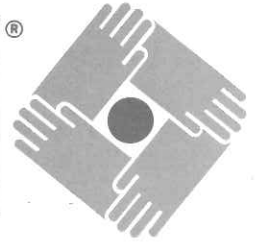


# FOCAL POINT<sup>®</sup>



## CHILDREN'S MENTAL HEALTH SERVICES IN HEALTH CARE REFORM

The 103rd Congress has set itself an ambitious agenda. Between now and October, five Congressional committees are to report out their versions of health care reform legislation, from which a single final piece of legislation must be written and forwarded to President Clinton for his signature.

If this goal is accomplished it will be extraordinary. Nonetheless, conventional wisdom in Washington in Spring 1994 is that it will occur. Concern that Congress will change significantly after the 1994 elections is the spur urging the Democratic leadership of the House of Representatives and the Senate to move a bill forward.

However, the form of the final legislation is far from clear. The first issue is: will Congress be able to pass a bill that truly reforms the health care system or will it pass a bill that only makes regulatory changes to the current health insurance industry? All pending bills deal with issues such as elimination of pre-existing condition clauses, requiring community rating, etc., and so passage of a bill making adjustments to the present system would be simple. In fact, this is the essence of the proposal of the Republican leadership in the House of Representatives (HR 3080 introduced by Congressman Robert Michel (R-II) and in the Senate as S 1533 by Senator Trent Lott (R-Ms)). Most Republicans in Congress have now co-sponsored these bills.

On the other hand, President Clinton continues to push

for meaningful reform and Congressional sponsors of the even more ambitious single-payer bill are also actively working for structural reforms to the health care system. The President's proposal, the Health Security Act (HR 3600, S 1757), has significant support, as does the single payer plan, the American Health Security Act, introduced by Congressman McDermott (D-Wa) and Senator Wellstone (D-Mn) as HR 1200 and S 491. However, no single approach seems to have majority support at this time.

Three House committees will have significant responsibility to write the health care reform legislation. The one with the least influence—the Education and Labor Committee—is the one which has the greatest understanding of issues concerning systems of care for children with serious emotional disorders. This Committee plays a role because it has responsibility for state insurance regulation, but it will use its limited role to approve a bill that includes a strong mental health benefit, particularly for children. Leading this initiative on that committee is Congressman George Miller (D-Ca), long-time supporter of children's issues and



original sponsor of the Child Mental Health Services program now run out of the Center for Mental Health Services. The Chairman of the Education and Labor Committee, Pat Williams (D-Mt), has also come out in favor of a broad mental health benefit in health care reform and is working with Miller and other members of his committee

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## CHILDREN'S MENTAL HEALTH SERVICES

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to ensure its inclusion in their bill.

Children's mental health issues are also being protected in the House Ways and Means Committee, which will play a major role in the debate. The Subcommittee on Health of Ways and Means (chaired by Pete Stark, D-Ca), proposed a bill based on Medicare but with significant amendments that add crucial children's services to the program. Chairman Stark offered changes to cover mental health services not now covered by Medicare. These include residential alternatives to hospitalization, such as residential treatment centers, therapeutic group homes and therapeutic family foster homes as well as intensive community services, such as day treatment, in-home services and behavioral aides. As a result of that amendment, adopted by a unanimous bipartisan voice vote, the benefit in the

Subcommittee's bill includes the same services as the Clinton benefit, but with higher limits. In addition, the Subcommittee set the precedent that children's services might be covered more generously than adult services by providing a 20% copayment for psychotherapy for children (psychotherapy has no annual limit in Medicare) while continuing to require a 50% copayment from adults.

In addition to a basic benefit, which would be mandated for all Americans, the Stark bill provides a mechanism for states to integrate their public and private systems, using Medicaid dollars more flexibly, and thus offer the comprehensive benefit without limits. In states that do not opt for this expansion, Medicaid would continue to be available. This mechanism is similar to a proposal in the Clinton bill that would allow pilot projects in states that wish to integrate their systems so as to remove the limits on the mental health benefit.

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We invite our audience to submit letters and comments.

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Mental health advocates were extremely pleased to see the first health care reform bill reported out of a committee (the Stark bill) include a mental health benefit significantly more workable than that in the President's proposal. The Ways and Means Subcommittee took the best ideas in the Clinton Bill—the fully comprehensive range of services and the option for states to provide an integrated and comprehensive benefit without arbitrary limits—but significantly improved the interim benefit, particularly for children.

The other House of Representatives' committee with a major role, Energy and Commerce, is having far more difficulty. The committee is nearly evenly divided between supporters of the Clinton bill and supporters of the Managed Competition alternative introduced by Jim Cooper (D-Tn), who sits on that committee. As a result, some compromise bill may have to be created, that does not include some of the basic reforms of the Clinton bill such as health alliances. The employer mandate provisions may also have to be weakened. Exactly what this will mean for the mental health provisions is unclear, but there appears to be significant support on that Committee for including at least the benefit in the Clinton bill, and there may be the possibility of improving it, at least for children.

In the Senate, two committees have jurisdiction: the Senate Labor and Human Resources Committee, chaired by Edward Kennedy (D-Ma), and the Finance Committee, chaired by Daniel Moynihan (D-NY). The Labor and Human Resources Committee is expected to mark-up first, and will use the Clinton bill as its starting point. Senator Kennedy has proposed a mental health benefit that covers all outpatient services, including intensive services such as day treatment, in-home services and behavioral aides, without arbitrary limits and with the same cost-sharing as physical health care. His package includes limits on inpatient hospital services (30 days a year) and residential treatment programs (up to 60 days a year, but for each four days of residential treatment one day of hospital care benefit is lost). Action on Senator Kennedy's proposal is expected before the end of May.

