

Research in the Service of Policy Change: The "Custody Problem"

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In this article we provide an example of some ways in which research can be used in the policy change process, using the issue of custody relinquishment ("the custody problem") as an example. Our view is that research findings alone rarely cause needed policy change; however, research can be used to inform policy in a number of ways: (a) identifying and describing the nature and extent of an issue or social problem, (b) revealing the negative consequences of the identified problem, (c) estimating the consequences of various strategies, and (d) studying the process and outcomes of policy implementation. In the case studies profiled here, research was most effective when combined with family stories. The stories gave the problem life, and the research helped find families with stories to tell, established that the problem was more than anecdotal, and suggested ways that the problem could be addressed. Research was also used to identify problems in the implementation of policy change and outcomes.

Research findings alone rarely stimulate needed policy change, but in the hands of effective advocates, research can be used to inform policy in a number of ways. These include describing the nature and extent of an issue or social problem, documenting the consequences of the problem, assessing the potential consequences of various strategies, and studying the processes and outcomes of policy implementation. In this article we provide an example of some ways in which research can be used in the policy change process, using the practice of custody relinquishment ("the custody problem") as an example. In the case studies presented, efforts to change policy were most effective when they included both data from formal research studies and well-articulated, powerful family stories. The research process assisted in estimating the scope of the problem suggested ways that the problem could be addressed and sometimes helped to identify families who were willing to share their experiences. Research was also used to identify problems with the implementation of policy change and to assess the outcomes of the policy implementation.

BACKGROUND OF THE POLICY ISSUE

"The custody problem" refers to the practice in many states and other jurisdictions of requiring that parents relinquish legal custody of their children in order to gain access to and payment for out-of-home treatment for their children who have serious emotional, behavioral, or mental disorders. Custody relinquishment is usually accomplished either through a *voluntary custody arrangement*, whereby parents agree to temporarily give custody of their children to the state for the purpose of placing their children in out-of-home treatment settings, or a *court order* that assigns custody of children to the state. In locales that do not have a voluntary custody option, parents often must go to court and claim that their children are out of their control or at risk of abuse in order to gain access to public funds to pay for costly and specialized residential treatments and services (Giliberti & Schulzinger, 2000). Once custody has been surrendered, the rights and responsibilities of families and the state vary according to the means of custody transfer (voluntary or court-ordered) and by local or state jurisdiction.

Problem Prevalence

The extent of the problem is not well documented, partly because this is an issue about which it is very difficult to gather reliable data. Many states use voluntary custody arrangements with a variety of families, including those where abuse or neglect is a documented problem, and do not differentiate the "mental health only" cases from

others. Furthermore, in those jurisdictions that require a court order, the official reasons given for custody relinquishment are likely to be that the child is "beyond parental control" or at risk of abuse or neglect; the voluntary nature of the court order for some families is unlikely to be reflected in the records.

Although no reliable prevalence estimates are available, two studies conducted 10 years apart (Friesen, 1990; National Alliance for the Mentally Ill, 1999) found that between 23% and 25% of the surveyed families who had children with serious emotional disturbance had been advised to relinquish custody for the purpose of obtaining services. Friesen and Koroloff (1991), extrapolating from estimates of the number of children in residential care at any given time (20,000 according to Young, Dore, & Pappenfort, 1988, and 29,000 according to Gilliland-Mallo & Judd, 1986) and the average length of stay (less than 1 year according to Young et al.), suggested that hundreds of thousands of children and families could potentially be affected.

Another approach to determining the extent of the problem involves identifying the number of localities where this practice exists. Cohen, Harris, Gottlieb, and Best (1991) conducted a survey of states and found that in 28 of 45 states (62%) that responded, at least one agency used custody transfer to obtain treatment for children with serious mental health problems. More recently, Giliberti and Schulzinger (2000) reported that the practice of requiring parents to relinquish custody occurred in at least half of the states. It most frequently occurred in 6 states (Colorado, Indiana, Iowa, Nebraska, Tennessee, and West Virginia), followed by 13 others (Arizona, California, Florida, Illinois, Kentucky, Louisiana, Maryland, Michigan, Missouri, New York, Ohio, Texas, and Utah). In addition, "despite statutory or policy protections against custody relinquishment," problems continued to be reported in Connecticut, Kansas, Maine, Minnesota, North Dakota, Oregon, parts of Pennsylvania, and Vermont (p. 16).

