Children Grow Better in Families. This was the slogan on a 1984 poster developed by the Children's Bureau to emphasize the benefits of adoption—not only to a waiting child, but to the adoptive home itself through the enrichment the new member brings to the existing family system. The slogan rings true for all types of families—not only those restructured through adoption or remarriage, but those that are formed in more conventional ways. The child welfare system today is heavily invested in family preservation and the philosophy of permanency for children who have been placed outside of their own homes. Yet, while we are working diligently to infuse these philosophies into all aspects of life, there are contrary forces that are not so supportive of families and strain the ties that bind parent and child together. One of these forces is the legal requirement in many states for a transfer of custody from parents to the state when assistance is needed to obtain necessary services for children with disabilities.

Telephones in the Children’s Bureau ring regularly these days with calls from parents and advocates who have sad stories about the inability of states to help with the costs of special services for children with disabilities unless legal custody is relinquished by the parents. These are not folks who have neglected or abused their children. They may be birth parents or adoptive parents—unquestionably involved in providing the best for them—but who must often seek a foster home or a special treatment facility when they reach the limits of their physical endurance and financial resources. They are no less a family because of the special needs of their children and wish to maintain their legal responsibility as well as the embrace of their love and concern.

Many states do not enter into voluntary arrangements with parents when their children are in need of services or placement for a variety of reasons. In some, state or local laws prohibit them. When we talk with these parents, we urge them to work with their state legislators and social welfare officials to bring laws and practices into harmony with family preservation philosophy.

There may also be concern about the possibility of runaway costs to the state where the deterrent effect of loss of custody would seem to provide some restraint. But, there are provisions in Title IV-E of the Social Security Act (Sections 472(d) and (f)) that allow for state-federal sharing in the costs of foster care maintenance for Title IV-E eligible children who are in voluntary placement. Under that section, "voluntary placement means an out-of-home placement of a minor, by or with participation of a State agency, after the parents or
guardians of the minor have requested assistance of the agency and signed a voluntary placement agreement, which specifies, at a minimum, the legal status of the child and the rights and obligations of the parents or guardians, the child, and the agency while the child is in placement.” Section 472 does not specify the extent of these rights and obligations or require that “custody” be transferred to the agency; by its silence, the statute leaves these details to the parties to the agreement. However, the law does require certain protections for each child—a case plan, a periodic review, and (within 180 days) the court must make a determination that the placement is in the best interests of the child. (Although a judicial procedure, the determination does not require a court hearing.)

I hope that states, child advocates, and parents of children with special needs will continue to work together in re-examining current laws and practices, so that children will grow better through nurturing families and the strength of state supports. Beverly Stubbee.

Beverly Stubbee
is Director, Division of Program Operations, Children's Bureau; Administration for Children, Youth, and Families; Department of Health and Human Services; Washington, D.C.

Editor's Comment: The Summer 1989 issue of Focal Point contained a discussion of barriers to accessing services with considerable focus on relinquishing legal custody as a means of obtaining services for children with serious emotional disabilities. This issue continues that discussion.
Pennsylvania Parents Battle the Custody Barrier

The issue of requiring parents to relinquish custody of their children to the child welfare system in order to access services is not new. Recently the custody issue has gained momentum across the country. The Portland Research and Training Center's efforts have been very important in increasing the visibility of this issue. Their research on state and federal laws, state practices and parents' experiences has added a critical dimension to the efforts parents have made over the past five years.

From the outset, Parents Involved Network (PIN), a self-help advocacy, information and training resource for parents of children and adolescents who have emotional problems, has approached the custody issue in two ways. One effort has been to educate professionals, advocates, policymakers and legislators at the local, state and national levels; the other has been to assist parents in becoming skillful and effective advocates for their children by providing information and training.

The custody issue was an agenda item from the beginning of the PIN Project in late 1984. Several parents in the first PIN group had previously relinquished custody and others were faced with that decision because the mental health system did not provide residential services other than hospitalization. These parents knew that they wanted to change this practice.

In 1985 PIN members began to participate in committees at the state and local level. When they raised this issue at these committee meetings, they found that some people did not know this was a practice and were shocked; others knew that the practice existed, but had not thought about the implications for parents; still others did not think this issue relevant for mental health planners. It was common to find that when people discussed children with emotional disorders in residential settings, they were referring only to children in state hospitals.

It became clear that PIN needed to educate the mental health community about the custody issue. We knew that others must understand the parent's perspective if PIN were to develop a constituency for change. Therefore, parents continuously spoke out at every opportunity, including press interviews, radio and television appearances, conferences, and at committee meetings and advisory councils in Pennsylvania and across the country advocating for the custody issue to become a priority.

Over the past five years PIN has successfully focused the attention of local, state and national people on this issue. Although we have not as yet changed the custody requirement in Pennsylvania, we have made an impact. This has become a priority issue for many parents, professionals, policymakers and advocates in Pennsylvania and other states. No longer are parents the only ones discussing custody as a barrier to accessing services. No longer are these children dismissed as outside the scope of mental health planners.

At the same time PIN was involved in public education efforts, PIN was also assisting parents in learning to assert their right to be fully involved in the planning and decision-making for their child when he or she is in custody of a state agency. To accomplish this we became very knowledgeable about the legal implications of custody. We learned state law, regulations and administrative codes. We learned about parental rights and children's rights, and how these rights were protected. Pertinent information about policy and practices as well as copies of forms used by county children and youth agencies were added to PIN's resource library.

Parents assisted each other by going to court hearings and family service plan, treatment team and Individual Education Plan (IEP) meetings. Parents became skillful and effective advocates for their children. They reported that even when they did not gain everything they were seeking, they achieved a greater degree of participation than when they had assumed their exclusion was the way it had to be.

The experience of PIN demonstrates that parent advocacy efforts can stimulate the development of a broad-based constituency to advocate for change. Furthermore, parents have shown that even when they have to relinquish legal custody in order to receive services, they can take a proactive stance. They can become experts in their rights and their child's rights and maximize their opportunities for full participation.

Joyce Robin Borden.
Commonwealth of Virginia Custody Relinquishment Studies

The Commonwealth Institute for Child and Family Studies, a facility of the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services, recently completed two custody relinquishment studies. In one study, questionnaires were sent to each of the fifty governors’ offices for distribution to all child-serving agencies for the purpose of developing a profile of the statutes, regulations, policies, and practices of state agencies with respect to requiring transfer of custody as a prerequisite to receiving funding for intensive services.