The Finance Committee has as yet given no indication of when it will mark-up, which bill it will use as a starting point, or how it might deal with the benefit package, including mental health. Finance will be one of the last committees to act, and yet it is likely to be one of the most important committees in the whole debate, since it has responsibility for raising the resources to pay for health care reform.

All of this clearly makes for a very uncertain situation at this time. However, children's mental health advocates are hopeful that Members of Congress will be sympathetic, within the constraints imposed on them by the overall

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structure of the bill they approve, to the needs of children with mental or emotional disorders. Certainly, there is far greater understanding of the need for mental health services in this debate than there has ever been before. The work of Tipper Gore, the insistence by the White House that mental health must be an integral part of reform, the involvement of former First Ladies Rosalynn Carter and Betty Ford in calling for a comprehensive benefit without arbitrary limits, and the joint lobbying by the mental health community in Washington, is paying off.

If Congress succeeds in passing a meaningful health care reform bill, look for it to have a reasonable mental health benefit (as compared with current private insurance) and some role for states to move faster toward a comprehensive and integrated benefit if they opt to do so. Remember also, the enactment of this bill is only the starting point. Adjustments and amendments can be made over time, particularly as cost and utilization data is collected. If the mental health benefit proves reasonable, it will be expanded. If it proves to be very costly and there are questions about the validity of services provided, it will be cut back.

At this crucial time, it is important for all child mental health advocates, especially families, to stay informed. Be sure to let your own Members of Congress know your views and emphasize the importance of the range of services children with mental and emotional disorders need. Health care reform is the greatest opportunity presented in this century to ensure that all children have access to a basic package of health and mental health services. We must not let it slip through our fingers.

**Chris Koyanagi, Co-director of  
Government Relations, Judge David  
L. Bazelon Center for Mental  
Health Law, Washington, D.C.**





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## HEALTH CARE REFORM AND MENTAL HEALTH

**T**he Development of the Clinton Plan for Health Care Reform. Health care reform presents a unique and timely opportunity to restructure and improve coverage for mental health and substance abuse disorders. The process for the development of President Clinton's proposal for health care reform began in January 1993 with the appointment of Hillary Rodham Clinton to chair the President's Task Force on Health Care Reform. While the task force was comprised of cabinet secretaries and senior White House officials, a second tier of activity involved approximately 35 working groups that extensively studied and deliberated various aspects of the plan. These working groups were led by the President's Health Care Advisor, Ira Magaziner, and under his leadership went through an intensive "tollgate process" designed to identify options in each area, analyze the pros and cons, narrow options, and develop recommendations. The Mental Health Working Group was comprised of experts in mental health and substance abuse policy and services as well as economists. The group was chaired by Dr. Bernard Arons, who subsequently became the Director of the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration. Tipper Gore served as an advisor to the Mental Health Working Group.

Once the basic parameters of the health care plan were designed, actuaries began the arduous task of costing out the various aspects of the plan. Adjustments were made based upon actuarial estimates, and the Health Security Act was introduced in Congress.

**M**ental Health Coverage in Health Care Reform. Since the Clinton plan was unveiled, there has been much discussion about whether we can afford to include mental health in health care reform. This debate misses the point about mental health coverage. Most people—employers and employees—already pay for mental health coverage because the vast majority of insurance plans today do cover mental health. In addition, we pay for those without adequate coverage through tax dollars and inflated insurance premiums. The fact is that we cannot afford to continue the way we currently provide mental health coverage. The debate should be focused on how to restructure the way in which mental health care is covered so that we do not perpetuate the problems and perverse incentives in the system today.

Traditionally, insurance coverage for mental health has included 30 or so days of hospitalization and 20 or so office visits for psychotherapy. By failing to include alternatives to hospitalization and options beyond office-based psychotherapy, current coverage has ensured neither cost

containment nor appropriate care. The result has been overutilization of the most expensive and restrictive type of care, namely, the hospital inpatient unit. In fact, hospitalization of adolescents with mental health and substance abuse disorders was the major factor in driving up the total cost of mental health care in the last decade. Studies conducted by states such as Tennessee, as well as Congressional hearings, have shown that nearly half of these hospitalizations could have been avoided if alternative services were available.

In the last decade, there have been remarkable advances in the treatment of mental illness and the development of community-based alternatives to hospitalization. Traditional insurance plans have been slow to understand the changing nature of mental health service delivery and its implications for controlling costs and improving care. However, in the last few years, some of the larger, more progressive companies, such as Honeywell, IBM, and Aetna, have developed plans that cover a far broader, more flexible array of services than hospitalization and psychotherapy alone. Their outcome studies are showing lower costs and improved employee satisfaction with the care received. Similarly, the development of comprehensive systems of care in the public sector, financed in part by more flexible Medicaid practices, has demonstrated that an array of home and community-based services can provide more cost-effective care and result in improved outcomes.

Health care reform, regardless of which plan is ultimately adopted, should build upon these innovations in both the private and public sectors to shift insurance-driven incentives toward less costly, community-based alternatives, such as day treatment, in-home therapies, ambulatory detoxification, and relapse prevention programs. This restructuring of the traditional benefit design would give consumers and providers alike far more choice in their efforts to use the most appropriate and cost-effective care.

**S**ervices included in the mental health benefit. The mental health coverage proposed in the Clinton plan includes three categories of services:

1. *Inpatient and residential care* that will cover hospital care or 24-hour care in other residential environments (such as therapeutic family homes, therapeutic group homes, crisis residential facilities, residential detoxification centers, or residential treatment centers). The non-hospital residential settings offer less restrictive and cost-effective alternatives to hospitalization.

2. *Intensive non-residential services* that include a



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range of services that could serve as alternatives to hospitalization—day treatment, partial hospitalization, psychiatric rehabilitation, ambulatory detoxification programs, home-based services, and behavioral aides.