Effects of Custody Relinquishment on Families

Many negative consequences related to custody relinquishment have been identified by families (e.g., Borden, 1990; Smith, 1989; Strickland, 1989) and advocates (Franz, 1990; Marchbanks, 1990), although no definitive study linking negative outcomes to custody relinquishment has been undertaken. McManus and Friesen (1989a) identified loss of basic parental rights as a fundamental issue and noted four other possible problems:

1. differential implementation of custody policies and practices with poor, minority, and single-parent families;
2. harmful effects on parents' self-concept and the perception of families by society;
3. negative influences on relationships between parents and agencies; and
4. erosion of relationships between parents and their children.

Giliberti and Schulzinger (2000) identified the following negative consequences of requiring parents to surrender custody of their children:

limits a family's involvement in key decisions about their children's mental health, physical health, and education; undermines family integrity and often keeps the child from sharing in family religion, culture, and traditions; is costly, burdening child welfare agencies with children who are not abandoned or neglected; and penalizes [families] for the state's failure to develop adequate services and supports. (p. 13)

Reasons for Custody Relinquishment

A number of reasons for requiring the transfer of custody from the family to the state have been identified (Friesen & Koroloff, 1991; Giliberti & Schulzinger, 2000; McManus & Friesen, 1989a, 1989b) and include financial issues, treatment issues (including those linked to psychological theories and blaming attitudes toward families), and a misunderstanding/misinterpretation of existing policies. The fundamental reason for transferring custody from the family to the state is financial; the practice has grown up as a way of gaining access to Title IV -E (foster care) funds, Title XIX (Medicaid) funds, special education funds, and other sources of financial support for out-of-home treatment. Private insurance plans generally place severe limits both on inpatient and outpatient service, and parents cannot afford to pay the high cost of these services. The financial issues converge with attitudes that blame families and operate to exclude them from participation in their children's lives and treatment (McManus & Friesen, 1989b). Some residential program staff may prefer to deal with child welfare caseworkers rather than the parents of children in their care, fearing that parents may prematurely remove their children from treatment or be uncooperative in other ways. Another important factor driving state- and county-level child welfare programs to require families to relinquish custody of their children involves a misunderstanding of the Title IV -E Foster Care and Adoption

Assistance Program, which partially reimburses states for the costs of caring for children in out-of-home placement (Giliberti & Schulzinger, 2000; McManus & Friesen, 1989a; Stubbee, 1990). Some jurisdictions operate under the incorrect assumption that the state must have custody when Title IV -E funds are used.

Policy Changes Needed

Overall, there are two major perspectives to solving the problem. The first perspective defines the issue somewhat narrowly, treating it as a negative practice that could be avoided by finding alternative approaches to helping families pay for out-of-home services. Defined this way, attention is given to (a) promoting policies that prohibit states from requiring custody relinquishment for the sole purpose of paying for services and (b) establishing alternative arrangements (e.g., voluntary placement agreements wherein parents retain custody and usually pay a portion of the cost of care, with the rest of the cost covered by the state). For example, the Oregon legislation prohibits the child welfare agency from requiring that parents transfer legal custody of a child so that the child can be placed out of his or her home for the purpose of receiving treatment (Oregon Revised Statutes 418.312).