Highlights of the study’s results include: (1) of the 45 states responding to this survey, 28 states had at least one agency that indicated that transfer of custody from parents to state or local agencies occurred in order to gain access to state funding for services for children with serious emotional disorders; (2) eleven states reported that more than one state agency used this practice; (3) the most common form of transfer of custody was temporary transfer of custody to state or local authorities for the purpose of obtaining placements; (4) states that used transfer of custody tended to be less densely populated and less wealthy than states that did not require a transfer of custody as a funding prerequisite; (5) some states have enacted legislation that prohibit transferring custody in order to receive financial assistance; and (6) other states have developed procedures that permit the child’s parent, guardian, or custodian to retain custody while a government authority prescribes supervision, treatment or care by an appropriate state agency.

In the second study, parents who have been advised to transfer custody of their children with serious emotional disabilities to the state for the purpose of receiving needed services at public expense were surveyed. At the request of the Institute, the parent questionnaire was included in the Summer 1989 issue of Focal Point. The 24 parents who responded all indicated that it had been suggested or recommended that they transfer custody of their child to state or local authorities in order to receive state funding for the services their child. Seventeen parents transferred custody in order to receive funding. The primary reasons given for the decision to relinquish custody were the high cost of the needed services—which might result in bankruptcy for the family—and the admitted inability of the parents to handle the child’s behavior. The majority of the parents stated that giving up custody had a negative impact on their relationship with the child, although the majority also stated that their child had improved as a result of the out-of-home placement.

Further information on these studies may be obtained from the following: Robert Cohen, Ph.D., Commonwealth Institute for Child and Family Studies, Virginia Treatment Center for Children, P.O. Box 1-L, Richmond, Virginia 23201; (804) 786-3129.

Idaho Family Struggles With Custody Relinquishment Decision

My husband and I adopted Heather in California in 1979 when she was two months old. At an early age it became apparent that she had significant psychological problems that have worsened as she has grown older. Heather is currently in a treatment center in Salt Lake City, Utah. In addition to Heather, our youngest child is adopted and we have two biological children.

Heather’s residential care costs approximately $60,000.00 per year. In addition to this expense—due to the nature of her disability—Heather regularly incurs other medical and financial expenses, such as medication costs and speech therapy. Other family members also need counseling on an individual basis. We have exhausted our insurance benefits and all of our other available financial resources. We requested support services from the Idaho Department of Health and Welfare and were told that financial and other assistance would be available for Heather only if we committed her to the custody of the state.

The question of custody is a very emotional issue for us. It deeply affects our family’s commitment to Heather. We had to go through home study placement and post placement visits by a social worker before we could legally become her parents. If the state takes custody where does that leave us? We are not her biological parents and we would not be her custodial parents either. We have lost count of the times we have been asked “Which ones are your own children?” If the state has custody will they all still be our own children or will our perspective change? The whole idea threatens and frightens us. Heather and her younger sister are currently grappling with the issue of belonging and ask, “Why didn’t my other mother want me?” Clearly, it would be emotionally damaging to all of us as a family to lose custody of one of our children. I think it is somehow even more difficult to consider giving up custody of an adopted child than a biological child. Whether we had custody of a biological child or not, we would always have our biological link; but what is left if we lose custody of a child
we adopted?

We are also worried about the idea of someone other than ourselves making decisions for and on behalf of our family. We know Heather better than anyone else; we have lived with her for eleven years and have experienced the full impact of the strain of living with her and the destruction and damage she can do. We know our family best and recognize our limitations. It is vitally important to us, therefore, to have a decision-making role in meeting the needs of all our family members. We want the very best treatment we can obtain for Heather and we need help, support, training, and guidance for the rest of the family.

There may also be a cultural component to our feelings. We are not American citizens and we come from a country where children are not denied medical treatment because of their parents’ inability to pay. This means government agencies take custody of only those children who have woefully inadequate parents. Given our determination to keep Heather as part of our family, we may lose the right to ever again live in England—our native country. We have been told by an immigration lawyer that unless Britain is a good deal more generous than the U.S.A., Heather—an American citizen adopted by British parents—has no automatic right to claim British nationality. With serious mental health problems she probably would be denied residency in Britain, since if the reverse were true, she would be refused entry to the United States. It seems ironic that because she is adopted we cannot take her back to our native land for treatment and yet, if we stay in her native country where we have lived and paid taxes for the last twelve years, we cannot get support to help us meet her financial needs.

We realize that we seem to fall between all the cracks. We have a seriously ill child whose problems are mental rather than physical. We adopted her too early to be eligible for adoption support. She was not born to us so we cannot take her home to England for treatment. Our income is too high to allow us to qualify for benefits for her, but not high enough to be able to pay for her expenses and meet the needs of our other three children. However, we cannot see what possible good it would do Heather, her parents, her brother or sisters to take away our right as loving parents to make decisions based on all of our children’s best interests, or to weaken the emotional glue that bonds us as a family by taking custody of one of its members. Even if custody is only a formality to the state as a means of accessing services, it has far reaching emotional implications for us. Catherine Dorling.

Catherine Dorling and her family live in Boise, Idaho. After exhausting all possible avenues for obtaining assistance, the Dorlings relinquished custody of Heather to the state of Idaho in order to ensure that she would receive necessary services.

Georgia Custody Survey

Georgia state policy limits access to troubled children’s funding to children in state custody. In an effort to determine how many Georgia families are affected by this policy an organization known as CATCH (Citizens and Agencies for Troubled Children) mailed a questionnaire to ninety-five local Troubled Children’s Committees and thirty-one community mental health centers. Responses were received from 24% of the local Troubled Children’s Committees and 19% of the mental health child and adolescent coordinators.