3. *Outpatient care* that includes such services as assessment, crisis services, psychotherapy, substance abuse counseling and relapse prevention, medical management, somatic treatments, collateral services, and case management.

The inclusion of this expanded range of services is, perhaps, the most significant step forward in the coverage of mental illnesses, yet, is not well understood. The intensive nonresidential services, in particular, represent state-of-the-art service technologies. This range of services is increasingly utilized for individuals with serious mental and emotional disorders based upon the recognition that psychotherapy alone has been ineffective in averting the need for treatment in hospitals and other residential settings and equally ineffective in maximizing their level of functioning in the community. These interventions move beyond the boundaries of traditional, office-based psychotherapy and provide high levels of therapeutic interventions and support, maximizing the use of normalized environments.

For children and adolescents, day treatment and partial hospitalization programs provide intensive treatment, education, family involvement and support while keeping youngsters at home. Provided in a variety of settings, day treatment and partial hospitalization programs generally employ a multi-faceted intervention approach (including individual and group counseling, individualized education, family counseling and support, skill-building, recreational therapy, and crisis intervention) and work with youngsters for many hours on a daily basis.

Home-based services provide therapists to work with families when a youngster is in imminent danger of out-of-home placement in hospitals or other residential treatment settings. Counselors work intensively with families, sometimes for ten to twenty hours a week, to help stabilize the crisis, to link the child and family with ongoing clinical services and supports, and to strengthen the child and family's coping skills and capacity to function effectively in the community. The interventions are delivered primarily in the family's home, and the hours of service delivery are flexible in order to meet the needs of the family. Home-based services are multi-faceted and include counseling, skill training, and helping the family to obtain and coordinate necessary services, resources, and supports; 24-hour crisis intervention is provided.

Behavioral aides can provide the extra supervision, assistance, and support needed by a child at home or in school. These services involve using a trained worker to assist an individual youngster and the other persons in-

involved in his or her care and treatment. Behavioral aides can spend a specified number of hours in the home to assist a child and family during difficult times during the day; they may be assigned to the classroom to support the teacher in managing the youngster's behavior and educational program; they may assist in the day-to-day implementation of therapeutic programs designed by youngsters' therapists and treatment teams. Behavioral aides have proven extremely effective in averting the need for hospitalization or other types of residential placements.

Thus, families of a child with an emotional disorder might avoid having to hospitalize their child if they had access to a day treatment program, home-based services, or behavioral aides. These services are not intended to be provided in isolation; often they are provided in conjunction with medical management and medication and with psychotherapy when appropriate.

The expanded service array plays a similar role for adults with mental illnesses. Day treatment and partial hospitalization provide effective alternatives to hospitalization for many individuals. Psychiatric rehabilitation allows persons with serious and persistent mental illnesses to overcome the functional disabilities that accompany these illnesses. While symptomatic improvement results from medications and other mental health treatment, many persons experience continuing social and vocational problems. Rehabilitation helps individuals to learn the social and vocational skills and acquire the supports needed to function as actively and independently in society as possible. These services have been shown to significantly reduce the rehospitalization rates of individuals with serious and persistent mental illnesses.

**T**he Importance of Restructured Mental Health Coverage in Health Care Reform. The restructuring of the benefit in the Clinton plan and the potential results have received little attention. Yet, it has major implications for altering the nature of the service delivery system, for creating more community-based service options for consumers and for controlling costs.

What is receiving attention in the Clinton plan are the limits that it places on the use of mental health services which is, indeed, a problem, one that is borrowed from traditional insurance plans. Mental health consumers and providers have advocated that the mental health benefit should not impose arbitrary limits on the number of days or visits allowed because limits make neither clinical nor economic sense. Traditional coverage teaches us that the more a mental health benefit is constrained by arbitrary day and visit limits, the more it pushes consumers into expensive hospital care. The limits in the Clinton plan essentially were a concession to actuarial concerns over costs. Lack-

ing experience with an unlimited, managed mental health benefit, the actuaries fell back on what they understood—imposition of arbitrary limits to control costs—in spite of compelling evidence showing that this approach actually exacerbates costs in the mental health sector.

The interim limits in the Clinton plan are diverting focus to the wrong issues, such as whether limit “x” is better than limit “y.” The focus of the debate should be on how to ensure the provision and use of the most clinically appropriate, least restrictive care, on a case by case basis, within a globally budgeted, managed system. This will require skilled gatekeepers, consumer education and advocacy, the right mix of services, appropriately trained providers, quality assurance and, undoubtedly, financial incentives to health plans to ensure that they do not underserve those with more serious illnesses (so-called risk adjustment). These are complex issues that are being missed in the current policy debate.

We should not continue to argue over whether mental health and substance abuse should be included in health care reform. Mental health benefits are not a luxury that we may or may not be able to afford. Mental health disorders are major health problems for which afflicted individuals should receive treatment as they would for any other health problem. It is spurious to argue over whether we should

pay for mental health coverage. *We already pay.* The real issue with which the country should be grappling is the best way in which to cover these disorders. Health care reform can seize the opportunity to redirect insurance-driven service incentives toward treatment that is both more effective and efficient—or, in a misguided attempt to control costs—it can simply perpetuate the present emphasis on the most expensive and inappropriate service settings.

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## MENTAL HEALTH CARE IN HAWAI‘I “THE HEALTH STATE”

In the course of Bill Clinton’s campaign for President of the United States and now in his campaign for health care reform, he has spoken about the remarkable example that the health care system in Hawai‘i sets for the rest of the nation. With 92-98% of the state covered by some measure of health insurance and a lifespan beyond the U.S. average, Hawai‘i must be doing something right. Right? The response from Hawai‘i’s children, adolescents and adults who have emotional disabilities or mental illnesses, especially those with lower incomes, is an equivocal one.