The second perspective views the "custody issue" as a symptom of a larger problem involving inadequate community-based services for children with serious mental health problems and their families. Within this view, if sufficient mental health services and supports were available, children would not need to leave their homes and communities in order to receive treatment. Giliberti and Schulzinger (2000) documented how policies and practices within the health-care, special education, and child welfare systems all contribute to the overall problem through fiscal incentives for placing children in out-of-home care. Viewed this way, attention is given to removing policy and practice barriers to accessing needed services and to obtaining sufficient mental health resources for children and families in their communities. The Medicaid waiver program used by the state of Kansas is an example of this approach. Basically, the Kansas waiver permits the state to expand eligibility for a defined group of children and to provide access for this group to a wider range of services than would normally be covered by the state's standard Medicaid benefit. This approach is not limited to state policies. A pending federal bill, The Family Opportunity Act (2002), would allow more states to implement the waiver and would create a Medicaid option to allow parents to buy into the existing state Medicaid plan, thus gaining access to mental health services and supports. Both the Kansas waiver and The Family Opportunity Act are designed to expand the number of children who have access to services.

In reality, these two perspectives are not mutually exclusive, and neither remedy is sufficient by itself. Even under circumstances where fiscal issues were sufficiently addressed, practitioners' beliefs about therapeutic considerations and their negative attitudes toward families, along with misinterpretations of federal law, could still create pressure on families to surrender custody to the state. Thus, policy change targeting the practice of requiring families to relinquish custody to obtain services may still be needed in states that have worked to increase access to a broad array of community-based services.

EXAMPLES OF POLICY CHANGE EFFORTS

The following three case examples detail various uses of research and advocacy to address the policy problem of custody relinquishment. Table 1 summarizes the use of research to support the policy change process in each instance, both prior to the enactment or revision of a policy and after its implementation. References to studies relevant to each policy phase are included in the table.

Table 1
Research to Support the Policy Change Process

Research type	Preparing for change		Assessing implementation	
	Describing the policy problem	Assessing policy change alternatives	Understanding the process	Measuring outcomes
Building an information base: National and cross-state research and evaluation	Parents' experiences with custody relinquishment ^{a,b}	Congressional testimony re: custody relinquishment and alternatives ^c		
	Survey of states and legal research re: custody ^d	Study of legal aspects and alternatives to custody relinquishments ^e		
	Study of state-level policies and practices re: custody ^f Documentation of families' experiences ^{g,h,i}			
Policy specific: Oregon's Voluntary Placement Agreement (O.R.S. 418.312)	Study of Oregon parents' experience with custody relinquishment ^j	Study of Oregon parents' experience with custody relinquishment ^j	Examination of implementation processes and survey of child welfare caseworkers in Oregon ^k	Interviews with child welfare staff and families re: changes in family involvement re implementation ^k
Policy specific: Kansas' Medicaid Home and Community-Based Waiver	Statewide family organization collected systematic information from families re: custody relinquishment, family testimony about their experiences ^l	Cost data from two CMHS-funded Comprehensive Community Mental Health Services for Children and Families Programs provided support for waiver application ^m	Evaluation of process and outcomes of waiver implementation in Kansas ⁿ	Evaluation of process and outcomes of waiver implementation ⁿ
Policy specific: Federal Family Opportunity Act	Incidence of families' giving up custody to gain access to services ^b			

^aFriesen (1990). ^bNational Alliance for the Mentally III (1999). ^cMcManus & Friesen (19896). ^dMcManus & Friesen (1989a). ^eCohen et al. (1993). ^fCohen et al. (1991). ^gBorden (1990). ^hSmith (1989). ⁱStrickland (1989). ^jMcManus et al. (1993). ^kBlankenship et al. (1999). ^lJ. Adams, personal communication, May 2, 2001. ^mGiliberti & Schulzinger (2000). ⁿR. Chamberlain, personal communication, May 8, 2001.

