

FOCAL POINT



BARRIERS TO ACCESSING SERVICES

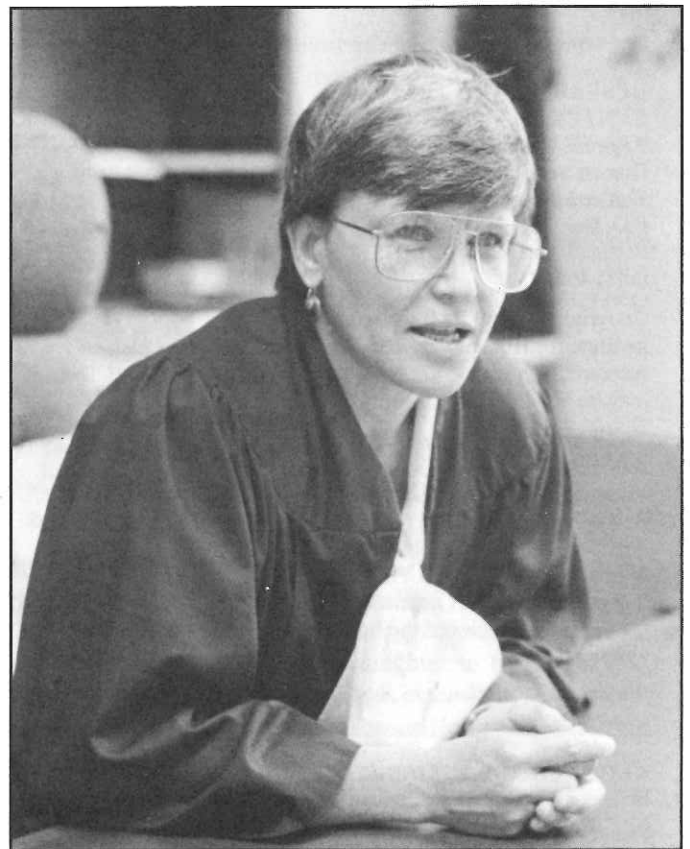
Relinquishing Legal Custody as a Means of Obtaining Services for Children with Serious Emotional Disabilities

We are concerned about parents who have children with emotional disabilities in need of a range of services—particularly out-of-home placement—who have, in countless instances, been required to transfer custody of their children to the state for the sole purpose of obtaining necessary services at public expense. This requirement appears to stem, primarily, from the following: (1) a mistaken belief on the part of state and local officials that federal reimbursement under Title IV-E of the Social Security Act is available only where legal custody of a child has transferred to the state; and/or (2) an attitude that time limited voluntary placement agreements are inconvenient (or disruptive to treatment) and, accordingly, that parental surrender of child custody to the state simplifies matters for the states and agencies involved.

These are not families who have abused, neglected or abandoned their children. Their children are simply in need of residential treatment, and the parents cannot pay the full cost of care. In other words, family circumstances are not such that, without the need for services, parents would consider relinquishing custody, or the state would consider taking legal custody.

We believe that parents should never be presented with a Hobson's choice that requires them to *either* surrender their children into the custody of the state and thereby receive necessary services *or* retain custody and concomitantly deny their children the services they require. Parents should be able to retain custody of their children, continue their involvement in decisionmaking on behalf of their children, and work collaboratively with state authorities to secure needed services at public expense.

Types of Out-of-Home Placements. Public Law 96-272, the Adoption Assistance and Child Welfare Act of 1980 (also known as Title IV-E of the Social Security Act, and



Senior Juvenile Court Referee Katharine English. Multnomah County, Oregon. (Photo by John Kirkland)

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the Permanency Planning Law), sets forth the conditions under which states may receive federal dollars for out-of-home placement. These conditions include a mandate that federal reimbursement for children removed from their homes pursuant to written voluntary placement agreements who have remained in the placement in excess of 180 days, is authorized only where there is a judicial determination (within the first 180 days of the placement) that such a voluntary placement is in the child's best interests.

Voluntary placement agreements do not involve transfer of legal custody to the state. They are, however, time limited—although the length of time varies from state to state—and, in many states, must be judicially reviewed after a specified period of time (often thirty days) to determine whether the arrangement should be continued.

Voluntary custody agreements entail temporary written parental relinquishment of legal custody to a state agency. There is marked variation between states in the legal rights and responsibilities surrendered by parents upon relin-

quishment of custody. For example, in Oregon, parents surrender their rights to make decisions regarding ordinary or emergency medical, dental, psychiatric, and other treatment decisions as well as to participate in decisionmaking about educational matters. Oregon parents retain guardianship of their children and may authorize non-emergency surgery, consent to marry, enlistment in the military, and other decisions of legal significance. In Pennsylvania, parents relinquish the right to make some decisions about treatment, placement and education; although they retain rights associated with the special education process. Pennsylvania parents may refuse placement, have the right to visit their children, and be consulted about medical and educational decisions. They may demand the immediate return of their children. The use of the term "voluntary" to describe this type of custodial arrangement for the purpose of obtaining state funded services may cause confusion as surrender of legal custody is a *prerequisite* to receiving services.

Court orders making children wards of the court by

RESEARCH AND TRAINING CENTER

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We invite our audience to submit letters and comments.

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virtue of a finding of *dependency* due to parental neglect, abuse, abandonment or *delinquency* are a third vehicle for the transfer of legal custody to the state. Four states have no provisions for voluntary placement or voluntary custody agreements. In these states, unless parents can pay the full cost of care, children must be declared dependent or delinquent to receive out-of-home evaluation and treatment services.