“The Health State” billing is accurate if one takes into account only physical health. Three times since 1986 Hawai‘i has been rated as having the worst mental health service system in the United States by the Public Citizens Health Research Interest Group. More recently, conditions at the state hospital (including the adolescent unit) were found to be “abhorrent” by the federal Department of Justice. In addition, a local Hawai‘i group—the Children’s Rights Coalition—filed suit in federal court against the Governor, the Director of Health and the Superintendent of

Education alleging a failure to comply with two federal laws intended to ensure that children with emotional disorders receive timely and appropriate services. Clearly, the lack of parity between physical and mental health in Hawai‘i makes “The Health State” designation questionable.

At least 39,600 children in Hawai‘i (12% of our state’s 330,000 children under age 18) suffer from mental health problems severe enough to require professional treatment. Between 6,600 and 20,000 of these youth (3-8% of all children) experience more severe emotional problems. The Department of Health Child and Adolescent Mental Health Division serves only 1,600 (less than 1% of those in need) of these children and then with quite varied results. The fact is that Hawai‘i does not have a system that adequately serves the needs of its children and youth with mental and emotional disorders. Troubled children “fall through the cracks,” become progressively worse and ultimately cost our state even more money. The state responds only when these children disrupt classrooms, use illegal substances, or become involved in other self-de-

structive and anti-social behaviors. Some enter residential treatment care programs (if there is room) and later the state hospital. Others enter the juvenile justice system and later the criminal justice system. Too many become dependents of the state's public welfare system.

Families do not know what range of services should be available to meet their needs. And—too often—our state systems do not reach out to those who need their services. For example, though all children are entitled by law to appropriate education regardless of their disability, many parents are not made aware of the process through which they can obtain special education services by the Department of Education (DOE). And, unlike the DOE, the Department of Health Child and Adolescent Mental Health Division has no mandate to serve all children and youth in need of its services.

A conflict between federal law mandating care for a child if that child's needs interfere with his or her receiving a free and appropriate education and a state law indicating that the Department of Health Child and Adolescent Mental Health Division should take care of children with emotional disorders, if funding is available, further exacerbates this problem and allows each system to blame the other. Unfortunately, the only people who suffer in this situation are the parents and their children with mental, emotional and behavioral disorders. In addition, most of the services needed in Hawai'i are simply not available because they have never been developed. And, if they are available on a limited basis on Oahu, they are almost nonexistent on neighboring islands.

The current patchwork of fragmented services in Hawai'i too often results in a lack of appropriate care and education for the children and youth who most need them. As you can see, "The Health State" moniker leaves something to be desired.

The recent good news is that—owing to the lawsuit and a new Child and Adolescent Mental Health Division (CAMHD) chief with a sound vision of what a system of care should look like—some 13.2 million new state dollars have been budgeted for service development. Another 9.7 million dollars is under consideration by the 1994 Hawai'i state legislature. In addition, a new agreement with the state's innovative Medicaid QUEST program will aid the CAMHD in developing and supporting a broad range of inpatient, outpatient and, most importantly, intermediate care level services with a federal match that will bring in another two million dollars. The new funding is helpful, but the trained professionals to provide the quality services that will meet the needs of our children and adolescents are still missing. This will likely take some five to seven years to accomplish and will require an ongoing commitment of new dollars from our legislators. In dollar terms, at least,

we are beginning to create some parity between physical and mental health here in "The Health State."

For "The Health State" to have strong families and communities as well as a stable workforce, youth with mental, emotional and behavioral problems must have a reasonable service support system. To ensure that those young people of Hawai'i who have emotional disabilities are afforded every opportunity to develop into capable, confident and mature adults, the state of Hawai'i must respond in a positive, proactive manner to the varied needs of those children through a real investment of adequate staff and funds for a "real" system of care. Again, the good news is that we finally appear to be heading in that direction!

**Mark J. O'Donnell**, *Executive Director, Mental Health Association in Hawai'i; Treasurer, Hawai'i Families as Allies; Honolulu, Hawai'i.*



## WHY NOT?

As this country plans changes in health policies, the mental health care coverage available to children needs to expand and become more flexible. *Why not* discontinue the practice most policies have of severely limiting the number of dollars allowed for mental health care? For example, my son's policy authorizes \$2000 every two years for mental health treatment. That translates roughly to ten visits a year for his treatment. What happens if he needs to be seen weekly, requires hospitalization or needs other services?

Children's mental health care services are expensive, but the current dollar limitations are short-sighted. Prevention and treatment services are much less expensive than the price paid for letting mental health problems go untreated or discontinuing treatment due to lack of funds. Children do not magically recover when they reach the limits of their insurance coverage. *Why not* provide the same funding to children's mental health as is provided to any other illness?

*Why not* cover all services that a child and family need in order for optimal recovery to occur? Traditionally, mental health care was defined as a series of one hour talk therapy visits. We now know that this is not always effective or appropriate for children. *Why not* include coverage for services individually designed to address each child's particular needs? *Why not* place children before the dollar sign? C.W.

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



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## INTEGRATION OF MENTAL HEALTH SERVICES INTO THE OREGON HEALTH PLAN WILL BENEFIT CHILDREN AND FAMILIES

**M**ost Americans now agree that the nation's health care system is more costly and less effective than it ought to be and is in need of reform.

- More than 15% of the American people are uninsured, with an equal number insured only part of the time.
- Health costs are increasing at a rate that simply cannot be sustained. This year the nation will spend more than one trillion dollars and the cost is increasing at 8 or 9 percent per year.
- Those who are insured have no security in their coverage. Many people with chronic conditions cannot purchase insurance and those employed are afraid to change jobs for fear of losing coverage.
- When available, mental health benefits are extremely limited.