Voluntary Child Placement Agreement

In 1993, Oregon formally addressed the problem of custody relinquishment by enacting legislation to prohibit the custody relinquishment requirement solely for a child to receive out-of-home services such as foster care or residential treatment. Through the passage of House Bill 3577 (O.R.S. 418.312), the Voluntary Child Placement Agreement (VCPA) was created to allow caregivers to voluntarily place their children in out-of-home care without relinquishing custody. Prior to 1993, the only options available to caregivers were to sign a voluntary custody agreement (relinquishing custody to the state), accrue substantial loans in order to pay for out-of-home care, or continue attempts to keep the child at home without relinquishing custody, but without sufficient community supports. Although some attention had previously focused on the custody problem in Oregon (McManus & Friesen, 1989a, 1989b), no action had occurred in the state legislature until efforts were initiated by Linda Reilly, the mother of an adolescent with a mental health disorder who had relinquished custody of her daughter to the state (Blankenship, Pullmann, & Friesen, 1999). Reilly served as the board chair for the Oregon Family Support Network (OFSN), an advocacy and support group of caregivers of children with serious emotional problems. Collaborative work involving Reilly, State Representative Kate Brown, the Oregon Family Support Network, the state child welfare agency, the Oregon Developmental Disabilities Council, and the Research and Training Center on Family Support and Children's Mental Health resulted in a work group called the Care and Placement Committee. The committee first worked toward an administrative solution to the custody problem and then shifted its efforts to preparation and passage of legislation (McManus, Reilly, Rinkin, & Wrigley, 1993).

Preparing for Change: Describing the Policy Problem. To help inform the policy process and in response to an estimate by the state child welfare agency that custody relinquishment happened rarely, the Research and Training Center on Family Support and Children's Mental Health conducted a study about parents' experiences with the custody problem in Oregon (McManus et al., 1993). All Oregon families on the Research and Training Center

and OFSN's mailing lists were invited to participate in interviews about their experiences related to custody relinquishment. Forty-one families responded to the interview request and reported being asked to relinquish custody. Of these families, 20 had relinquished custody and 21 had refused. Although these numbers were not considered reflective of the actual numbers of families in Oregon faced with the custody problem, the interviews provided important detailed accounts of family experiences and identified families who were willing to describe their experiences in public. The findings from this study were used by advocates to document and illustrate the consequences of custody relinquishment in preparation for legislative testimony.

House Bill 3577 became law (O.R.S. 418.312) on November 4, 1993. The new policy abolished any requirement to relinquish custody solely for the purpose of gaining access to out-of-home services for children with disabilities, and offered the VCPA as an option for nonabusive families who could not afford to place their child out-of-home and did not want to relinquish custody. Because custody relinquishment was a problem for families whose children had a variety of disabilities, the proposed legislation was written to include all disabilities. In addition to mental health advocates, representatives of the Oregon Developmental Disabilities Council were instrumental in reviewing and advocating for the bill.

Between 1993 and 1995, several families who used the new VCPA reported that the Oregon Support Enforcement Division (OSD) had issued a court order requiring payment for their child's services based on the parent's potential income. This did not take into account expenses related to transportation, doctor's appointments, and other services for the child's care. Some caregivers reported that their wages had been garnished. A legal appeal was the only means to challenge the court order. To address this loophole, another piece of legislation was introduced and passed in 1995 that required the child welfare agency to offer "nonadversarial child support agreements" to families of children placed under the VCPA. These agreements are an alternative to court-ordered support; they allow a payment plan to be designed based upon family income and child expenses prior to contact with the Support Enforcement Division.

Assessing Implementation: Understanding the Process. In 1998-1999, 5 years after implementation of the Oregon law abolishing the custody relinquishment requirement, the Research and Training Center conducted an assessment of the implementation of the law. The investigators interviewed child welfare staff and family advocates about their experiences with the implementation of the VCPA and the process for the nonadversarial child support agreements. In addition, the research team reviewed documents on administrative rules and child welfare agency policies and practices related to staff training. Lack of data about the implementation process and lack of staff training were noted as problems. There was no way to discover how many children were placed using the VCPA because the data collected by the state child welfare agency did not distinguish between the two types of "voluntary" agreements (the VCA and the VCPA). Aside from four initial training sessions for agency supervisors and an article in the agency newsletter, there was no required training regarding the VCPA for new or existing staff.