Twenty-three parents were reported to have given up custody of their children in order to receive services; while fifty-one parents decided not to relinquish custody. As CATCH members noted, “The irony is that [the twenty-three children in state custody] climbed immediately to the top of the priority list when the parents turned them over to the state. Was their disability and need for treatment any more than before? Of course not. Their needs or severity of their disability did not figure in their position on the…priority [funding] list while in parental custody.” They additionally observed: “[O]ur experience, as parents and from 8 years spent on a local TCC, convinces us that parents, both natural and adoptive, will endure and cope with very serious emotional disturbance and disruptive behavior before they seek help from the state. Disturbed children living with caring and capable parents are often more seriously ill than some who are in state custody and therefore eligible for treatment through the TCC funding. We know that Georgia is responsible for those in its custody, but CATCH thinks Georgia is also responsible to treat all of its disabled citizens equitably.” For further information on the Georgia survey contact: CATCH, 100 Edgewood Avenue, N.D., Suite 502, Atlanta, Georgia 30303; (404) 527-7175.

Adapted from the CATCH Newsletter 3(3).

Upcoming National Respite Care Conference

Challenge to Change—Respite Care in the '90s is the theme for the national conference on respite care to be held on November 27-30, 1990 at the Hyatt Regency on the Riverwalk in San Antonio, Texas. The conference is sponsored by Texas Respite Resource Network, a program of the Texas Planning Council for Developmental Disabilities funded by the Texas Rehabilitation Commission and a special effort of Children's Hospital, Santa Rosa Health Care Corporation. Stipends will be available to Texas families. For further information contact: Texas Respite Resource Network, P.O. Box 7330, 519 W. Houston, San Antonio, Texas 78207-3198; (512) 228-2794.
LEGAL ADVOCATES ADDRESS CUSTODY ISSUE

The following are excerpted from letters received from three attorneys

Wisconsin

To the Editor: I am very interested in your Center's ongoing investigation into issues relating to the placement of children in residential treatment programs. I thought you might be interested in hearing about the situations and issues we are facing here in Wisconsin.

The Wisconsin Approach. A central focus of your work is the problem faced in many states in which a parent is forced to surrender legal custody of his or her child in order to obtain services at a residential treatment center. Currently in Wisconsin almost all placement of children into privately operated residential treatment centers (which are termed Child Caring Institutions or CCIs under our administrative nomenclature) is by court order. There is, however, a statutory presumption against any transfer of custody as part of the placement.

Section 48.34(4) of the Wisconsin Statutes prohibits the transfer of legal custody as part of a juvenile court disposition unless "it is shown that the rehabilitation or the treatment and care of the child cannot be accomplished by means of voluntary consent of the parent or guardian." Most county agencies making placements find the ongoing participation of a child's parents to be essential if they are to accomplish a reunification of the family as part of the statutorily required permanency planning that must attend an out-of-home placement, including one in a CCI.

Another point considered in the article on treatment center placements in last summer's Focal Point compares voluntary with court-ordered placements. As the article points out, placements under either route can be accomplished either with or without a transfer of legal custody. However, Wisconsin counties strongly favor the use of court-ordered placements. I think this is appropriate because the court is in as good a position as any entity to ensure that this expensive and intrusive alternative is used appropriately and effectively.

CCI placements in Wisconsin cost $3,000 or more per month. This expense is borne by the counties (with a small amount of federal financial participation under Title IV). CCI placements can form a major portion of a county's child welfare budget and force out other services including prevention and in-home treatment programs which, if instituted, might reduce the level of out-of-home placement of children with severe emotional disorders. On the other hand, residential treatment may be the only realistic program that can meet the immediate needs presented by a child and family in crisis.

Extensive waiting lists now exist for voluntary placements in our state mental health institutions. These placements are funded by medical assistance if parents do not have private insurance and thus do not affect a county's child welfare budget. Not surprisingly, there has been about a 400% increase in juvenile hospitalizations over the past five years. During the same period adult placements, no longer funded by medical assistance, have declined by a similar amount.

Private hospital placement is an option for parents who have sufficient private insurance, but even when a hospital will admit a child, the treatment plan is usually severely limited both in terms of length of stay as well as aftercare services. Involuntary commitment of children will result in a placement in a public institution regardless of the waiting list, but these commitments are appropriately rarely issued.

Under our state statutes, when children are hospitalized in either public or private mental health facilities, as opposed to CCI's, permanency planning rules and procedures do not apply. Currently we are working on ways to extend the principles of permanency planning to hospitalization without inappropriate interfering with medical decision-making.

Issues Related to Providing Community-Based Services. At present, however, our main focus is on ways to meet more of the needs of children with severe emotional disorders using community-based modalities. A grant from the Robert Wood Johnson Foundation is funding the development of a model program in Dane County for this purpose and state funds are being used to operate pilot projects in four other counties. We have also recently adopted a new legislative act called "Children Come First," which establishes a procedure counties can use to set up systems of care integrating planning and funding of treatment programs for children with severe disorders.

In establishing these programs and in our advocacy for children around the state we must balance many countervailing factors. Two key issues are: (a) the difficulty parents experience in obtaining services for their children; and (b) the apparent increased severity of problems in children served by county agencies.

Using the juvenile court to mediate these concerns is often necessary. Our statute allows parents to petition the court for services, including an out-of-home placement, if their children are in need of special treatment or care, which is defined as "professional services which need to be provided to a child or his or her family to protect the well-being of the child, prevent placement of the child outside the home or meet the special
needs of the child. This term includes but is not limited to, medical, psychological or psychiatric treatment, alcohol or other drug abuse treatment or other services which the court finds to be appropriate.” [s. 48.02(176m) Wis. Stats.]. The juvenile court cannot, however, use this statute to order a child to take psychoactive medication or to commit the child to a mental health facility.

A precarious balance must always be sought in designing regulatory schemes. Thus, while I am in complete agreement with getting rid of the need to relinquish parental rights to obtain out-of-home services, I am not in favor of moving to a system that favors voluntary placements in CCI’s. As several of the articles in Focal Point about parents caught in the crush of inappropriate state policies point out, the real issue is often money, not legal custody. There is no assurance that changing legal status will increase funding.

Treatment and care for children with severe emotional disorders and their families must be offered in a comprehensive and planful way. Statutes that somehow try to serve a child without recognizing that child’s necessary connection with and immersion in the context of his or her family are outdated and short-sighted. Unfortunately, statutes that do not take into consideration the need for the management of conflicts over treatment options and resource allocation are also unrealistic. John Franz.

John Franz, J.D., is an attorney and legal consultant to The Calliope Project, Wisconsin Council on Human Concerns; Madison, Wisconsin.