Oregon spent more than ten billion dollars on health care in 1993, double the 1988 figure. Oregon health insurance premiums are rising twenty percent annually while the number of uninsured Oregonians grows by five percent annually. Nevertheless, more than 600,000 Oregonians have either inadequate or no health insurance. One in five Oregonians who return to welfare do so to obtain medical coverage.

Since 1989 the Oregon Legislature has been addressing this health care crisis through the Oregon Health Plan, a set of initiatives designed to assure health coverage for all Oregonians and access to a basic package of benefits.

**Who gains insurance?** The state will bring 120,000 more poor people under Medicaid, which now covers about 250,000 Oregonians. It will cover most people below the federal poverty level (\$991.00 per month for a family of three), and pregnant women and young children up to 133 percent of poverty.

In addition, an employer-paid "plan or pay" plan affecting the 300,000 working uninsured and their dependents goes into effect for large employers beginning March 31, 1997, and for small employers on January 1, 1998. It requires employers either to provide group insurance to permanent employees working 17.5 or more hours weekly and to their dependents, or to pay into a state insurance pool. Small employers who start coverage before July 1995 receive tax credits. Already in effect is a high risk pool, covering more than 3,300 Oregonians who could not otherwise buy insurance because of pre-existing medical conditions. And an affordable small-business insurance package, similar to Medicaid coverage, went on the market March 1, 1993.

**What is covered?** The Standard Benefit Package covers all major diseases of women and children; covers virtually all current Medicaid treatments, including all preventive and screening services; exceeds Medicaid requirements by providing services such as dental, hospice, prescription drugs, most transplants and routine physicals and mammograms; and stresses prevention with services such as maternity and newborn care, immunizations, well-child exams and preventive dental care.

**What is not covered?** The Standard Benefit Package does not pay to treat conditions that get better on their own (such as a viral sore throat), conditions where home treatments are effective (food poisoning, sprains), cosmetic conditions (benign skin tumors, scar removal), and conditions where treatment is generally ineffective (aggressive medical treatment for advanced cancer) although in such cases comfort care is provided.

These benefits were the result of a public process that established values for making decisions about which services are most important. Using these values, the State Health Services Commission developed a list of diagnoses and their treatments ranked in priority order. Mental health and chemical dependency disorders have been ranked and are scheduled for future inclusion on the list.

**Implementation.** Coverage for most low-income people began February 1, 1994. Criteria for Medicaid eligibility was expanded to 100% of the federal poverty level which means an estimated 120,000 more people will be insured through Medicaid, which now covers about 250,000 Oregonians. During this phase of the plan people eligible for Medicaid but not covered by the Oregon Health Plan include seniors, people with disabilities and children in foster care. Mental health and chemical dependency services are not included in this phase of the health plan although all Medicaid eligible individuals, including the 120,000 eligibles, will have access to the existing public mental health system.

**How does the plan improve access to care and growing costs?** The plan is expected to slow the climb of health-care costs by giving poor Oregonians a regular family doctor or nurse who has first-hand knowledge of the family's medical history. The plan employs managed care, paying health plans a fixed amount per month to treat a stipulated number of enrolled patients (rather than paying individually for office visits and treatments). Because patients will have access to care when they need it, they will not wait to go to hospital emergency rooms for more

costly care after conditions have become more serious.

**When will mental health be included?** In January 1995 the populations exempt from the first phase will become eligible for services under the health plan. In addition, mental health and chemical dependency disorders will be integrated into the prioritized list. Chemical dependency services will be a covered benefit for everyone, but mental health services will be phased in for up to 25% of the eligible population. Mental health services will be covered for 100% of the eligible population by July 1996, with the approval of the 1995 legislative session.

**How will the Oregon Health Plan affect children and adolescents with mental, emotional and behavioral disorders and their families?** Children with severe mental, emotional and behavioral disorders will be entitled to access the same mainstream health care as every other citizen. Families will eagerly enroll in plans that offer services needed by their family members with disabilities. Health plans assuming responsibility for new enrollees will want to emphasize clinical strategies that include a wide range of services from early identification and wellness to the deployment of intensive care in the normalized and cost-effective settings of home, school, and community.

The principles of managed care that reward efficient medical practice in the least costly settings are compatible with Child and Adolescent Service System Program (CASSP) values and the family support philosophy. Greater emphasis on in-home care, respite services, and the development of a system of care to replace the traditional limited provision of inpatient and outpatient treatment will both

reduce cost and improve outcomes for families. This approach to health reform joins the energy of the private sector health care marketplace to the values of public mental health service delivery. Thus, the Oregon Health Plan will sustain the improvements in child and adolescent mental health of the last ten years, and increase access to those who have been denied sponsorship in the past.

For further information on the Oregon Health Plan, contact: D'Anne Gilmore, Manager, Oregon Health Plan Unit, Mental Health and Developmental Disability Services Division, Oregon Department of Human Resources; 2575 Bittern Street, N.E., Salem, Oregon 97310; (503) 945-9827.

**Barry S. Kast,** M.S.W., *Interim Administrator, Mental Health and Developmental Disability Services Division, Oregon Department of Human Resources;* and **Ralph Sum-**



*Barry Kast*



*Ralph Summers*

**mers,** M.S.W., *Robert Wood Johnson Foundation Project Coordinator, Office of Mental Health Services, Child and Adolescent Services Section, Mental Health and Developmental Disability Services Division, Oregon Department of Human Resources.*

## PARENTS' PERSPECTIVE

We decided against the recommendation of the doctors, which was to place our fourteen year old (then thirteen) son in residential treatment. We brought him home because one caring psychiatrist said that he felt, "home—a stable, loving home—is the best thing for him." Our son was born with fetal alcohol syndrome. He has a deep bond with us and us to him. He has been our son for nine years.

We feel his medications and a personal care attendant have helped us so much. His education still remains a problem. He cannot attend regular classes, and so far can go only one hour a day to a vocational class where he enjoys making objects out of wood.