Another major feature of the implementation assessment was a study of caseworker knowledge about the VCPA and nonadversarial support agreements (see Blankenship et al., 1999, for a full description of the study; see also Note 1). All child welfare workers who would have occasion to use a VCPA (excluding staff such as adoption workers, foster home certifiers, and similar roles) were randomly sampled. A total of 180 caseworkers was contacted, and 127 of them agreed to participate. The branch manager at each office distributed to all caseworkers correspondence asking for their participation. During 10-minute telephone interviews, caseworkers were asked to describe (a) the differences between the VCPA and the VCAs and (b) the appropriate situations in which to use these agreements. Caseworkers were told that they could treat the interview as if it were a real case and that they could access any information they might need.

Overall, caseworkers had very limited knowledge of the VCPA or the nonadversarial financial agreement. Of the 127 caseworkers interviewed, 25.2% said they did not know enough to complete the interview. Of the 97 caseworkers who said they knew enough about the VCPA to answer questions, 18.5% said they did not know the answer to the question, "When is it appropriate, in your judgment, to use a Voluntary Child Placement Agreement?" Several more gave partial or incorrect answers. Caseworkers were also presented with six hypothetical situations and asked if a VCPA would be appropriate in those situations. Of the 97 caseworkers who said they knew enough about the VCPA to answer questions, 3.1% answered all six hypothetical questions correctly, 6.2% responded correctly to five situations, 23.7% answered four correctly, and 67% answered three or fewer situations correctly. Finally, caseworkers were asked about their knowledge of the policies and procedures surrounding OSD when a VCPA is used. According to state law, the child welfare agency must inform caregivers of the opportunity to enter into a nonadversarial support agreement at the time the VCPA is established. Of the caseworkers who said they knew enough about the VCPA to answer questions, 45.3% responded that they did not know how the OSD was involved in a VCPA. In contrast to the overall low level of knowledge evidenced by caseworkers, designated staff

members in a few branch offices answered most of the questions correctly because the branch had concentrated responsibility for VCPAs in a few "expert" caseworkers. The other caseworkers in the branch had been trained to know when to involve these experts.

The study revealed that 6 years after the implementation of the law abolishing custody transfer for the purpose of paying for out-of-home treatment, and 4 years after the implementation of the law establishing nonadversarial support agreements, there was a low level of implementation, training, and knowledge about the proper use of VCPAs. These data and recommendations for improvement based upon the interviews with caseworkers and families were summarized in two research reports (Blankenship et al., 1999; Giliberti & Schulzinger, 2000). After being made aware of the study findings, and with growing public attention being given to the issue, including an inquiry to the Research and Training Center from a national human rights organization, the Oregon child welfare agency (State Office of Services to Children and Families) agreed to implement many of the changes recommended. The agency joined the Research and Training Center in formally issuing the report (Blankenship et al., 1999). Table 2 details the report's recommendations and the response from the child welfare agency.

RTC report recommendation	SOSCF response
Find alternative means to avoid the necessity of the VCPA.	SOSCF agreed that additional, appropriate means are needed to serve these children and families and has pledged to participate with other agencies and community partners to seek preventative measures.
Using input from key stakeholders such as family members, child welfare administrators, child welfare caseworkers, and other relevant parties, change the VCPA forms to make them easier for both families and caseworkers to understand and use.	SOSCF agreed to have the forms edited by the attorney general's office.
Increase training to child welfare workers, treatment providers, juvenile court judges, school personnel, inpatient hospital staff, and other relevant persons.	All intake and screener training now includes information on voluntary placement.
It may be useful to concentrate responsibility for executing VCPAs with one to three workers in each branch.	Branch offices have designated from one to three workers as expert/resource people.
Establish a means of tracking children and families where placement has occurred using a VCPA.	All VCPAs and VCAs are now sent to the central office for tracking and for monitoring the fulfillment of requirements.

Note. RTC=Research and Training Center on Family Support and Children's Mental Health; SOSCF= State Office of Services to Children and Families; VCPA=Voluntary Child Placement Agreement

Medicaid Home and Community-Based Waiver

Kansas is an example of a state that chose to address the custody problem by expanding the array and availability of community-based mental health services for children with behavioral and emotional disturbances. The policy change chosen to accomplish this goal was to apply to the Health Care Financing Administration (HCFA) in 1997 for a Medicaid Home and Community-Based Waiver. The waiver application addressed children with mental health problems who are in imminent danger of being institutionalized. The waiver was approved in 1997 and implemented in 1998.