Reasons State and Agency Personnel Require Parental Relinquishment of Legal Custody to Obtain Services. Voluntary custody agreements and/or court ordered wardship are routinely sought for the following reasons:

Financial. Some child welfare personnel mistakenly believe that states cannot be reimbursed with federal funds

for the expenses incurred on behalf of children in need of out-of-home services (pursuant to Public Law 96-272) unless legal custody has transferred to the state. (In fact, voluntary placement agreements are permissible and a judicial determination that the voluntary placement is in the best interests of the child is required for reimbursement *only* where the placement extends beyond 180 days.);

Treatment concerns. Residential treatment program staff may prefer that the state child welfare agency have custody so that they do not have to involve or consult parents or risk parents' removing their children from treatment programs prematurely. (Some residential care staff believe that children will be upset, or treatment will be impeded if parents and children have "too much" contact, especially when children first enter a program; accord-

National Survey of Parents Whose Children Have Emotional Disabilities

Parents who participated in a national study conducted by staff of the Research and Training Center's Families as Allies Project were asked, "Has it ever been suggested to you that you give up custody of your child in order to get services?" Of 966 parents who completed the questionnaire, 240, or 25% answered "yes" to the question. Thirty-five percent of those who answered "yes" to this question reported that they *had* given up custody in order to get services—typically residential care.

As the parents who responded to the questionnaire do *not* constitute a random sample of the population it cannot be predicted that giving up custody has been suggested to 25% of all parents whose children have emotional problems. There is, however, no reason to believe that the sampling strategy used for this study selectively included parents to whom this suggestion was more likely to have been made.

Comments of parents about why they were asked to surrender custody, *but chose not to*, include the following:

"To get funding for residential placement."

"Needs long-term treatment and our insurance won't cover this."

"If my son is unable to cope outside the state-supported hospital, I would have to place him in state custody for a group home situation—details are fuzzy on this."

"Children's psychiatric hospital wanted custody in order to get state funds."

"This issue was raised while child was in inpatient treatment. Insurance ran out. We decided to assume financial liability. Glad we did."

"Mental health social worker suggested it the first time we went to see him."

"My child has been in inpatient treatment for nearly a year. Because of extensive costs, a Ph.D. suggested giving up custody so state would handle cost but I decided against it and have applied for financial help from social services."

"To get the proper special education for him."

Comments of parents about why they were asked to give up custody, *and did surrender custody*, include the following:

"For our child to receive care and for the funding to be provided we had to go through dependency hearing and give the county guardianship."

"State law required me to voluntarily surrender custody in order for my daughter to be placed in a residential treatment facility."

"It was felt that my child needed long-term treatment but did not need the restrictive environment of a hospital. I had insufficient funds to pay for a private residential treatment facility. To receive services I had to turn to the state social services agency and give custody."

"After she had lived in the state hospital for one and a half years, we were told that the county would place her in a group home only if we gave up custody because of inability to pay. Diagnosis was that she was not well enough to come home yet."

ingly, visits, telephone calls, and mail may be restricted.);

Legal liability. Some child welfare personnel believe that Public Law 96-272 requires states to have legal custody if children are in out-of-home placement and, moreover, believe that states are "safer" and at less risk of legal liability if they have legal custody of children in their physical custody.

Consequences of Legal Custody Relinquishment Decision. Families who relinquish legal custody of their children for the purpose of receiving services often find that their surrender of custody creates a subsequent *impediment to parent involvement* in their child's treatment. Depending upon the particular state, when parents surrender legal custody, they may lose the right to make certain decisions on behalf of their child. Treatment agencies may or may not choose to involve parents and consult with them on important matters.

Parents may feel *alienation, discouragement*, or perhaps *relief* when their child enters residential care. They may experience *frustration* if they do not know how to be involved with their child and his or her treatment and are not invited to participate.

The decision to relinquish legal custody to the state may

become a *self-fulfilling prophecy*. Although often both parents and professionals are clear that the transfer of custody is voluntary and intended to be of temporary duration, the public perception (and often that of professionals) is that parents who surrender custody to the state are those who do not want their children.

There may be a number of *negative impacts on family integrity*, the ability to stay together, and on *prospects for reunification*. The *psychological separation* as well as physical separation of parent and child may be promoted by the family's lack of familiarity with plans for the child and by the absence of family involvement in decisionmaking and treatment planning. Additionally, *parents' authority may be undermined*. Parents may lose their ability to deal authoritatively and decisively with their children.

Children may not receive necessary services. Parents who are unwilling to surrender legal custody to the state may have no other means of securing services and; accordingly, their children will remain unserved.

Recommendations for Changes. Systematic research is required. This is a complex and confusing area. At a minimum, the following are needed:

Survey of States' Out-of-Home Placement Provisions for Children with Emotional Disabilities

In 1988, Research and Training Center staff sent a questionnaire to all fifty states, the District of Columbia, and Puerto Rico about their provisions for out-of-home placement for children with emotional disorders. Respondents were primarily professionals in the child welfare system. Several specifically mentioned that it is very destructive to families and their children to require parents to surrender custody of their children to the state in order to receive necessary services at public expense. Thirty-nine states, the District of Columbia, and Puerto Rico responded to the questionnaire. Policies vary from state to state and the policy categories may overlap in some instances. Responses from this preliminary examination, however, suggest that:

- Twenty-nine states have provisions for voluntary placement whereby parents agree to out-of-home placement, but retain full legal custody of their children. Depending upon the state, the voluntary placement option is limited to periods of no more than 30, 45, 60, 90 or 180 days respectively. Six

months (180 days) is an insufficient period of treatment time for many children and adolescents with serious emotional disabilities in need of out-of-home care.

- Twenty-two states have voluntary custody provisions, whereby parents may place their children with a state agency that assumes temporary legal custody. Ten of these states have time limits on the length of temporary custody.
- Twelve states have special provisions for placement of children with emotional disorders. Follow-up telephone contacts with some of these states disclosed that the special provisions are often that youth may voluntarily or through a court order enter state mental hospitals for treatment.
- Four states have no provisions for either voluntary placement or voluntary custody. In these states, children must be declared dependent or delinquent to receive out-of-home evaluation and treatment services at public expense.