Minnesota

To the Editor: In the interest of being helpful to advocates in other states who will address the issue of transferring legal custody to receive necessary services in their state legislatures, I wanted to share my concerns regarding the Iowa model described in the Summer 1989 issue of Focal Point. My concern is that where a child needs longer than six months of residential care, the burden is placed on the parents under the Iowa statute to document their willingness to participate in case planning and fulfill their responsibilities to the child “as defined in...the case plan.” The statute creates a presumption that treatment beyond six months can only be accomplished where the child is committed to the commissioner or legal custody is transferred, unless the parent meets that burden.

I would argue that the presumption should always be in favor of the parent/child legal relationship and that the burden should always be on the state to show good reason why that should be altered. That is the presumption in almost every area of law that touches on the parent-child relationship; why should the presence of a disability or the need for treatment shift that presumption?

Furthermore, I have seen all too many instances where parents were unaware of their right to participate in any case plan development, and the result is often the creation of case plans that are truly stacked against the parent—that is, case plans that create unreasonable and impossible responsibilities that parents could never fulfill and case plans that offer no supportive services to help families. The county agency is then able to argue in juvenile court later on that the parent “violated the terms of the case plan” or failed to meet up to their agreed upon responsibilities under the case plan. Excuse my cynicism, but it is fairly well founded upon the experiences of many parents who lacked the legal savvy to look down the road at the possible consequences of a case plan, or who were told that they had to sign the agency-drafted case plan in order to receive services, or who did not keep the type of “documentation” necessary to avoid the presumptive transfer of legal custody when their child’s treatment needed to extend beyond six months. As we all know, these are people under severe emotional and economic stress.

Minnesota has a similar six-month renewable voluntary placement provision for children in foster care that requires that after six months, the county social service agency must file a juvenile court petition (usually seeking transfer of legal custody) or within two years petition to terminate parental rights. This statute, however, long has had an exception for children with developmental disabilities which requires that there only be a court review of the placement but does not require the agency to bring any type of petition.

As was also described in the Summer 1989 Focal Point, I successfully lobbied an amendment to add children with emotional disorders to that exception. As a result, children with emotional disabilities who are in residential care for more than six months must have court review every six months to determine that the placement is in the best interest of the child but the requirement of a juvenile court petition or termination petition does not apply to them either. I wanted the more frequent court review of children in treatment for emotional disabilities in order to assure that these children were not dumped or allowed to be forgotten in possibly inappropriate treatment settings. This review every six months also allows the child’s attorney or other advocate the opportunity to present any evidence that perhaps a given treatment setting is not in the child’s best interest.

The important difference between this statute and the Iowa model, however, is that children with disabilities who are in need of out-of-home care because of their disabilities are not lumped together with children whose out-of-home placement may be due to abuse, neglect, abandonment, etc. Keep in mind also that this language does not preclude the social service
agency from bringing a juvenile court petition and seeking legal custody or other dispositions where independent grounds (such as neglect) might exist in the case of a child with an emotional disorder. It merely removes the requirement that such a petition be brought when it is not necessary or appropriate.

There has been one ongoing problem since the law was changed in Minnesota. With respect to parents who had relinquished custody prior to the date the legislation went into effect, the juvenile court has said, “So what? This law didn’t go into effect until later.” If I had it to do over again, I would add language requiring the court to review the reasons for the initial relinquishment. Parents who relinquished custody prior to the date of the amendment should have the opportunity to regain custody. Kathy Kosnoff.

Kathy Kosnoff, J.D., is an attorney with the Minnesota Mental Health Law Project; Minneapolis, Minnesota.

Idaho

To the Editor: The requirement of state social service agencies that parents relinquish custody so that their children can receive services is a nationwide problem. Idaho’s Coalition of Advocates for the Disabled (CO-AD, Inc.) represented a young person with a developmental disability eight years ago who was in need of community residential placement. The parents adamantly refused to sign the standard affidavit stating that they had “abused and/or neglected” their child in order to obtain funding for such placement. We were successful in asserting our client’s right to such community placement without reference to his custody status under our state developmental disability statute. Unfortunately, in a subsequent case the Idaho Supreme Court ruled that the statute was, to a large extent, unenforceable to those people it was intended to benefit.

I am afraid that there is, in many states, an additional barrier to the provision of services to children that relates to custody. In Idaho and other states, the Title XX Social Services Block Grant plans submitted by the state makes those funds available for services only to those children who are in the custody of the state. In Idaho at least, this provision of the plan is not based on a mistaken belief that such a custody transfer is required. Rather, the requirement is imposed on the state by its own plan as a “gatekeeper.” The theory is that only those children who are most severely in need of services should get the limited funds. It is assumed that those children in state custody are those most in need of services. Brent Marchbanks.

Brent Marchbanks, J.D., is an attorney and director of the Coalition of Advocates for the Disabled; Boise, Idaho.

Parents’ Perspective

I am the mother of a twelve year old child with a serious emotional disorder who has been institutionalized at a state hospital for three years now. He recently got a new label—schizophrenia. After many years, my husband and I have finally accepted that our son will never lead a “normal” life. The doctors say that he will have to live his life in a sheltered environment.

There are many questions in our heads and many feelings to be expressed. Do you know how it feels to have your son so out of control that he does not even recognize his own mother? Do you know how angry and helpless it feels to see your son in a strait jacket and four-point restraints for the first time?

Do you know what it feels like to have your son away from home for so long that you don’t know what his favorite foods are or what he likes to watch on TV? We have had some very short passes—eight hours at the most because that is all that the doctors say he can handle. But this is not nearly enough time to reacquaint yourself; to have him home is like having a stranger visit—not your own flesh and blood.

It is heartbreaking to know that your son is spending his young years in an institution when this is the very time that he needs to be growing up with his family. He is only little once and we are missing out on an important part of his life. Sometimes I wonder, though, if he even cares.

Do you know what it is like to wonder what is really going on in his head; to wonder why he does (or doesn’t) do certain things? To try to understand him and his illness is really very hard. All we can do is accept and love him as he is.

Anyone who has a child with a serious emotional disability who is maintained at home on medication is very lucky. Although I went through hell before we finally got him institutionalized, I would give anything to bring him home to stay. Anonymous.