Kansas based its service model on the system-of-care approach and incorporated four new services to be covered by Medicaid: parent support, wraparound facilitation, independent living, and respite care. In addition to an expansion of the array of available services, more children qualified for Medicaid because of changed income requirements. The waiver based financial eligibility exclusively on the child's income rather than on that of the parents. The state estimates that two thirds of the children served under the waiver would not previously have been eligible (P. Dickey, personal communication, May 22, 2001).

Preparing for Change: Describing the Problem/Assessing Alternatives. In order to provide a rationale for the cost neutrality requirements of the waiver, Kansas relied heavily on cost data provided by two Kansas demonstration sites that had been funded by the Center for Mental Health Services' Comprehensive Community Mental Health Services for Children and Families Program. These grant communities were able to provide cost data connecting specific services, duration, and intensity of care to positive child outcomes. The sites were able to show positive outcomes in a number of critical domains, including living at home versus institutional care, educational data, juvenile justice encounters, and symptomatology as reflected on the *Child and Adolescent Functional Assessment Scale* (CAFAS; Hodges, 1996, 2000) and the *Child Behavior Check List* (CBCL; Achenbach & Edelbrock, 1983). The statewide organization of the Federation of Families for Children's Mental Health, Keys for Networking, maintained an extensive database containing information from families about their experiences with the custody issue. Data from the grant communities were presented to the legislature in support of the waiver and were combined with summaries of information from families and family testimony. This combination of summary data and personal accounts was very powerful in convincing the legislature to allocate funding to the waiver program.

The state already had data on the costs of institutional care, which averaged \$25,000 per child/per year. By extrapolating from the grant communities' data, the state was able to project an average cost of \$10,900 per child/per year for community-based mental health services. The Kansas legislature provided all new dollars for the state match. On average, Kansas was able to stay within its cost projections for the first 3 years. In the fourth year (2001), the costs increased to \$12,000 per child/per year. Kansas could have gone considerably higher in projecting the costs of community-based mental health services and still met the cost-neutrality requirement, but the state was constrained by the limited state funds appropriated to satisfy the match requirements.

In 2000, the number of waiver slots available was significantly reduced by the legislature in response to budgetary concerns. The local mental health centers had not used all of the allocated slots from the previous year, which gave the legislature a rationale for reducing them. Reasons suggested for the shortfall in use of slots included lack of sufficient guidance and procedures from the state, problems with billing mechanisms set up by a state contractor, lack of enthusiasm from some mental health centers, and an inadequate time period to implement the waiver procedures (J. Adams, personal communication, May 2, 2001).

Assessing Implementation: Understanding the Process. Advocates and the state agree that the waiver helped bring system-of-care principles to the Kansas mental health system. Before the waiver was implemented, the federal demonstration project covered only 14 of the 105 counties, and 91 counties outside of the demonstration project were not making use of innovative community-based alternatives to institutional care (P. Dickey, personal communication, May 22, 2001). The waiver provided a mechanism for disseminating information about innovative practices and incorporating them into the entire Medicaid program. Wraparound services became more available to Medicaid and waiver children. Advocates remain concerned about the lack of services, continued lack of enthusiasm and participation by some of the community mental health centers, and decreasing lengths of stay in the waiver program. They would like to see the legislature enact a statute prohibiting custody relinquishment to help those families who are not benefiting from the waiver because of these problems (J. Adams, personal communication, May 2, 2001). It is generally agreed, however, that the program has made a positive difference for many families who would otherwise have turned to the child welfare system and relinquished custody. It has also provided alternative community-based mental health services without requiring any juvenile court involvement.