1. thorough legal analysis of federal law and policy;
2. thorough state-by-state legal analysis of each state's respective laws and policies; and
3. study of the impact that different types of custody arrangements have on families, the treatment process, and family and child outcomes.

An amendment to Title IV-E of the Social Security Act may be one potential vehicle for addressing this national issue. For example, such an amendment could strengthen the incentives for states to use *renewable* voluntary placement agreements and discourage parental surrender of custody of their children to the state solely to receive treatment at public expense.

Changes in state laws may be required. It is difficult to ascertain the changes that may be required pending completion of an analysis of state laws and policies. At present, it is difficult to know where the problem is law and where it is practice.

Creative attempts at problem-solving are required within states. Professionals and parents must work together to examine the problem and its consequences, as well as seek solutions. Suggestions include:

1. ensure that current state laws are followed (i.e. that practice is consistent with the law);
2. emphasize voluntary placement agreements that do not involve the transfer of legal custody whenever possible;
3. although difficult, identify and use non-federal funds or other funding sources that do not have negative consequences for families and children; and
4. develop standards for residential treatment centers related to parent involvement and provide training incentives.

Conclusion. The provisions of Public Law 96-272 were designed to end "foster care drift," and to assure that children have a permanent place to live. The population of children addressed by this legislation, by and large, are children in foster care by virtue of neglect, abuse, abandonment, and other forms of dependency. This "permanency planning" law was not created with children who have serious mental or emotional problems in mind, and does not fit their circumstances or needs very well. These are families who consider surrendering legal custody of their children to the state solely because their children need specialized out-of-home services that they cannot afford.

Relinquishing legal custody to the state for the purpose of obtaining services poses an enormous hardship on families. They lose both the right and the responsibility to make important decisions on behalf of their children.

Among other parental rights and responsibilities, they may be denied access to medical records, information on planned educational activities, and the opportunity to participate in treatment planning. Their children may be moved from one location to another and parents may not even be notified of the change. The possibility of family reunification may be seriously compromised.

Professionals may lose access to information about the children in their care that only family caregivers have. They may lose the unique perspective that only parents can offer in treatment and other planning activities.

Contrary to public policy, state mandated requirements—whether in law or simply in practice—that families surrender custody of their children to the state in order to receive necessary services may (1) discourage families from obtaining needed evaluation and treatment services for their children *or* (2) if families do relinquish custody, seriously jeopardize the integrity of the family unit.

Such a Hobson's choice is unconscionable. Parents should be able to secure necessary (but unaffordable) services for their children with emotional disabilities at public expense, participate in decisionmaking and treatment planning, and retain legal custody throughout the duration of their children's receipt of out-of-home services.

Marilyn C. McManus and Barbara J. Friesen

Adapted from written testimony before the Subcommittee on Human Resources, Committee on Ways and Means, United States House of Representatives. June 1, 1989.



Marilyn C. McManus, J.D., M.S.W. (at left), is Editor, Focal Point; and Resource Services Coordinator, Research and Training Center. Barbara J. Friesen, Ph.D. (right), is Director, Research and Training Center; and Principal Investigator, Families as Allies Project. (Friesen photo by Claude Neuffer)

New York Class Action Suit Unsuccessfully Challenged Custody Relinquishment Law

An unsuccessful class action suit was filed by New York children whose parents could not afford the expense of obtaining needed out-of-home special services challenging a state law that requires parental relinquishment of custody of their children to the state as a condition of the children's admission to residential care facilities at state expense. *Joyner v. Dumpson*, 533 F. Supp. 233 (1982), reversed *Joyner v. Dumpson*, 712 F. 2d 770 (2nd Cir. 1983).

The U.S. Court of Appeals Second Circuit noted:

[B]oth the plaintiffs and the district court conveniently overlooked the voluntary nature of the temporary foster care system...[T]his case involves parents who want their children to enjoy the benefits of a voluntary state-subsidized program while they retain the right to dictate how the service should be administered. In essence, plaintiffs read the Fourteenth Amendment's Due Process Clause so broadly as to render prima facie unconstitutional any strictures in a voluntary social welfare program which *have an incidental effect on family life*. 712 F. 2d at 780.

and furthermore stated:

New York has not been straining family ties by either removing children from their homes or forcing children to

participate in state-funded programs. Rather, the state has simply subsidized a voluntary social service program and allowed each family to decide whether that service satisfies their needs. *The severing of family ties cannot be attributed to the state's administration of the program, but can be attributed to the parents' placement of the child in the program*. Therefore, we cannot conclude that the state's custody transfer requirement 'significantly infringed' plaintiffs' fundamental right to family integrity. 712 F. 2d at 781. (References omitted. Emphasis added.)

In contrast to the Court of Appeals, we firmly believe that limiting parents' rights to access and decisionmaking on behalf of their children produces not an "incidental effect on family life," but, rather, an extraordinary and devastating impact on families. Moreover, the Court "blames the victim" when it attributes the severing of family ties to parents' relinquishing legal custody to the state solely for the purpose of receiving necessary services. The use of the term "voluntary" to describe temporary written parental relinquishment of legal custody to a state agency to obtain services is a misnomer—surrender of legal custody is a *prerequisite* to receiving services.

Alternatives to Relinquishing Custody

Iowa

Iowa uses six month *renewable* voluntary placement agreements specifically for obtaining necessary services at public expense for children with disabilities. This arrangement is contingent only upon the ability and willingness of parents to remain involved with their children.

Iowa Administrative Code Section 441-202.3(234) provides in pertinent part:

Voluntary placements. 202.3(1) All voluntary placement agreements shall terminate after six (6) months unless the placement is extended or court action is taken to commit the child to the commissioner or to transfer legal custody to the department. Voluntary placements may be extended for six (6) months at a time only when:

..., or

(b) There is documentation that the child has an emotional, physical, or intellectual handicap which necessitates care and treatment of a longer duration than six (6) months and documentation that the child's parents or guardian have demonstrated a willingness to participate in case planning

and to fulfill their responsibilities to the child as defined in the voluntary placement agreement and the case plan.