Reprinted with permission from Key Notes (Second Quarter 1990), the newsletter of Keys for Networking, Inc. (Topeka, Kansas), a statewide information and support network for families of children with emotional disabilities.

Editor’s Note: Parents are invited to submit contributions, not to exceed 250 words, for the Parents’ Perspective column.

National Clearinghouse on Family Support and Children’s Mental Health
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
1-800-628-1696.
Having Our Say

This column features responses to questions posed to readers. In this issue we feature responses by parents to the question “What is the most helpful thing a professional ever said to you?”

- “It’s not your fault! You are not powerful enough to have caused the kinds of problems your child has.”
- “What do you need for yourself?”
- “I think your son could be a success story for our agency.”
- “No professional has ever been helpful in this situation with my son.”
- “I value your input.”
- “Under the circumstances, you are doing the best you can do. Frankly, I don’t know what I would do or how I would be able to carry on.”
- “If you were a perfect parent, your son would still be in this condition.”
- “I agree with you.”
- “Your son has made progress and I know he can do more, so we will continue to work with him.”
- “Why are you taking all of the blame? It takes two to make or break a relationship.”
- “I don’t know. I can’t tell you what’s wrong with your child or what caused the problem.”
- “Your child knows right from wrong. She knows most of society’s values and that’s because you taught them to her.”
- “There is a lot of love in your family.”
- “You know, it’s okay to take care of yourself too.”
- “I don’t know. I have to give that serious thought.”
- “Believe in your instincts. You’re the expert on your child.”
- “You’re being too hard on yourself.”
- “Our agency will take your case.”
- A professional wrote to a parent who was shy about participating in a support group: “Thanks so much for your participation in the group. Your intelligence and your calm reasonableness are important influences in the group.”

Editor’s Note: We would like to thank the following for their help in collecting these comments: Glenda Fine, Parents Involved Network and Research and Training Center National Advisory Committee (Pennsylvania); Mary Gentry, Keys for Networking (Kansas); Maggie Mezera, Wisconsin Family Ties; and Barbara Melton, Research and Training Center National Advisory Committee (Oregon).

Why Not?

Why not speak frankly to our children who have behavioral, emotional and/or mental disorders about their disabilities? Why not divulge all—to our inner selves, our families, our spiritual communities, educators and, in particular to our children who experience their disabilities every day? Why talk around it, gently and timidly, when naming or describing it can demystify and disarm the power that makes us afraid of it? Unfortunately, some of our children live with disorders that will always remain part of their everyday lives. Why not, as soon and as far as possible, include them in education about their disorder, consider them part of the planning team for their IEPs and medical care, and teach them to collaborate with those providing care?

Why not teach our children with disabilities to advocate for themselves and to educate their peers? Why not equip them to speak frankly about their needs, wants and feelings? Why not give them the tools they will need to gain and keep as much control over their lives as possible? Some of our children with disabilities will become adults with disabilities. Why not raise them to be knowledgeable, comfortable and accepting of themselves, articulate and assertive? Why not give them the gifts we want all our children to receive—courage, self-determination, knowledge of themselves, self-acceptance and self-sufficiency? C.W.

Editor’s Note: Readers are invited to submit contributions, not to exceed 250 words, for the Why Not? column.
New Resource Materials Available

Seven new publications are now available through the Research and Training Center's Resource Service.

- **Therapeutic Case Advocacy Trainee's Guide: A Format for Training Direct Service Staff and Administrators** is an aid for trainers, managers, administrators, and other professionals for establishing a collaborative unit or a task group to deliver services to children and youth with serious emotional disabilities and their families. The guide addresses the primary activities of professionals using interagency collaboration to establish comprehensive systems of care for children and their families and is supported by the *Therapeutic Case Advocacy Workers' Handbook*.

- **Issues in Culturally Competent Service Delivery: An Annotated Bibliography** summarizes articles and books that address theoretical perspectives regarding culturally-appropriate service delivery and that suggest practice applications of theory and research. Multicultural issues that are applicable to more than one group are reviewed and culturally-specific sections address issues relevant to African-American, Asian-American/Pacific Islander, Hispanic-Latino American, and Native American groups.

- **Brothers and Sisters of Children with Disabilities: An Annotated Bibliography** provides a comprehensive review of the literature on brothers and sisters of children with emotional disorders and also includes considerable materials addressing brothers and sisters of children who have physical, mental, or developmental disabilities. The topics addressed include: (a) the effects of children with disabilities on their brothers and sisters; (b) the relationships between children with disabilities and their siblings; and (c) services and education for family members.

- **Next Steps: A National Family Agenda for Children Who Have Emotional Disorders** briefly describes each of the four major issues addressed at the conference and includes the work groups' recommendations. The booklet is designed for use in educating administrators, policy-makers, and the general public about children's mental health issues. The concise format of the twelve page booklet is intended for wide distribution and easy review by busy policy-makers.

- **The Statewide Parent Organization Demonstration Project Final Report** summarizes project efforts to: (a) stimulate and support the development of model statewide parent organizations that have the capacity to provide technical assistance, information, support, and networks to parents and parent organizations within states; and (b) evaluate the conceptualization, implementation, and outcome of these models to inform decision-makers about the most effective approaches in promoting such activity within states. Efforts funded by the Statewide Parent Organization Demonstration Project in Hawaii, Minnesota, Montana, Virginia, and Wisconsin are described.

New Resources for Legislators Available

The National Conference of State Legislatures has recently published *What Legislators Need to Know About Children's Mental Health*. This monograph addresses such issues as: What is an emotional disorder? What services do children with emotional disabilities need? How are services delivered in the educational, juvenile, health, child welfare, and mental health systems to children with emotional disorders? How are children's mental health services financed?

