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ADVOCACY FOR THE MENTAL HEALTH NEEDS OF CHILDREN IN CALIFORNIA

*James Preis**

My address today concerns how advocacy on behalf of children in California has evolved from focusing on procedural due process issues—such as commitment hearings and other protections from unwanted institutionalization—to a focus on developing a right to individualized treatment in less restrictive community alternatives.

Early cases such as *In re Roger S.*¹ established due process protections for children prior to their placement in public hospitals. In the early 1980s, child advocates spent their efforts extending *Roger S.* protections into private psychiatric facilities. At that time most psychiatric care was not in the public mental health system. Most care was in private psychiatric hospitals funded by insurance policies that provided very generous psychiatric inpatient benefits. Private insurance fueled the harm as there was tremendous abuse of the hospitalization of children who were not very disabled, but rather whose parents had significant insurance policies.

Advocacy efforts in private psychiatric hospitals culminated in 1989 with the passage of due process protections for minors whose parents had placed them in private psychiatric hospitals.² The legislative process, however, led to watered-down provisions which did not provide children with the level of protection provided in public facilities under *Roger S.*

Concurrently in the early 1980s, attorneys in my agency, Mental Health Advocacy Services, began representing minors in dependency court who were identified as seriously emotionally disturbed. Our

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1. 19 Cal. 3d 921, 569 P.2d 1286, 141 Cal. Rptr. 298 (1977).

2. See CAL. WELF. & INST. CODE §§ 6002.10, .15, .20, .25, .30 (West Supp. 1998).

goal was to keep these children out of state institutions. Early on we discovered that procedural protections alone were insufficient to accomplish that goal. What ultimately determined whether a particular child would be hospitalized was what alternatives were available. On an individual basis, we struggled to identify alternative services available in the community. The availability of these alternatives, and not procedural due process arguments, was determinative of whether or not our client was placed in a less restrictive setting.

Discussing the right to the least drastic means or the least restrictive alternatives does not mean very much if alternative services are not available. We have seen California statutes reflect this dilemma. These statutes condition the requirement of treatment in the least restrictive alternative by adding the word "available." Available is an ugly word in this area and in this context. It means that if there is something out there that you can show is less restrictive than being locked up in a psychiatric hospital, then the child will be placed in the less restrictive setting. If those alternatives do not exist, which they seldom do, the child will be placed in an unnecessarily restrictive hospital because it is the best option available. Procedural due process that only focuses on choosing between available options does not adequately protect the child.

As a way of protecting minors' due process rights, the challenge for our advocacy must be to move from the focus on due process procedures to the establishment of real alternatives to highly restrictive placements of minors. It is interesting that the lack of alternatives cannot be attributed to a lack of agreement that such alternatives are preferable to institutional care. In the area of children's mental health in the last ten or fifteen years, it has not been difficult to convince mental health professionals that children fare much better outside of institutions than they do within the traditional psychiatric hospital setting.

As early as 1984, the National Institute of Mental Health started the Child and Adolescent Service System Program (CASSP). CASSP became the standard bearer for a set of principles that now have been adopted throughout the United States. These principles recognize that for children with serious disorders, who are unable to live at home without additional support, there is a need to provide services in the community that wrap around the family. The term often used to describe these services is "systems-of-care." They bring together—in an interagency, coordinated fashion—services for children that wrap around the child and focus on the family to support the

child's strengths. These services must be available at whatever level of intensity is necessary to keep the child in the home, in school, safe, and out of the criminal justice system. These fundamental principles have been adopted throughout the United States.

There is a theoretical consensus: Children should not be warehoused in psychiatric facilities. Yet today, advocates still find it necessary to threaten legal action to keep children from being warehoused in these restrictive facilities. I ask why, despite a theoretical consensus embracing systems-of-care, these services are still not available to most of the children who need them? In discussing this question, I will go back a few years in terms of our agency's own litigation, strategies, and development.

Six years ago a group of us—including Mental Health Advocacy Services, Protection and Advocacy, Inc., National Health Law Program, and the American Civil Liberties Union of Southern California—looked at the issues generated by our representation of seriously emotionally disturbed children in dependency court. Specifically, we looked at issues around the placement of dependent children in highly restrictive settings. These restrictive facilities included state hospitals and, what we call in California, RCL-14 Facilities (Residential Care Level 14) and RCL-13.³ We were interested in developing a strategy to move our clients from these highly restrictive programs to systems-of-care and wrap-around services in the community.

The question then became why, despite the clinical consensus in support of these services, they remained unavailable to our clients. As in all institutional and least restrictive alternative litigation, the first obvious answer was that there were not enough resources in the children's community mental health system. Our initial litigation, therefore, needed to create additional mental health resources.