Minnesota

Minnesota Statutes Annotated Section 260.191 was recently amended (effective August 1, 1989) as follows:

Subdivision 1. [Dispositions.] (a) If the court finds that the child is in need of protection or services or neglected and in foster care, it shall enter an order making any of the following dispositions of the case:

...

(3) if the child is in need of special treatment and care for reasons of physical or mental health, the court may order the child's parent, guardian, or custodian to provide it. If the parent, guardian, or custodian fails *or is unable* to provide this treatment or care, the court may order it provided. *The court shall not transfer legal custody of the child for the purpose of obtaining special treatment or care solely because the parent or guardian is unable to provide the treatment or care.* (Amended language in italics.)

Testimony Before the Minnesota House of Representatives' Judiciary Committee on Surrendering Custody to Obtain Treatment Services

As you know, families whose children have chronic, serious illnesses face incredible stresses—both personal and financial. Even middle class parents who seek appropriate care and treatment for their children with mental illness soon find out that private resources and insurance are quickly used up—particularly if any form of residential treatment is required. For the single parent, the low income parent, or the parent with other children who must turn to county social services agencies for help, the difficulties become even more aggravated.

Approximately one year ago, I began to notice in my law practice that, in addition to the usual obstacles in applying for social services, parents of children who have mental illnesses or emotional disabilities were often told that they would have to give up legal custody of their children to the county social service agency in order to obtain treatment services. When I began to investigate how widespread this practice was, I learned that while this is uniform practice in at least one major metropolitan county, it is a practice frequently used in several out-state counties as well.

Of the parents who have contacted me over the last year or so, many had already voluntarily relinquished legal custody of their children. Typically, they were so desperate to get needed care for their children that they didn't stop to question the necessity of this transfer. Most were unaware of the implications and meaning of legal custody in terms of the ability to make critical decisions regarding the future treatment and care of their children.

Those who did question the necessity of transferring legal custody were usually told that Minnesota law re-

quired it and further that federal law (Title IV-E) required that a county have legal custody of a child in order to obtain federal reimbursement for the cost of placement. Neither of these things are true.

Transferring legal custody is an inappropriate disposition where a caring, responsible parent is trying to provide needed care or treatment for a child with a mental or physical disability and simply lacks the financial ability to do it alone. Under these circumstances, taking legal custody of the child away from the parents (a) is contrary to the entire purpose of the juvenile code—which is to strengthen families; and (b) creates additional stresses and confusion for an already troubled child and his or her family.

One of my fourteen year old clients, awaiting a juvenile court hearing on the county's petition to transfer legal custody, asked me, "When this is over, will my mom still be my mom?" We have also found in our practice that a county's policy of taking legal custody also has a significantly chilling effect on the willingness of parents to request county assistance in providing residential treatment. Those who are aware of the significance of losing legal custody (and therefore critical decision-making powers in the life of their child), must weigh such a question long and hard. Unfortunately, many children will not get the care they need so long as such a policy creates this dilemma.

Excerpted from the testimony of Kathy Kosnoff, Staff Attorney, Minnesota Mental Health Law Project. February 21, 1989.

Giving Up Custody—A Georgia Parent's Personal Odyssey

We adopted Dani when she was three years old. In our ignorance, we believed that all Dani needed was a good, stable home and plenty of love. We knew nothing about mental illnesses or serious emotional disabilities. Dani demanded 120% of all the energy in the household. Constant raging fits alternated with bizarre behavior. She cut up my clothes, put dirt in my gas tank, set fire to our house, and threatened our lives.

Immediately upon entering first grade, we were told that something had to be done. For the next several years we went from psychologists, to psychiatrists, to private schools. When we ran out of money, we returned to the

public system. Everyone who treated or taught Dani had quit and said that there was nothing more they could do—she needed long term residential treatment.

On our first visit to a psychologist at the local mental health center, we were told that no services exist for us other than very expensive private residential treatment. We were, by then, far too poor to pay for any of these. Due to limited funds, only the most "in need" children in the custody of the state are funded for private residential treatment. This was the first inkling we had that custody might make a difference about whether Dani got needed treatment or not.

Last year, at a point of desperation, I was referred to a case manager at the Mental Health Association. She became my guardian angel and together we embarked on the painful journey of getting treatment for Dani. With her able help, we got Dani in the state psychiatric hospital where she stayed for eight weeks. Dani was out of the hospital for less than two weeks before she needed readmittance and long term treatment. The case manager told us that Dani could receive residential treatment, but we would have to give up custody to the state.

I hesitated only long enough to realize that we had to do whatever it took to get treatment for Dani. I believe that not to do this for Dani would have been criminal, probably costing my daughter her only chance at a somewhat stable life. I called the Juvenile Court. A staff person told me that a third party had to file charges. The Mental Health Association case manager filed charges of neglect against us, stating that Dani was deprived and neglected because we could not afford (\$40,000 to \$90,000 per year) the necessary hospitalization Dani had to have.

We were summoned to a preliminary court hearing one week later. We met Dani's caseworker and an attorney was appointed to represent Dani. We were asked about our personal bills and, although I handle the family financial affairs, only my husband was allowed to talk. The court took short term temporary custody of Dani until the next hearing. She was to remain in our house until a long term facility could be found and we were ordered to pay \$225.00 per month child support.

The preliminary court appearance had been in June and we were not scheduled to return to court until August. It was a long, hot, frustrating summer, waiting, hoping, praying, that at last relief was on the way.