Additionally, the National Conference of State Legislatures has published *What Legislators Need to Know About Mental Retardation and Developmental Disabilities*. Among other topics, the monograph describes mental retardation and developmental disabilities; necessary services; available federal assistance; and state efforts on behalf of persons with developmental disabilities in the areas of family support, housing, supported employment, integrated education, and transition programs. For ordering information contact: National Conference of State Legislatures, Book Order Department, 1050 Seventeenth Street, Suite 2100, Denver, Colorado 80265; (303) 623-7800.
OSERS Assistant Secretary Appointed

Robert R. Davila, Ph.D., has been appointed by President Bush to serve as Assistant Secretary, Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education. Dr. Davila has become an international spokesperson on issues affecting the education of individuals who are deaf and hearing impaired. Assistant Secretary Davila is fluent not only in English and American Sign Language but Spanish as well, and he has authored articles appearing in numerous professional journals related to education of students with hearing impairments. Prior to his role as Assistant Secretary, Dr. Davila appeared regularly on Capitol Hill to testify as an expert witness on issues relative to deafness, hearing impairment and education, and rehabilitation of individuals with disabilities. Dr. Davila brings to his new position a strong determination to promote collaboration between various disability and advocacy groups and among special educators, vocational rehabilitation and research professionals. “Of course each group’s needs, situations and perspectives are unique,” Dr. Davila has said, “but we have an overwhelming need in common: we must advocate for all people with disabilities and ensure that all our educational and rehabilitation needs...are met.” As the new head of OSERS, Dr. Davila will administer an annual budget of nearly four billion dollars, and will have authority for federal involvement in programs affecting the nation’s thirty-six million individuals with disabilities. Prior to his appointment as Assistant Secretary, he served as a Professor of Education and as a Vice President for Pre-College Programs at Gallaudet University.

Toward a Culturally Competent System of Care: Effective Services for Children of Color Who Are Severely Emotionally Disturbed in Boulder, Colorado July 22-26, 1990. The training institutes addressed the development of effective services for African-American, Asian-American, Hispanic-American, and Native American children and adolescents who have serious emotional disabilities. The intent of the training sessions was to provide in-depth, practical information on how to adapt services to fit the needs of children and adolescents of color and their families. Program examples covering a wide variety of service alternatives including in-home services, crisis services, case management, school-based, outpatient, day treatment, and comprehensive service systems were highlighted. The Institutes additionally covered topics such as cross-cultural training, approaches to bilingual and bicultural services, an Afro-centric service delivery model and a county-wide, multicultural service delivery model. A feature of the conference was the opportunity to meet informally with workshop leaders and speakers. For further information on the training institutes contact: CASSP Technical Assistance Center, Georgetown University Child Development Center, Georgetown University Child Development Center, 2233 Wisconsin Avenue, N W, Suite 215, Washington, D.C. 20007; (202) 338-1831.

House of Representatives Approves Education Program

The United States House of Representatives has approved legislation (HR 1013) that would reauthorize the discretionary programs of the Education of the Handicapped Act (Public Law 94-142). Both this proposed legislation and its counterpart in the Senate (S 1824), include a new program specifically for children and adolescents with serious emotional disorders. The house bill would authorize grants to states and local school districts for, among other activities: improvement of special education services for children with emotional disorders, development of strategies to increase the use of day treatment and reduce out-of-community residential treatment, placement of mental health services in the schools, and improvement of the working relationship between families, community agencies and the schools. According to a recent Legislative Alert from the National Mental Health Association, HR 1013 would also expand the definition of children.

Training Institutes on Cultural Competence

The Child and Adolescent Service System Program (CASSP) Technical Assistance Center at Georgetown University hosted
eligible to receive special education services to include children with attention deficit disorder, expand opportunities for students with disabilities at the preschool and postsecondary levels, and establish funding priorities for activities serving minority children with disabilities.

A House-Senate conference committee must meet to reconcile the differences in HR 1013 and S 1824. A key difference is the different funding levels for the program for children with serious emotional disorders. The Senate bill would provide $28 million in funding, while the House bill would authorize $50 million in funding over the next five years. For further information contact: National Mental Health Association, 1021 Prince Street, Alexandria, Virginia 22314-2971; (703) 684-7722.

Bill Introduced in Congress for Children's Mental Health Services

A bill has been introduced in Congress to establish a new federal grant program for the development of comprehensive community-based services for children with serious emotional, behavioral or mental disorders. The bill (HR 5206), known as the Children's and Communities Mental Health Improvement Act, is based upon the recommendations of an ad hoc coalition led by the National Mental Health Association and the Children's Defense Fund. The bill was introduced by Representatives George Miller (D-CA), Henry Waxman (D-CA), Steny Hoyer (D-MD), William Goodling (R-PA), and Doug Walgren (D-PA). As the National Mental Health Association has described in a recent Legislative Alert, the bill would: authorize grants to states on a competitive basis; require states to establish local systems of care; ensure collaboration among agencies; involve parents in the planning and delivery of services; ensure that each child has an individual service plan and a designated case manager; and authorize funds to be spent for services such as day treatment, intensive home-based services, respite care, therapeutic foster care, and transition services. For further information contact: National Mental Health Association, 1021 Prince Street, Alexandria, Virginia 22314-2971; (703) 684-7722.

NIDRR Director Selected

William H. Graves, Ed.D. was appointed by President Bush to serve as director of the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services (OSERS), U.S. Department of Education, in March 1990. The NIDRR funds a wide range of research, demonstration and utilization projects (including rehabilitation research and training centers such as the Portland, Oregon center) that relate to disabling conditions in humans of all ages and of all nature, including physical, sensory, and mental impairments. Dr. Graves is a widely respected authority in the field of rehabilitation of people with visual disabilities and is the former director of the Rehabilitation Research and Training Center on Blindness and Low Vision at Mississippi State University. He has authored more than thirty articles in professional journals in the field of rehabilitation and has served on the editorial boards of a number of rehabilitation journals. Dr. Graves was the recipient of the Mary E. Switzer Fellowship award for research on “Leadership Behavior in Rehabilitation,” in 1979 and the Distinguished Service Career Award from the National Council on Rehabilitation Education in 1988. He has also been the project director on many funded programs dealing with rehabilitation of individuals who are blind and visually impaired.

