuse Benefits and Cost-Sharing Policies of Approved State Children's Health Insurance Program Plans*.

The National Disability Rights Network
900 Second Street NE, Suite 211
Washington D.C. 20002
(202) 408-9514
www.ndrn.org

NDRN is the national association for the organizations in every state that provide legal assistance to adults and children with disabilities. NDRN can refer you to your local protection and advocacy system, which you can call to request legal help in a particular situation or on the broader problem of access to mental health services for children. The protection and advocacy agency will evaluate your request and decide whether it can help you, given its resources and priorities.

Research and Training Center on Family Support and Children's Mental Health
Portland State University
P. O. Box 751
Portland, OR 97207-0751
(503) 725-4180

The Center has produced an extensive report analyzing Oregon's statute, which prohibits custody relinquishment. The title is *Keeping Families Together: Implementation of an Oregon Law Abolishing the Custody Relinquishment Requirement*. To order it, you can call or write to the publications coordinator. The report costs $8.50.