At the August hearing, Dani's caseworker approached us in the courtroom and told us we had one last chance to change our minds. She asked, "Certainly you must realize that you will have to stand up in court and say that you do not want your child?" That entire afternoon stands out in my mind as a nightmare. Can you imagine what you would have thought of your parents if they had gone to court to give you up?

I got angry. My husband and I have worked for years and pay our taxes. We spent all of our money trying to help Dani. When we could go no further and had to have help, we were made to feel, over and over again, that we have failed. I do not believe that most families who have been dealing with mental illness for years can stand the pressure of this process. If only a few can stand the pressure, the system will be relieved of serving the rest. I am angry enough to believe that this is a deliberate strategy.

At the end of that painful August day in court, Dani was

placed in the temporary custody of the State of Georgia for 18 to 24 months. She remained in our home until placement. We could not take Dani out of the state unless we received special permission and could not take her to the doctor without permission. Dani fell and hurt herself. We had to contact her caseworker before taking our daughter to the hospital.

Someone from the residential treatment program called in October and said that they could take Dani the next day, if we could get her there. Of course I could get her there! Hadn't I been waiting for this day for nine years? Dani and I sat together and cried. We felt that if help truly is available, then we had come one step closer to its beginning.

In order to understand Dani it is important to know that she knew from the beginning that something is wrong with her. When she was very little she used to say that her computer was shorting out. Even now she will say, "It's starting again. Please help me!" Dani is a very intelligent, bright child. She does have some learning disabilities that make it difficult for her to study. She has now been in the residential treatment facility for six months and there is noticeable improvement.

I am frequently frustrated because—even though I tell everyone that I want to be contacted, consulted and included in decisions made about Dani—I am often not contacted. I find out about dentist and doctor's appointments after the fact when Dani tells me about them.

I feel that this entire process is very detrimental to the family. It is detrimental to me and to my husband, but most of all to Dani. Her chances are not as good as they would be if she could remain in the custody of her family while she receives treatment. It feels as if Big Brother is here.

We are in contempt of court for non-payment of child support. We truly do not have the money or we would pay it. We would pay it because it would be the least we could do. We still owe thousands of dollars of doctor's bills that we are paying off. If we paid the child support, we simply would have no home when Dani was ready to return to her family.

Please do not mistake my anger and hurt as not being grateful and appreciative. I am grateful. The most important thing has been accomplished—Dani is in treatment. And let there be *no* mistake, for this I am truly thankful.

Sue L. Smith. Atlanta, Georgia.



*Thirteen-year-old
Dani Smith*

An Idaho Parent Relinquishes Custody

When asked to share my personal experiences and feelings about the barriers to services for children with emotional disabilities, I felt my wounds reopen and the pain ooze from them. We adopted Scott at the age of seven, not having any idea of what lay ahead. Our family suffered pain and frustration when our son was identified as having a serious emotional disability. I found it difficult not only to fight for the label "serious emotional disability" in order to receive services, but also to accept that label once it was established. It was very difficult to come out and say, "I am the mother of a child with an emotional disability." Like millions of other Americans, I am guilty of hiding mental illness in the closet.

Here is my list of barriers to receiving services:

1. General public's lack of education with regard to mental health issues;
2. The stigma of mental illness;
3. School system inadequacies;
4. Improper diagnoses;
5. Distance and appointment scheduling problems with social and human services agencies;
6. Lack of available foster homes or respite care;
7. Not understanding how the system works;
8. Lack of treatment programs; and
9. Required relinquishment of parental rights.

We used to live in a small, remote logging town in North Idaho. I look back now and see that the geographic distances involved were certainly a barrier for our family in attempting to access services. I kept in telephone contact with our caseworker, but actual visits were minimal due to distance.

Scott's school days were constant hell and we were grasping for help. I felt like melting as I walked through the

door of Idaho's social services department. I realize now that I was suffering from the undeserved "stigma" that social services often carry. When we received private treatment, we found that it was expensive, I had to drive a great distance, and I had to take time off from work.

As time passed, our son's problems only became larger. Fortunately, Scott's seventh grade counselor recognized what was happening and really understood, but there was still no help of the type that Scott needed and respite care was unheard of. We did, however, become involved with a support group of parents and families. A lot of tears and anger were shared in that group and through the group we found a private foster home that allowed us to get some occasional rest.

In the end, Scott had to spend a night in jail before we could get him "plugged into" the system. We compared the experience to a cat with a mouse—our family was tossed from one professional or agency to another. Finally we did get Scott the help he needed in an intensive treatment program. But to access this treatment we had another hurdle to cross. We had to go through court proceedings, terminating our parental rights and giving the state custody of Scott. Through the judge's eyes we were seen as neglectful. The pain and frustration of that experience was humiliating to us as parents. And when Scott was finally in treatment, we had one more surprise in store. After two and a half years of intensive residential treatment for Scott during which we received very little information and no bills, we received a lump sum \$95,000 bill.

There are many barriers to receiving the help families may need. Persistence and believing in yourself will help carry you through. I wish good luck to each of you from a mother and a family who have been there.

Linda Weinmann, St. Maries, Idaho.

Kansas Family Refuses to Surrender Custody of Their Son

When our son Terry was in the seventh grade, he began to skip school, get into fights, threaten me, and threaten to commit suicide. A counselor from the local mental health center helped us get Terry into a private hospital for a two week stay. From there he went to a private hospital in Wichita for about six weeks. We drove four hundred miles roundtrip to participate in family therapy sessions and continued the therapy sessions after Terry returned home. He later needed to be readmitted to the private hospital for another six weeks. This time he was initially diagnosed as

having an oppositional disorder and, prior to his release, we were told that Terry suffered from manic depression and possibly had schizophrenia.