Call For Papers

The Research and Training Center for Children's Mental Health has issued a call for papers for its annual research conference A System of Care for Children's Mental Health: Expanding the Research Base. The conference is scheduled for February 18-20, 1991 in Tampa, Florida. The conference will focus on research information about how to best organize and deliver services to children and adolescents with serious emotional disorders and their families through systems of care. The Center seeks papers that present findings on service system research, evaluations of service systems, studies of the effectiveness of innovative services, or epidemiological research in children's mental health. They are additionally interested in descriptions of proposed research, pilot research or initial data collection for poster sessions. For further information contact: Dr. Al Duchnowski, Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Boulevard, Tampa, Florida 33612-3899; (813) 974-4500.
"Dare To Dream" Theme of Federation of Families Annual Meeting

The second annual meeting of the Federation of Families for Children's Mental Health will be held on Saturday and Sunday, November 10 and 11, 1990 at the Sheraton National Hotel in Arlington, Virginia. Conference sessions will focus on research, advocacy, issues in education and family support and other topics of interest to family members, professionals, and others who wish to improve services for children and adolescents with emotional, behavioral or mental disorders. A pre-conference workshop for state contact persons will be held on Friday, November 9, 1990. For registration information contact Al Duchnowski, Research and Training Center for Children's Mental Health, Florida Mental Health Institute, University of South Florida, 13301 Bruce B. Downs Boulevard, Tampa, Florida 33612-3899; (813) 974-4500.

In Memorium

Duane Doidge, former director of the Tennessee Child and Adolescent Service System (CASSP), died June 12, 1990 of leukemia. His loss is felt not only by those closest to him, but also by his colleagues across the United States. In addition to his efforts on behalf of Tennessee's children and families, Duane was active nationally as a voice for troubled children. A tribute from his "CASSP family" read at his memorial service noted, "Duane had a 'gift for giving'—whether it was sharing ideas, listening to a colleague's frustrations, or simply telling wonderful stories. One of our fondest memories of Duane is his masterful rendition of ghost stories told at the tomb of Edgar Allen Poe in Baltimore several years ago...We want it known that Duane will always remain a part of the CASSP family in our hearts."

CASSP and SMHRCY (State Mental Health Representatives for Children and Youth) members established a scholarship fund on behalf of Duane's eight year old daughter.

We extend our sympathies to Duane's family and friends.

Family Resource Coordinator Joins Research and Training Center

Colleen Wagner has joined the staff of the Research and Training Center as the Family Resource Coordinator. Colleen responds to telephone and mail requests for information about a variety of topics of interest to family members, professionals, and policymakers related to children's mental health; staffs the National Clearinghouse's toll-free telephone line; and maintains the Center's library. She is actively involved in a local group of family members who are working to improve services for families whose children have serious emotional disabilities. In conjunction with other group members, Colleen is currently planning an October workshop on individualized education programs (IEPs) for parents whose children have emotional disorders.

Colleen is the mother of four children. Her seven year old son has autism. She has sought services for her own son and family and has provided support and information to other families seeking a variety of services including assessment, schooling, and speech therapy. Colleen has presented oral and written testimony in the Oregon Legislature in support of early intervention services for pre-school children with disabilities. She also participated in the development of a videotape at the Oregon Health Sciences University that is designed for use as a teaching tool for professionals who work with parents of children with disabilities. The Research and Training Center is particularly fortunate to have Colleen on staff. Colleen is a valuable consultant to other staff members about the interests, needs, and experiences of families.

Social Work Educators Focus on Family Preservation

Helping families stay together was the theme of the Family Preservation Institute for Social Work Educators held in Kansas City, Missouri August 9-11, 1990. The meeting was sponsored by the National Association of Family-Based Services, which
identifies the following value base for family-based services:

- The family is the best environment for the growth and development of children;
- Services should focus on the entire family;
- The purpose of services is to empower families;
- Services build on family strengths; and
- Services to families represent a shared family, professional, and community responsibility.

The phrases, "family preservation, family-centered care, and family-based practice" were heard in presentations, work sessions and informal discussions as faculty from schools of social work focused on ways to integrate family-centered practice into professional social work curricula. In his opening presentation, "The Leadership Challenge for Family-Based Practice," James K. Whittaker compared traditional, specialized, "child saving" approaches with a family-centered approach based on the concepts of a service continuum, promoting competence in children and families, the central place of family support, and a re-emergence of the person-in-environment perspective.

Ann Hartman, Dean of the School of Social Work at Smith College, discussed theoretical and value issues related to family-centered services, beginning her address with the observation that the definition of family is a political issue. Key concepts and definitions related to family preservation and family-centered service were reviewed by Anthony Maluccio, University of Connecticut School of Social Work. Grafton Hull, Council on Social Work Education, addressed accreditation and implementation issues. Marylee Allen, Children's Defense Fund, addressed current legislation and policy affecting the provision of family-centered services. She emphasized the importance of professional education, noting that, "Congress needs to understand the connection between good services, good staff and good outcomes."

Other presentations addressed research on current curriculum content, the connection between family preservation and ethnic-competent practice, agency-university partnerships, locating funding for specialized training programs, and identifying key practice skills and knowledge.

During the two-day conference participants also met in interest groups to exchange ideas about curriculum content as well as to develop strategies to bring about curriculum change. For more information about the conference or about the National Association of Family-Based Services contact: Neal Sheeley, President, National Association of Family-Based Services, P.O. Box 005, Riverdale, Illinois 60627.

Midwest and Western CASSP Directors Hold Meeting

Directors of Child and Adolescent Service System Programs (CASSP) from Midwest and Western states met in Jackson, Wyoming from August 21-25, 1990 to review their CASSP initiatives and discuss common concerns in developing effective services for children with emotional disorders and their families. Major topics covered included issues of service delivery in rural areas, program development with Native Americans, collaboration with special education, research and evaluation methods, and changes within the Medicaid program. The meeting included representatives from the National Institute of Mental Health, the American Public Welfare Association, the Mountain Plains Regional Resource Center, and the Research and Training Centers in Portland, Oregon and Tampa, Florida.

One of the highlights of the meeting was a presentation by Glen Latham and Carl Smith from the Mountain Plains Regional Resource Center on the current state of special education services for children with emotional disorders. The Center is funded by the U.S. Office of Special Education to conduct research and training in the area of special education and serves ten western states and the Bureau of Indian Affairs. Latham and Smith outlined the need for improved training of both special education and regular classroom teachers in techniques that can benefit students with emotional disorders. Both cited work done by the Center as well as others which indicated that special education students are often differentially treated in the classroom, are too often excluded from educational opportunities available to other students, and have a substantially higher school drop out rate than the general student population.