Our community and our school are not set up to accommodate our children with such conditions. I wish that they could understand what parents go through to appreciate what parents need. I feel frustrated at the meetings, which seem to all lead to dead ends. I feel that

parents are the ones who best know the needs of the child. Parents should be given the authority to make the decisions on what best will help the child and themselves and there should be providers for those services. The services should be community-based, and should be found not *only* in cities hundreds of miles from the child's home—when this happens, parent-child relationships become strained.

We *live* with the child. The professionals read and study but this doesn't mean they understand because most professionals have never lived with these children 24 hours a day, 365 days a year. Put the power in parents' hands. Let them do what is right for their child and the child will be best served, happier and healthier.

**Irene Bakker. Tracy, Minnesota.**

**EDITOR'S NOTE:** *Parents are invited to submit contributions, not to exceed 250 words, for the Parents' Perspective column.*



## INTERVIEW WITH SENATOR EDWARD M. KENNEDY ON THE ISSUE OF HEALTH CARE REFORM

**Senator, what role do you play in the Senate with respect to health care reform?**

I serve as chairman of the Senate Committee on Labor and Human Resources. Our committee, along with the Senate Finance Committee, has principle jurisdiction over health care and health care reform. Our responsibility is to consider the many different aspects of the issue and to recommend legislation to the full Senate.

**Do you support President Clinton's health care proposal? Briefly, if not, why not? What alternative plan do you support and why?**

I support the goals of the President's proposal, and I have been working closely with the Administration on specific provisions. My proposal being considered by the Labor and Human Resources Committee builds on the central elements of the President's plan, and contains a number of modifications. It saves money by targeting the employer subsidies more effectively. It expands access to the Federal Employee Health Benefits Program, which provides excellent coverage for members of the Congress and the President. It provides additional benefits for women, children, people with disabilities, and the needy. My proposal provides additional benefits for mental health and substance abuse treatment. It expands long-term care by establishing a new, self-financing voluntary program to protect against the high cost of nursing homes. Additionally, my proposal increases investment in biomedical research and academic health centers.

**Please describe the mental health benefit for children and their families under your bill.**

The benefits in my proposal provide unlimited outpatient treatment; unlimited intensive nonresidential treatment; organized systems of care for children with emotional disturbances; 60 days per year of residential mental health treatment; 30 days per year of inpatient hospital treatment; no lifetime limits on benefits; grants for states to integrate their public and private delivery systems; and quality managed care standards.

These benefits are designed to reflect the experience of innovative companies and states that a comprehensive, well-managed, and flexible benefit can serve more people more effectively at lower cost.

**If there were room to improve the mental health benefit, how would you do it?**

The mental health and substance abuse benefit should be comprehensive and flexible, without arbitrary limits on inpatient and residential care. But the Congressional Budget Office and the Congressional Research Service feel that providing full benefits at this time would be too costly.

I believe that the benefit I have included strikes the proper balance between comprehensiveness and affordability. My goal is to see that there are no arbitrary limits on mental health benefits, just as there are no such limits on other health services.

**Thank you, Senator Kennedy.**

*Senator Edward M. Kennedy, a Democrat from Massachusetts, serves as the chair of the Senate Committee on Labor and Human Resources.*



## PORTLAND RESEARCH AND TRAINING CENTER HOSTS SPRING FAMILY RESEARCH CONFERENCE

The Research and Training Center on Family Support and Children's Mental Health hosted a national conference, *Building on Family Strengths: Research, Advocacy, and Partnership in Support of Children and Their Families*, April 10-12, 1994, in Portland, Oregon. Designed as a forum for the examination and dissemination of state-of-the-art research findings and issues in the areas of family support and family-centered care, the conference brought together approximately 350 family members, researchers, policy-makers, service providers, and advocates interested in strengthening practice in response to the needs of children and families.



Pauline Jivanjee,  
Conference  
Coordinator

Conference presentations addressed four major themes: developments in family research methods; family member/consumer involvement; research on family support services; and recognizing family diversity. Conference participants selected paper and symposium presentations that they wished to attend out of fifty offered over the three days of the conference. There was also a poster session with over twenty presenters providing visual displays of their work.

A high proportion of conference workshops were made jointly by parents and professionals. Conference presentations described research and program innovations from many parts of the country and many provided participants with new ideas to take back to their local areas. Participant questions and comments were encouraged, leading to lively discussions in many workshops.

There were high levels of ethnic and cultural diversity among both participants and presenters. Participants and presenters were drawn from Canada, Britain and forty states, including Alaska and Hawaii. Approximately fifty parent stipends were awarded. The stipends subsidized conference-related expenses including air fare, lodging, meals, conference registration fees and child care.

The keynote presentation was given by Lee Gutkind, Professor of English at the University of Pennsylvania and the nationally acclaimed author of *Stuck in Time: The Tragedy of Childhood Mental Illness* and Elizabeth Scanlon, a parent advocate whose family was featured in the book. Professor Gutkind described the research that caused his outrage about the children's mental health system and led to his writing the book. He



Lee Gutkind,  
Keynote Speaker

urged the audience to become active in efforts to change the system of mental health care for children. Ms. Scanlon focused on the process of a parent becoming "professionalized" and suggested strategies for parents to become more active in advocating for children's and families' needs to be met.



Dr. Cleopatra  
Caldwell

A plenary session was presented by Dr. Cleopatra Caldwell, Research Investigator at the African American Mental Health Research Center, Institute for Social Research, University of Michigan. Dr. Caldwell's presentation used the results of an intergenerational family study of early child-bearing to explore ethnic issues in mental health service delivery for a group of adolescent mothers.