Following Terry's initial six week stay at the private hospital, our insurance company notified us that they only covered \$30,000 in lifetime benefits for the entire family. I know that \$30,000 sounds like a lot of money, but it isn't, particularly when you turn in a \$10,000 hospital bill for one stay and a \$2,000 doctor's bill. When Terry was released after his second stay, the hospital bill came to approxi-

mately \$7,000. His doctor's bill was \$1,500, and our deductible was \$1,500. We also had bills from the treatment Terry received at the local mental health center both before and after his hospital stays. We were going deeper and deeper into debt. We and our local counselor wanted to keep our family together and have Terry treated at home. The school and the mental health center tried to help.

When things again soured, we went by the books to get Terry into the state hospital. Our son entered the state hospital for a two week evaluation and a court hearing was scheduled. Two days before the hearing a social worker called and told us Terry would be staying at the hospital. The school counselor, the school psychologist, and my husband and I were served with papers ordering us to appear and we all drove one hundred miles each way to attend the hearing. We brought papers from Terry's school that said he needed help. We had to trick our son to get him to court or else the sheriff's department would have brought him.

When we got to court the social worker and the county attorney told us that they had just discovered that Terry was not in the custody of the state social services department. Since he wasn't in their custody he would be released from

the hospital that day and sent home with us. The two of them and the judge told us that we would have to swear that we were "unfit parents" before Terry could get help. Our heads were spinning. We twice asked if we could admit him to the hospital on a voluntary basis and were told that they could not as they did not have bed space.

I wrote a letter to the governor. As soon as I did that, Terry was admitted to the state hospital on a voluntary basis for eighteen months. I drove two hundred miles roundtrip at least once every week (sometimes two or three times a week) to see him and participate in counseling. He was later readmitted to the hospital for another nine months.

Our insurance is all gone. We still owe the hospital money. We have refinanced our home several times to pay medical fees and cannot afford to borrow again. The financial burden is nothing, though, compared to the stress on the family. Terry is now eighteen and has been home for two years. He has had five jobs in the last six months. One minute he is the most wonderful young man and the next minute he is not the same person. I hear from parents every day and don't know what to tell them to do.

Hellen Strickland. Garden City, Kansas.

Travelling the Oklahoma Panhandle to Receive Services

Our son has a serious emotional disability. Like many other parents, we have received many types of services for our child. There is only one thing that separates us from other parents raising a child with special needs: the distance we must travel to receive services. We live in the Oklahoma Panhandle ten miles from the nearest community. There are *no* services available for our son.

Anyone who has lived or is living with a child with a disability knows how much energy goes into raising that child. We find distance adds tremendous strain to an already difficult situation. When Mark entered the public school system he had many problems adjusting. We drove forty-five miles to the nearest guidance center. They could not help. The next year we drove four hundred miles to a child study center. Still there was no help.

When Mark was in the fourth grade we received a call from the superintendent. Our son had been expelled until we could find help. We were shocked and had no one to turn to for help. There were no support groups or services available close to home. We asked our physician for help. He referred us to a neurologist in Oklahoma City. We cancelled our Labor Day vacation, found child care for our

twelve year old son and sixteen year old daughter, and began our four hundred mile round trip.

After an evaluation and diagnosis that Mark has serious emotional disabilities, we began 250 mile round trips three days a week to receive therapy for him. Because of the distance, these trips took all day. Our son was also attending school two days a week for four hours each day. We were emotionally and physically exhausted. We had to leave very early so that we would be back when the other children arrived home from school.

As Mark improved, our trips decreased and his attendance in school increased. After two years of these 250 mile drives, our school joined a cooperative for children with emotional disabilities. This was both



*Sixteen-year-old
Mark Weaver*

good news and bad news. Mark would finally receive services at school, *but* he would have to be transported 55 miles to another rural school. As there were no alternatives, he began his 110 mile round trip travel to attend classes. Because of the distance, he was scheduled to be in the classroom for four hours each day for two years. More pressure was added to our family life. We felt we had no communication with our son's school. Our other son was in junior high school, our daughter was a high school senior, and Mark was 55 miles from home. Keeping up with each child's activities added still more pressure.

The pressure on our family life was simply too much. We found ourselves in a due process hearing in an effort to receive services at home. We lost the hearing and had to

"mainstream" our son in a regular classroom to keep him at home.

Our daughter is now a senior in college and our oldest son is a senior in high school. Mark is sixteen. This summer we had to admit him to a psychiatric hospital. This was emotionally *very* hard. To add to our stress, we must travel four hundred miles to visit him and participate in family therapy.

Distance *does* make a difference. Without the Lord, our support from friends and employers, and a will to receive help, we could not do it.

David and Vickie Weaver. Buffalo, Oklahoma.

Financing Treatment Services for Children with Serious Emotional Disabilities

One of the most difficult tasks confronting families whose children have serious emotional disorders is paying for treatment and other necessary services. Expenses frequently exceed the limits of family insurance policies—especially if psychiatric hospitalization, residential treatment, or other out-of-home placement is involved. Many families are compelled to refinance their homes in an effort to meet mounting bills and some may face bankruptcy proceedings or even find themselves in contempt of court for their failure to pay expenses that may total hundreds of thousands of dollars. The following materials may be of assistance to families struggling to meet these expenses and to professionals working on their behalf.

Cox, M. & Gittler, J. (1986). *The Title V state programs and the provision of case management services for children with special health care needs*. National Maternal and Child Health Resource Center, College of Law Building, The University of Iowa, Iowa City, Iowa 52242; (319) 335-9046.

Craig, R.T. & Wright, B. (1988). *Mental health financing and programming. A legislator's guide*. National Conference of State Legislatures, 1050 17th Street, Suite 2100, Denver, Colorado 80265; (303) 623-7800.

Fox, H.B. & Yoshpe, R. (1987). *An explanation of Medicaid and its role in financing treatment for severely emotionally disturbed children and adolescents*. Child and Adolescent Service System Program Technical Assistance Center, Georgetown University Child Development Center, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016; (202) 364-4164.