Assessing Implementation: Measuring Outcomes. At the inception of the waiver program, the state contracted with the University of Kansas School of Social Welfare to collect data on outcomes for the waiver children compared to children who were receiving case management services at the mental health centers. Children receiving case management services generally had less severe mental health conditions than did the waiver children. Data were collected on the number of children who remained in a permanent home, avoided contact with law enforcement, received passing school grades, and had good school attendance rates. Children on the waiver scored higher on all outcome measures, despite the fact that a larger percentage of them had clinically significant CBCL scores indicating a higher level of psychopathology (R. Chamberlain, personal communication, May 8, 2001). These outcome data have been used to show the effectiveness of community-based services, but because of budget constraints, the information has not recently been used to expand or increase the program.

Federal Legislative Initiative

The Family Opportunity Act of 2002, also referred to as the "Dylan Lee James" Act, died with the end of the 107th Congress, but we anticipate that it will be reintroduced in the 108th Congress. The bill contained several

provisions that would ameliorate the custody problem by expanding access to health and mental health services. First, it would create a new state option to allow states to expand Medicaid coverage to children with disabilities up to age 18 who would be eligible for Supplemental Security Income (SSI) disability benefits except for family income or resources. Any family with a child whose disability meets SSI criteria and whose income does not exceed 300% of the poverty level could be covered under Medicaid if the state chooses this option. Thus, families meeting these criteria could access health care and mental health care through a new opportunity to "buy into" Medicaid on a sliding fee scale without having to relinquish custody to the state.

The bill also would create a time-limited demonstration program to extend Medicaid coverage to children who have a disability that would become severe enough to qualify under SSI if they were left to deteriorate without health care. The demonstration will provide useful information on the cost effectiveness of early health-care intervention for children with potentially severe disabilities.

It also would allow the states more freedom to pursue a home- and community-based waiver for children with serious emotional disturbance. Currently, a state can apply to the Centers for Medicare and Medicaid Services (formerly the Federal Healthcare Financing Administration) to waive rules for Medicaid eligibility related to parental income by showing that their Medicaid costs for home- and community-based care would not exceed the costs of hospital coverage for these children. Parental income is not counted toward Medicaid eligibility after children reside in a hospital for more than 30 days, but it is immediately counted again once children return home, so they lose Medicaid coverage. Most children with serious emotional disturbance do not reside for long periods in hospitals; instead, they are sent to residential treatment facilities, which are not specifically mentioned in the current waiver statute, even though they have the same deeming rules that provide financial incentives for out-of-home care. The Family Opportunity Act would add residential treatment centers to the waiver statute and thus allow states to provide waivers to families seeking home and community-based services instead of more restrictive care in such centers (see Note 2). Because most families face relinquishment of custody when they are seeking residential treatment, this provision will be very helpful in addressing the problem in states that apply for the waiver.

The Act would also create Family-to-Family Information Centers to provide technical assistance and information to families on the various health-care programs available and appropriate for children with disabilities. The Centers would also assist health-care insurers, providers, and purchasers who were interested in developing ombudsman programs.

Preparing for Change: Describing the Problem. Several research studies have been used to prepare and support The Family Opportunity Act. In the area of custody relinquishment, information submitted to the relevant committees included some of the prevalence data discussed above, such as the study by Virginia Commonwealth University conducted for the National Alliance for the Mentally Ill, which found that 20% of families of children with serious emotional disturbance had given up custody of their child in order to access mental health services (National Alliance for the Mentally Ill, 1999). The Bazelon Center's finding that custody relinquishment for services was occurring in at least half the states was also cited (Giliberti & Schulzinger, 2000).

It is the deeply moving story of a mother and member of the Federation of Families for Children's Mental Health who testified at a hearing for The Family Opportunity Act that gave meaning and life to the statistics (The Family Opportunity Act, 2000). When her husband became employed at a better job, the family lost Medicaid coverage and with it, the ability to pay for treatment for their daughter, who has bipolar disorder. The mother could not work because of her daughter's needs, and one income was not sufficient to support the family and the child's treatment needs. The family had to declare bankruptcy twice. They were unable to obtain day-treatment services. After finally getting their child to the top of the waiting list for these services, they found that the school district refused to pay for services under the special education mandates because the district claimed that the child had stabilized. Two months after the school district's refusal to provide services, the mother found her child with a rope around her neck. When she tried to remove the rope, her daughter attacked her, and she had no choice but to call the police. She described what happened:

The next morning we had a meeting with our family therapist and a caseworker from what was then the Children's Services Division. When we were asked what we wanted, I told them that my daughter needed help and our family needed help in maintaining her at home. We were told that if we wanted to receive any services, we would have to place our daughter in the State's custody and then the State would pay for her care. Since we did not have private insurance and could not qualify for Medicaid, we had no choice but to agree to give her up.