Dr. Henry Levin, Professor of Education at Stanford University, and director of the Accelerated Schools Program was a luncheon speaker. Dr. Levin used his presentation as an opportunity to explore the ways that schools fail to meet the needs of many children and described the Accelerated Schools Program. This program is designed to bring all students into the educational mainstream by transforming schools to offer enriched and accelerated experiences in place of remedial ones. There are currently over 500 Accelerated Schools in 33 states.

The conference concluded with a panel discussion entitled "Family Participation in Research: Perspectives of Family Members and Researchers." Panelists were Leonard Bickman from the Center for Mental Health Policy at Vanderbilt University; Barbara Huff, director of the Federation of Families for Children's Mental Health; Peter Marsh from the University of Sheffield, England; and Judith Mayer, project coordinator of the Roosevelt Community Family Resource Center (a state integrated services site) in Portland, Oregon.

The *Building on Family Strengths* conference was sponsored by the Research and Training Center on Family Support and Children's Mental Health, the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, Child, Adolescent and Family Branch, U.S. Department of Health and Human Services; the National Institute on Disability and Rehabilitation Research, U.S. Department of Education; and the Annie E. Casey Foundation's Urban Children's Mental



Judith Katz-  
Leavy, Presenter

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## Health Initiative.

Conference proceedings are being prepared and will be available in September 1994. For additional information contact: Pauline Jivanjee, Conference Coordinator, Re-

search and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751; (503) 725-5197.

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# OREGON ABOLISHES CUSTODY RELINQUISHMENT REQUIREMENT

Parents who have children with serious disabilities must, in many states, transfer legal custody of their children to state authorities in order to receive necessary, but unaffordable, out-of-home services. Treatment providers as well as state child welfare authorities often explain that relinquishment is required by the Federal Adoption Assistance and Child Welfare Act of 1980 (also known as Public Law 96-272 or Title IV-E of the Social Security Act) or that treatment needs are best served if parents do not have the authority to remove their children from a treatment setting. In fact, such relinquishment is not required by federal law.

The Oregon Family Support Network, a state-wide parent organization composed of parents whose children have serious mental or emotional disorders, spearheaded a successful effort to enact legislation prohibiting the custody relinquishment practice in the state of Oregon. A group of individuals interested in the custody relinquishment issue was assembled. This group was composed of the executive director of the Oregon Family Support Network (OFSN), the chair of OFSN's board of directors, one governmental relations specialist who is the parent of a child with a developmental disability, two attorney-social workers and the director of Portland State University's Research and Training Center on

Family Support and Children's Mental Health. Staff from Oregon's Children's Services Division, the state child welfare agency, were also assigned to participate in the group's activities.

Committee tasks included: (1) drafting the proposed legislation; (2) surveying Oregon parents in an effort to demonstrate that parents did relinquish custody to obtain services for their children or declined to relinquish

custody and their children remained unserved; (3) receiving training by legislative liaisons; (4) drafting an information sheet describing the bill; (5) personally meeting with legislators; (6) seeking support for the bill from Oregon families and professionals; and (7) testifying on behalf of the bill in the Oregon House of Representatives and in the Oregon Senate.

Barbara J.

Friesen, director of the Research and Training Center said, "Our center had been concerned about the issue on a nationwide basis for several years. I thought to myself, 'Here we are, we've taken a national leadership role on this issue, and Oregon still has this problem.'"

Linda Reilly, chair of the Oregon Family Support Network's board of directors, has personally experienced the agony caused by being required to give up custody of her child to the state of Oregon in order to receive necessary out-of-home mental health treatment. She is the mother of a 19 year-old daughter who has



*Surrounded by supporters of the bill, Oregon Governor Barbara Roberts signed House Bill 3577 into law on July 14, 1993.*

chronic schizophrenia.

"This really upset me," Linda Reilly said. "You don't want to lose custody for several reasons. First, there's the horror and trauma of giving up your child. Also, by giving up custody you lose the authority to help make decisions as part of your child's treatment."

Judy Rinkin, the mother of a 22 year-old son diagnosed as bipolar (manic-depressive) and the director of the Oregon Family Support Network commented, "For many parents, giving up custody is not an option. Parents should have been getting another option a long time ago. We've not abused, neglected or abandoned our children."

The bill sailed through the Oregon Legislature. Oral and written testimony provided by parents and family advocacy organizations helped the bill pass 58-0 in the Oregon House of Representatives. The Oregon Senate passed the bill 29-0 and Governor Barbara Roberts signed the bill into law on July 14, 1993. The law took effect on November 4, 1993.

Colleen Wagner, family information coordinator for the Research and Training Center, believes the new law will help ensure that parents have the opportunity to participate in treatment planning for their children. Wagner also emphasized that Oregon's new law applies to children with mental, emotional or behavioral disorders, as well as to children with developmental or physical disabilities. She further noted, "The history of families who have children with emotional or developmental disabilities has been that if you don't know what your rights are and what's available, it's not given to you."

With staff support from the Research and Training Center and funding support from the Meyer Memorial Trust, the Oregon Family Support Network has published a detailed account of the efforts to pass this legislation. Entitled *An Advocate's Approach to Abolishing Custody Relinquishment Requirements for Families Whose Children Have Disabilities: The Oregon Experience*, this step-by-step guide is available by contacting: Publications Coordinator, Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751, (503) 725-4040; or Judy Rinkin, Executive Director, Oregon Family Support Network, 555 24th Place, N.E., Salem, Oregon 97301, (503) 581-2047. Marilyn McManus, manager of the Research and Training Center's National Clearinghouse, commented, "We hope it will be used as an advocates' guide that can have the ripple effect of eliminating the custody relinquishment requirement in states outside Oregon."