Latham and Smith emphasized the need for state mental health and special education systems to coordinate efforts on behalf of these students and their families. In this regard, the Center is sponsoring a working conference in Denver, Colorado in early October that will focus on assisting western states to develop coordinated service delivery for children with emotional disorders. State delegations consisting of heads of mental health and special education departments as well as parents of special education students will be attending the conference and developing action plans for improved services. Information on the conference and its results may be obtained from: Dr. Glen Latham, Mountain Plains Regional Resource Center, Utah State University, 1780 N. Research Parkway, Suite 112, Logan, Utah 84321; (801) 752-0238.
Research and Training Center Resource Materials


- Annotated Bibliography. Youth in Transition: Resources for Program Development and Direct Service Intervention. Transition needs of adolescents: educational and vocational issues, programs and curriculums, research overviews, interpersonal issues, skills training. $6.00 per copy.

- NEW! Brothers and Sisters of Children With Disabilities: An Annotated Bibliography. Addresses the effects of children with disabilities on their brothers and sisters, relationships between children with disabilities and their siblings, services and education for family members. $5.00 per copy.

- Changing Roles, Changing Relationships: Parent-Professional Collaboration on Behalf of Children With Emotional Disabilities. The monograph examines barriers to collaboration, the elements of successful collaboration, strategies for parents and professionals to promote collaborative working relationships, checklists for collaboration, and suggested resources for further assistance. $4.50 per copy.

- Child Advocacy Annotated Bibliography. Includes selected articles, books, anthology entries and conference papers written since 1970, presented in a manner useful to readers who do not have access to the cited sources. $9.00 per copy.

- Choices for Treatment: Methods, Models, and Programs of Intervention for Children With Emotional Disabilities and Their Families. An Annotated Bibliography. The literature written since 1980 on the range of therapeutic interventions with children and adolescents with emotional disabilities is described. Examples of innovative strategies and programs are included. $6.50 per copy.


- Gathering and Sharing: An Exploratory Study of Service Delivery to Emotionally Handicapped Indian Children. Findings from Idaho, Oregon, and Washington, covering current services, successes, service delivery barriers, exemplary programs and innovations. $4.50 per copy.

- Glossary of Acronyms, Laws, and Terms for Parents Whose Children Have Emotional Handicaps. Glossary is excerpted from the Taking Charge parents' handbook. Approximately 150 acronyms, laws, and words and phrases commonly encountered by parents whose children have emotional disabilities are explained. $3.00 per copy.

- Interagency Collaboration: An Annotated Bibliography for Programs Serving Children With Emotional Disabilities and Their Families. Describes local interagency collaborative efforts and local/state efforts. Theories of interorganizational relationships, evaluation of interagency programs, and practical suggestions for individuals contemplating joint programs are included. $5.50 per copy.

- NEW! Issues in Culturally Competent Service Delivery: An Annotated Bibliography. Perspectives on culturally-appropriate service delivery; multicultural issues; culturally specific African-American, Asian-American/Pacific Islander, Hispanic-Latino American, Native American sections. $5.00 per copy.

- Making the System Work: An Advocacy Workshop for Parents. A trainers' guide for a one-day workshop designed to introduce the purpose of advocacy, identify sources of power and the chain of command in agencies and school systems, and practice advocacy techniques. $8.50 per copy.

- The Multnomah County CAPS Project: An Effort to Coordinate Service Delivery for Children and Youth Considered Seriously Emotionally Disturbed. A process evaluation of an interagency collaborative effort is reported. The planning process is documented and recommendations are offered. $7.00 per copy.

- National Directory of Organizations Serving Parents of Children and Youth with Emotional and Behavioral Disorders. The 344 U.S. organizations in the second edition provide one or more of the following services: education and information, parent training, case and systems level advocacy, support groups for parents and/or brothers and sisters, direct assistance such as respite care, transportation and child care. $8.00 per copy.


- Conference Proceedings: $5.00 per copy.

- Conference Proceedings and Companion Booklet: $6.00 per set.


- Single Copy: $2.50.

- Five Copies: $7.00.

- Parents' Voices: A Few Speak for Many (videotape). Three parents of children with emotional disabilities discuss their experiences related to seeking help for their children (45 minutes). A trainers' guide is available to assist in presenting the videotape. Free brochure describes the videotape and trainers' guide and provides purchase or rental information.

- Respite Care: An Annotated Bibliography. Thirty-six articles addressing a range of respite issues are summarized. Issues discussed include: the rationale for respite services, family needs, program development, respite provider training, funding, and program evaluation. $7.00 per copy.

- Respite Care: A Monograph. More than forty respite care programs around the country are included in the information base on which this monograph was developed. The monograph describes: the types of respite care programs that have been developed, recruitment and training of respite care providers, the benefits of respite services to families, respite care policy and future policy directions, and a summary of funding sources. $4.50 per copy.

- NEW! Statewide Parent Organization Demonstration Project Final Report. Describes and evaluates the development of statewide parent organizations in five states. $5.00 per copy.

- Taking Charge: A Handbook for Parents Whose Children Have Emotional Handicaps. The handbook addresses issues such as parents' feelings about themselves and their children, labels and diagnoses, and legal issues. The second edition expands upon emotional

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disorders of children, including post-traumatic stress disorder and mood disorders such as childhood depression and bipolar disorder. $7.00 per copy.

- NEW! Therapeutic Case Advocacy Trainee's Guide: A Format for Training Direct Service Staff and Administrators. Addresses interagency collaboration among professionals in task groups to establish comprehensive systems of care for children and their families. $5.75 per copy.


- Transition Policies Affecting Services to Youth With Serious Emotional Disabilities. The monograph examines how state level transition policies can facilitate transitions from the child service system to the adult service system. The elements of a comprehensive transition policy are described. Transition policies from seventeen states are included. $5.75 per copy.

- Working Together: The Parent/Professional Partnership. A trainers' guide for a one-day workshop for a combined parent/professional audience. Designed to identify perceptions parents and professionals have of each other and obstacles to cooperation; as well as discover the match between parent needs and professional roles, and practice effective listening techniques and team decision making. $8.50 per copy.

- Youth in Transition: A Description of Selected Programs Serving Adolescents With Emotional Disabilities. Detailed descriptions of existing youth transition programs are provided. Residential treatment, hospital and school based, case management, and multi-service agency transition programs are included. Funding, philosophy, staffing, program components, and services information is provided for each entry. $6.50 per copy.

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