Fox, H.B. & Yoshpe, R. (1987). *Medicaid financing for early intervention services*. National Center for Networking Community Based Services, Georgetown University Child Development Center, 3615 Wisconsin Avenue, N.W., Washington, D.C.; (202) 687-8635.

Lakin, K.C., Jaskulski, T.M., Hill, B.K., Bruininks, R.H., Menke, J.M., White, C.C., & Wright, E.A. (1989). *Medicaid services for persons with mental retardation and related conditions*. Center for Residential and Community Services, Institute on Community Integration, University of Minnesota, 207 Pattee Hall, 150 Pillsbury Drive S.E., Minneapolis, Minnesota 55455; (612) 624-6328.

McManus, M.A. (1988). *Understanding your health insurance options: A guide for families who have children with special health care needs*. Association for the Care of Children's Health, 3615 Wisconsin Avenue, N.W., Washington, D.C. 20016; (202) 244-1801.

Pizzo, P. (Producer). (1988). *Meeting the medical bills*. (Videotape). National Center for Clinical Infant Programs, 733 Fifteenth Street, N.W., Washington, D.C. 20005; (202) 347-0308.

Next Issue

The next issue of *Focal Point* will report on the first national respite conference for families whose children have emotional disabilities, which is scheduled for October 1989 in Covington, Kentucky. We will also provide an overview of the Research and Training Center's projects in the next five years.

Parent Survey on the Issue of Custody Relinquishment

The Commonwealth Institute for Child and Family Studies, a facility of the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services, is surveying 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. The Portland Research and Training Center is collaborating with the Commonwealth Institute in the dissemination of this questionnaire. The results of the survey will be reported in a future issue of *Focal Point*.

Parents, if someone has suggested or recommended that you transfer custody of your child to state or local authorities in order to receive public funding for necessary services, please participate in this survey. Please *do not* participate if surrendering custody of your child has not been suggested to you. Use as many separate sheets of paper as you need to answer the following questions as thoroughly as you can. It is essential that you carefully number each answer to correspond with the question you are answering.

(All survey participants please answer Questions 1-7)

1. Has anyone ever suggested or recommended that you transfer custody of your child to state or local authorities in order to receive funding from the state for the services your child needed? (Yes or No) (Again, please *do not* participate in the survey if your answer is no.)
2. What was your decision? (Answer **Surrendered**, **Did Not Surrender**, or **Still Deciding**)
3. What were the factors that influenced your decision whether or not to transfer custody?
4. How old is your child now?
5. What is your child's diagnosis?
- 6a. Does your child currently live at home? (Yes or No)
6b. *If Yes*, was there a time when your child lived away from home? (Answer **Yes** or **No** and explain if you choose.)

More Next Issue

The next issue of *Focal Point* will review activities and trainings during the last two years in the following areas: parent support efforts including parent groups and other approaches; examples of successful advocacy endeavors on behalf of children and their families; and collaborative efforts between family members and professionals at the individual family, agency, and systems levels.

6c. *If No*, how many years/months has your child been away from home?

7. Please list the state and county or city in which you now live.
8. (Optional) Please provide your name, address, and telephone number if you would not mind being contacted in the future concerning your experiences upon being asked to surrender custody of your child to receive funding for needed services.

(Answer 9 & 10 only if you *did not* give up custody)

9. What impact did your experience of not giving up custody have on *your relationship* with your child?
10. If you chose not to give up custody of your child in order to obtain state-funded services, how have your child's needs been met?

(Answer Questions 11-15 only if you *did* give up custody)

11. My decision to transfer custody in order to obtain state funded services was: (Answer **a**, **b**, **c**, or **d**, and include an explanation if you choose)
 - a. Temporary (As long as services are needed)
 - b. Permanent (My child will most likely not come home)
 - c. Uncertain (My child's status is not yet determined)
 - d. Other
12. How often did you visit your child in the out-of-home placement while he/she was there? (Answer **a**, **b**, **c**, **d**, or **e**, and include an explanation if you choose)
 - a. Almost Every Day
 - b. About Weekly
 - c. About Monthly
 - d. Every Couple of Months
 - e. Never
13. What impact did the experience of giving up custody have on *your relationship* with your child?
14. What impact has out-of-home placement had on your child?
15. How have other members of your family been affected by your decision to transfer custody?

Please return your answers, on or before Nov. 15, 1989, to: Commonwealth Institute for Child and Family Studies, Virginia Treatment Center for Children, P.O. Box 1-L, Richmond, Virginia 23201; Attention: Custody Survey.

Parents' Perspective

Does my child have a mental illness? I don't know and neither does anyone else. She has been difficult, aggressive, tactily defensive and non-compliant since birth. She has a lesion on her brain and takes medication to control her epilepsy. She's had only two seizures this past year. My child has been called "seriously emotionally disturbed."

She does not have mental retardation, schizophrenia, nor manic-depressive illness. She does have a DSM III-R diagnosis—"conduct disorder; undersocialized, aggressive." She was committed to a children's psychiatric hospital when she was six and she (we) received treatment there for ten months. My child has been a consumer of mental health services since she was two years old and has had weekly and monthly sessions with a child psychologist for years.

All seven years of public education have been spent in small, self-contained classrooms for students with behavior disorders. She receives weekly speech and language therapy and has received occupational ther-

apy. My daughter is "significantly academically delayed" and has been kicked out of every day care program she has attended.

She dislikes school, has no friends, and doesn't like baths, blue jeans, or having her hair brushed. She loves her brother, her dog and the snow. Her favorite movie is "E.T." She wears braces, likes to sing, and is quite good on the computer. She loves Michael Jackson, dangling earrings, and things that sparkle. Her favorite food is pizza and she will eat broccoli.

She is beautiful, compassionate, and caring. She is kind and full of love. Sometimes I wonder why. She is the center of my world—my every thought, my every prayer. Does my child have a mental illness? I don't know. And neither does anyone else.