In developing a litigation strategy, we had an extremely strong federal mandate, Early Periodic Screening Diagnosis and Treatment⁴ (EPSDT). The EPSDT entitlement was the result of a 1989 amendment to the Federal Medicaid Act.⁵ The EPSDT mandate provides that eligible children are entitled to receive, through the state's Medicaid system, any treatment listed in the Medicaid Act that is

3. These facilities are very restrictive non-hospital, but still institutional, kinds of settings. Often, they are used as a placement for dependent children who the court does not have the power to place in a psychiatric hospital.

4. 42 U.S.C. §§ 1396d(a)(4)(B), (f) (Supp. 1997).

5. *See id.* (Supp. 1997).

medically necessary, even if it is not available to adults in the state.⁶ Medical necessity is defined very broadly to include any treatment or service necessary to ameliorate a mental or physical condition, defect, or disease.⁷

Although the Medicaid Act was amended in 1989 to include the EPSDT mandate, it was not adopted in California. I believe that state officials looked at the federal law and decided it was too expensive to implement. So they waited to be sued before taking any action. To force the state to implement full EPSDT services for children, a lawsuit had to be constructed.⁸ Once the lawsuit was filed, the state did not litigate aggressively. It would have been difficult for them to do so. Therefore, the case was settled and regulations were developed.

There was an assumption that the current services, which were already part of the state plan, were adequate to serve the needs of the children of the state. The real focus of the litigation was on the diagnosis and treatment part of EPSDT. The litigation resulted in regulations that were structured so that services outside the state plan would be provided through Supplemental EPSDT Treatment Authorization Requests.

Part of the MediCal plan in California included a program called Short-Doyle MediCal. Short-Doyle MediCal is the part of the MediCal system that funds county mental health services. Short-Doyle MediCal funds are distributed to counties in a capped amount, which effectively limits the amount of MediCal available for mental health services. Under the EPSDT mandate this cap on services is illegal.⁹

After the litigation a meeting occurred between the Department of Health Services—which is the single state agency responsible for

6. *See id.* (Supp. 1997).

7. *See id.* § 1396d(r)(5) (Supp. 1997).

8. In formulating the lawsuit, we considered that the EPSDT mandate required not just diagnosis and treatment, which was the care we were seeking, but also screening and assessment. Early periodic screens were required to include behavioral and developmental components, which at that time they did not. At the early stages of the EPSDT litigation, we included claims that addressed a lack of behavioral screening for children. However, these claims were abandoned when adult consumers of mental health services objected. They expressed an extremely strong belief that screening children for a mental disorder was a way of medicalizing social problems. This was at a time when the Federal Center for Mental Health had a director who thought all juvenile delinquency was the result of mental disorders. Primarily, we were interested in developing alternatives for children in hospitals. Therefore, we did not pursue the issue of screening children for behavioral problems.

9. *See id.* (Supp. 1997).

Medicaid—and the Department of Mental Health. At that meeting they agreed there were not enough services for MediCal eligible children in the county mental health system. However, it was unclear what the actual need was.

The Department of Health Services agreed to augment funding for the counties by providing additional dollars for children's mental health services. They pledged to reimburse any additional spending that was beyond the annual amount spent in 1994-1995, the base year of the litigation. Therefore, as a result of the litigation, counties can now spend as much money on children's mental health as is needed and the state will reimburse the Medicaid matching share out of the state general fund. The federal government's share automatically will match the state Medicaid share. This means that when asked to provide community mental health services, counties can no longer respond: "we do not have enough resources."

Today, counties in California can provide as many mental health services as are necessary for MediCal eligible children and do not have to worry about not having enough money. This is our current reality in California. Our problems should be solved. Now we should be able to provide children with alternatives to restrictive institutions. However, we still are not providing these alternatives. That is the frustration of children's advocates today. Even though there is unlimited funding for children's mental health services in California, children are still confined in high level institutions. There are few wrap-around services. There are no therapeutic foster-care homes. There are only limited systems-of-care services. The most seriously emotionally disturbed children still do not have individualized treatment plans.

Today there is unlimited money. If money is no longer the problem, why are there so many children still without appropriate services? The problem is the system itself. When we set out to increase resources in the mental health system and when we won the EPSDT litigation, the response of the mental health community was: "Great! You got us all this money. There is a new funding source. We can build new programs." However, the decision of the EPSDT case was not grounded on the mental health system's entitlement to money. Rather, it was based on children's individual entitlements to services.

An individual entitlement to services seems to be what is lost. The response of the system is to create programs and then to try and fit the children into them. We need systems-of-care. A system-of-

care cannot start with a program. It must start with an individual child. We must start by assessing what the individual child needs and from there develop the appropriate services.

We are now at a stage where new litigation is necessary, not to seek to increase resources, but to enforce the entitlement for the assessment and individualization of services for children. This type of litigation will be based on the EPSDT mandate and the integration mandate of the Americans with Disabilities Act¹⁰ (ADA). There is some irony in this. Prior to these federal mandates, the mental health community in California fought to increase resources in order to provide individualized services. Here we are in 1997, with unlimited funding, and we are still in the position of arguing for individual services.