When J. was in State's custody, our family had little to say in decisions regarding her treatment or care. At times, we were not allowed to even come pick her up and take her to church or do anything. After 2 years' time and several psychiatric hospitalizations, we finally got her back. The caseworker the day she came home told me, "She is yours. Come and get her, and I hope you know that now you do not have medical insurance."

The impact of giving up legal and physical custody so that J. could receive the help we felt she needed devastated us all. J. felt more than abandoned. Our family was thrown into a great turmoil. Is this the price tag that families must pay to help their children with a severe emotional disability? With the legislation before the Senate today, at State option, my family could buy into the Medicaid Program to provide us with the help we so desperately needed for J. without the tragic consequences that have plagued our lives. (The Family Opportunity Act, 2000, p. 39)

Several other witnesses testified that they had turned down promotions and increases in wages in order to maintain Medicaid coverage. Another study that figured prominently in the debate showed that in a family survey of 20 states, 64% of families with children with special needs reported that they were turning down jobs, turning down raises, turning down overtime, and were unable to save money for the future of their children and family in order to stay income eligible for Medicaid (Wells et al., 2000).

Preparing for Change: Progress to Date. The combination of powerful family stories and research studies detailing the loss of employment opportunities and family unity has been instrumental in supporting The Family Opportunity Act. It currently has bipartisan support in the House and Senate, with sponsors from both parties. Advocates are cautiously optimistic about passage.

CONCLUSION

Custody relinquishment is an inhumane practice with dire consequences for families and children. Not only does the practice limit a family's involvement in decisions regarding the well-being of their child, it also keeps the child from sharing in family activities, including religious and cultural traditions. Moreover, the loss of basic parental rights produces harmful effects on parents' self-concept and negatively influences the relationships between parents and agencies. The state's failure to develop adequate mental health services and supports—in lieu of custody relinquishment—thus erodes relationships between parents and their children and wrongfully penalizes families.

Currently, two perspectives exist concerning approaches to this problem. The first approach prohibits the practice of custody relinquishment but does not address the underlying cause, the lack of access to appropriate community-based services due to the gap in service availability and to the high financial burden placed on families when services do exist. The second approach addresses the underlying cause by expanding access to services and reducing the financial burden for eligible families but does not prohibit the practice. Researchers and advocates should consider a combined approach that bans the practice while providing increased access to mental health treatment for children.

In order to achieve this policy change, researchers and advocates need to work together to gather data to document the prevalence of custody relinquishment for the sole purpose of gaining access to services and should continue to work together to assess implementation successes and failures once policies have been changed. In addition, family stories are needed as part of a legislative strategy to change the current approach to mental health services. Clearly, positive change can be achieved through a partnership of researchers and family members working together, and the system can be reformed so no family is ever asked to give up custody of a child in order to obtain mental health services.

Notes

1. As context for understanding the findings of the implementation study, it is important to note that the majority of services that the child welfare agency provides are designed to meet the needs of children who have been abused or neglected. The average caseworker only rarely encounters a family who is appropriate for the VCPA. This study was conducted in conjunction with a national study of custody issues and strategies mounted by the Judge David L. Bazelon Center for Mental Health Law (Giliberti & Schulzinger, 2000).

2. The bill adds the words "inpatient psychiatric hospital services for individuals under 21" to the waiver language. This phrase is defined in the Medicaid statute to include any facilities that the Secretary of Health and Human Services (HHS) includes in regulations. HHS has promulgated a regulation that includes residential treatment facilities as inpatient psychiatric services for individuals under 21, if the facilities meet certain criteria.

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