Rebecca Viers. Albuquerque, New Mexico.

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

Why Not?

When asked to write something under the title "Why Not?" my immediate reaction was—Why not?

Why not share my story of Joshua, an adopted son, fragile and yet strong, young and yet old in ways beyond our imagination?

Why not put into words the frustrations and barriers that people with children who are emotionally bent feel every day?

Why not ask for help just one more time? Maybe this time someone will listen and come to his aid.

Why not admit that this child's beautiful face hides a Jekyll who manipulates, lies, controls, and even hates?

Why not realize and admit that adoption isn't a storybook tale of forever love and bonded emotions?

Why not fight to keep custody when agencies, states, and the financial "powers that be" say you must **relinquish in order to receive?**

Why not ask questions, challenge decisions, be a pest,

show concern, speak up, write letters, make telephone calls, read everything you can, while struggling on behalf of the life you promised to nurture?

Why not call out for help to others who face similar problems so that strength can come from weakness?

Why not show that fragile little life, through your actions, that you won't **give up or give in**, knowing all the while he won't believe you?

Why not fight for his life, while sending him away to be taught and guided, at the hands of those in residential care, who are the experts, or so they say?

Why not remind him of the love you hold for him even though distance and feelings separate you for months and even years?

Why not, indeed!!

Beth Cheney. Mountain Home, Idaho.

Editor's Note: Readers are invited to submit contributions, not to exceed 250 words, for the *Why Not?* column.

NOTES & COMMENTS

Research, Training and Technical Assistance Efforts to Continue

Federal funds to continue research, training and technical assistance provided by three centers have been approved. The centers include the Research and Training Center at Portland State University, the Research and Training Center for Children's Mental Health at the Florida Mental Health Institute, and the CASSP Technical Assistance Center at the Georgetown University Child Development Center. The Research and Training Centers, which are jointly funded by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education, and the National Institute of Mental Health (NIMH), U.S. Department of Health and Human Services, have been funded for the 1989-94 five-year period. The CASSP Technical Assistance Center is funded jointly by the Office of Maternal and Child Health and NIMH for a three year period.

The Portland Research and Training Center will focus on improving services to families whose children have emotional disorders through a set of related research and training programs and expansion of the current resource service to include a national clearinghouse. Research efforts will include a study of the ways families use services for their families, a project focusing on the needs and experiences of minority families, two projects aimed at increasing the involvement of family members in planning, implementing and evaluating policies and services, and a study of the collaboration between professionals and family members. Dr. Barbara Friesen will continue to serve as the Center Director.

The Florida Research and Training Center, directed by Dr. Bob Friedman, will extend a longitudinal study of children with serious emotional problems, study successful transition programs for older adolescents, conduct a study of alternatives to residential treatment, and examine financing options, in addition to its training activities.

Dr. Phyllis Magrab directs the CASSP Technical Assistance Center, which is part of the National Network for Children with Special Needs at Georgetown University. She is assisted by Sybil Goldman, Deputy Director and Ellen Kagen, Coordinator. Major projects will include Training Institutes on developing services for minority children and their families, and a national

survey of programs serving minority children and families. The Center will continue to provide technical assistance to states and to focus on financing of services and children at risk.

New Resource Materials Available

Four new publications are now available through the Research and Training Center's Resource Service. *Interagency Collaboration: An Annotated Bibliography for Programs Serving Children With Emotional Disabilities and Their Families*, consists of summaries of articles and books in five sections: descriptions of local interagency efforts, descriptions of local/state efforts, prescriptive publications, attempts to develop and elaborate various theories of interorganizational relationships and evaluations of interagency programs. Some articles contain checklists and practical suggestions for administrators who are contemplating joint programs.

Choices for Treatment: Methods, Models, and Programs of Intervention for Children With Emotional Disabilities and Their Families explores the range of therapeutic interventions used with children and adolescents with emotional problems. The authors attempted to cover the range of interventions and find examples of innovative strategies and programs.

Youth in Transition: A Description of Selected Programs Serving Adolescents With Emotional Disabilities presents detailed descriptions of existing youth transition programs through a national survey conducted during 1988 and 1989. Programs are categorized into five areas, including traditional seven day residential treatment settings, hospital based transition programs, school based programs, case management programs and programs that are part of multi-service agencies.

Transition Policies Affecting Services to Youth With Serious Emotional Disabilities is a monograph that examines how state level policies can facilitate the orderly planning and delivery of transition services to youth with serious emotional disabilities as they move from the child service system to the adult service system. The monograph describes six categories of policies that have been identified and the way in which each category supports transition planning for youth with serious emotional disabilities, examines the nine elements of a comprehensive transition policy with examples from existing state policy, summarizes the transition policies collected from seventeen states, and includes copies of policy documents.

Research and Training Center Resource Materials

- Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals.* Covers relationships between professionals and parents, parent self-help, support and advocacy groups, parent participation, parents' problems and guidelines. \$7.50 per copy.
- Annotated Bibliography. Youth in Transition: Resources for Program Development and Direct Service Intervention.* Transition needs of adolescents: educational and vocational issues, programs and curriculum, research overviews, interpersonal issues, skills training. \$6.00 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.
- NEW!** *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 used with children and adolescents with emotional disabilities is described. Examples of innovative strategies and programs are included. \$6.50 per copy.
- Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families.* Held in April 1986 and attended by delegations from thirteen western states. Includes: agenda, presentation transcriptions, biographical sketches, recommendations, worksheets, and evaluations. \$7.50 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.
- NEW!** *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, evaluations of interagency programs, and practical suggestions for individuals contemplating joint programs are included. \$5.50 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.
- NEW!** *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.
- 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.
- 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 disorders of children, including post-traumatic stress disorder and mood disorders such as childhood depression and bipolar disorder. \$7.00 per copy.

More listings and order form on reverse 

- NEW!** *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.

- NEW!** *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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