In thinking about this future litigation and reviewing previous cases, we look back to the *Willie M.*¹¹ case, which was brought in 1979 in North Carolina. The *Willie M.* decision relied on different legal theories. Instead of the EPSDT mandate and the ADA, *Willie M.* included traditional civil rights and due process theories. However, the case settled and those theories were never tested in court.

The settlement in *Willie M.* is exactly what we are seeking today in California.¹² The settlement required that each child who was a member of the class would be assessed and provided services in a no-eject, no-reject mental health system.¹³ The class was defined as those children who were the most difficult to serve in the mental health system of North Carolina. Under this system each child received what he or she needed. According to the consent decree, if the services did not exist, the child had to be provided with an available alternative that was as close to that service as possible and only for the period of time that it took to create the needed service.¹⁴ As you look at North Carolina today, this was an extremely powerful order that has pushed the state far ahead of almost all other states in terms of individualized services for children. These services minimize the institutionalization and maximize the availability of less restrictive alternatives. Twenty years later we hope to achieve similar results in California.

The foundation of our litigation strategy is the EPSDT mandate,

10. 42 U.S.C. § 12101(b) (1995).

11. 657 F.2d 55 (4th Cir. 1981).

12. *See id.* at 57-59.

13. *See id.*

14. *See id.* at 58.

which unfortunately has been under attack in Congress in recent years. Obviously, the longer that EPSDT remains a federal mandate, the more likely it becomes that California will achieve a system of providing for the individual mental health needs of children similar to the results achieved in *Willie M.*¹⁵ Unfortunately, if Congress takes away the statutory entitlement, it is unlikely that the arguments made in *Willie M.* will be upheld by the courts today. We need the EPSDT mandate to survive long enough for us to obtain creative relief through successful litigation. This relief would require providing services based on individual assessments and those services “wrapped” around each child.

What our experience has shown is that without accountability to individual children, money is not enough. Because the system has been underresourced for so long and in so many different areas, it has been hard to prove that we need to do more than just increase resources to provide adequate mental health services to children. We have demonstrated this to be the case. Currently, there is plenty of money to provide adequate service, but the will is not there.

There are still immense bureaucratic barriers, and clearly this is where we must focus our attention. Our advocacy efforts, other than litigation, are also focused on the same issue: working with the bureaucracies to try to get them to individualize their services. It is not all done through litigation. Litigation is the last resort. We have established the funding source for the bureaucracy. The statute is there.¹⁶ The entitlement is there. However, the effect is like kicking a brick wall. Every time we talk about services for a particular set of individuals, the response is: “Well, we are developing a new program.” The mental health bureaucracy has never really developed a mechanism for effectively responding to the needs of children on an individual basis.

One of the major bureaucratic barriers to individualized services for children is the lack of interagency collaboration. Cooperation between different agencies is one of the fundamental principles in systems-of-care. Everybody agrees. However, in practice interagency cooperation has come to mean that every agency serving children will

15. The parties worked out a comprehensive settlement in which they agreed to the scope of the class, plaintiffs’ rights, the scope of North Carolina’s obligations, and the basic outline of the remedy to be awarded. The settlement further outlined the procedures for identifying, notifying, and evaluating potential class members for administrative review. *See id.* at 57.

16. *See* 42 U.S.C. § 1396d(a)(4)(B) (Supp. 1997).

develop its own interagency cooperative. As a result, child welfare departments have a program called Family Preservation. The Department of Mental Health has something similar called Systems of Care. The Department of Probation in Los Angeles has its own interagency program called Mary C., which is a demonstration project to help children who are at risk of ending up in the juvenile justice system. In addition, schools have their Healthy Start programs.

Each initiative requires all the other agencies participate. However, while each agency discusses cooperation, they are only talking about it within their own sphere. For example, there are a lot of discussions at the Los Angeles County Department of Children and Family Services about developing cooperative interagency efforts. There are similar discussions at the Department of Mental Health. Unfortunately, they are not talking effectively with each other, even though they are talking about the same things.

Clearly, litigation is undesirable if children can receive the wrap-around services they need without requiring a lawsuit. However, because the bureaucratic barriers that separate services for children are so ingrained in the system, it is likely that real change will require a court order to force individual bureaucracies to truly cooperate. I think it is beyond the capacity of the bureaucracies to do this on their own. A major component of any litigation, seeking to force individualized services for children in non-institutionalized settings, is that it must also address interagency cooperation. Without interagency cooperation children's total service needs will remain unmet.

In conclusion, advocates for children's rights in the mental health system must now focus on the creative use of legislative mandates. Advocates must utilize legislative mandates to fashion judicial remedies that will break down the bureaucratic barriers that currently result in a failure to provide adequate mental health services that keep children out of institutions.