## HOUSE BILL 3577

House Bill 3577, enacted as Oregon Revised Statute 418.312, provides:

ORS 418.312. (1). The Children's Services Division of the Department of Human Resources shall not require any parent or legal guardian to transfer legal custody of a child in order to have the child placed under ORS 418.205 to 418.310, 418.480 to 418.500 and 418.992 to 418.998 in a foster home, group home or institutional child care setting, when the sole reason for the placement is the need to obtain services for the child's emotional, behavioral or mental disorder or developmental or physical disability. In all such cases, the child shall be placed pursuant to a voluntary placement agreement. When a child is placed pursuant to a voluntary placement agreement, the Children's Services Division shall have responsibility for the child's placement and care. When a child remains in voluntary placement for more than 180 days, the juvenile court shall make a judicial determination, within the first 180 days of the placement, that the placement is in the best interests of the child. In addition, the juvenile court shall hold a dispositional hearing no later than 18 months after the original voluntary placement, and every two years thereafter during the continuation of the placement, to determine the future status of the child.

(2) As used in this section, "voluntary placement agreement" means a binding, written agreement between the Children's Services Division and the parent or legal guardian of a minor child, in which legal custody does not transfer to the Children's Services Division but specifies, at a minimum, the legal status of the child and the rights and obligations of the parent or legal guardian, the child and the Children's Services Division while the child is in placement.

A number of members of Congress are considering proposing federal legislation that would instruct states to proceed by a vehicle other than requiring a transfer of legal custody in order for families to receive federally reimbursable assistance from their states for the out-of-home placement of a child. Such legislation would be specifically targeted to children who require out-of-home supportive services for their disabilities. Such legislation would enable families to retain legal custody of their children, participate in decisionmaking on behalf of their children, and—most importantly—ensure that children receive the essential services they require for their particular disability.



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## CAN JASON LIVE AT HOME? YES—WITH WRAPAROUND SERVICES

For almost three years “Can Jason Live at Home?” was the key question asked by Jason’s parents and by professionals as we worked together to develop a program that would meet both his needs and those of his family. Jason has autism and is now twelve years old. For the first seven years of his life he experienced an ever-increasing number of problems. Jason’s violence and the inability to manage him in his own home resulted in psychiatric hospitalization. Unfortunately, when Jason was ready to return to the community, there was no place for him to go.

In Louisiana, home supports are available for children who have become a ward of the state, but few supportive services are available to families who raise their own children. Jason’s parents made the decision that they would maintain custody of their son. As the family explored community alternatives they became firm in their resolve that no care-giving situation such as a therapeutic foster home or community home could substitute for their own home. There were many frustrating circumstances faced by the family such as having to change neighborhoods, change schools, and change the constellation of human services available to them and to Jason. These obstacles motivated the family to work with a team of professionals to develop a unique plan of care for Jason in his own home.

The family team included an interagency network of parents, professionals (representing community agencies, schools, hospital and state mental health office staff) and parent advocates. Additionally, planners and program developers from around the United States provided encouragement for the development of a plan that would bring Jason home under the supervision and management of his father who would be paid as Jason’s personal care attendant. Funding from multiple sources was made available through the following: (a) the Jefferson Parish Developmental Disabilities Agency (lead agency on the team); (b) the parish’s mental health agency; and (c) the school system.

The following services were “wrapped around” the child and family:

1. A transition training program was offered to Jason’s parents to assist with their son’s transition home. This

training program included information on effective behavioral strategies to assist Jason to follow a daily routine, how to deal with challenging behaviors, suggested communication techniques, as well as information on crisis intervention and physical management strategies.

2. The parish mental health agency provides a \$258.00 monthly cash subsidy.

3. The parish developmental disabilities agency provides \$6,950.00 annually from their “Family Ties” funds to fund Jason’s father’s position as his son’s personal care attendant and also augments that funding with an additional \$5,000.00 annually through a family subsidy contract. Additionally, the agency paid \$800.00 to fund the construction of a fence around the family’s yard.

4. The parish mental health agency funds a psychologist who works with Jason and additionally funds psycho-social skills training and treatment integration to ensure Jason’s success at home and at school. Due to the intensity and severity of Jason’s challenging behaviors, the mental health agency also funds an additional individual to work with Jason in his home.

5. Medication management and supervision are provided through a local mental health clinic.

6. Parish crisis intervention services are available for the family’s use in instances where planned interventions are unsuccessful in modifying Jason’s behavior.

7. The family has access to one day of respite care each month.

8. Jason received an aide upon his return to public school. This aide has been trained in Jason’s behavior support plan, and assists the boy in participating in his individualized education plan.

When Jason returned home, his condition, although somewhat improved, was not much changed. What had changed, however, was the definition of home. Home was no longer an isolated family trying to cope with an impossible situation. Home was now the place where Jason could live as normal a life as possible. This was because the structure Jason needed was provided. The team working for Jason creatively put together the supports and services that were required for him to live with his family.

“As Jason’s mother it is impossible for me to express the



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gratitude I feel for all who helped to bring my child home. The arrangement, although difficult at times, is working. His daily routine resembles that of any other child. He goes to school, spends time with his family, plays and enjoys being outdoors. Since regularly attending school it has been discovered that Jason reads and can do basic math. When he was hospitalized, it was assumed that these kinds of skills far exceeded his simple abilities."

"Home life with Jason remains a challenge. My husband has become a full time handyman as he strives to keep the damage under control. Our life does not have the freedoms found in most families. We are not able to 'get up and go.' Jason is always a major consideration. We do not take vacations; we have never had a Christmas tree—but both of our sons live at home. All of the services, the time and the money, have given us a complete family. Autism placed a hole in our heart that can never be mended. When Jason went to live at the hospital another hole was made. This hole was repaired when Jason came home. It was

filled with the love and compassion of those who cared about what happened to one family. It was filled by those who gave of themselves and received very little in return. For my part, all I can do is thank them. The gratitude of my family is eternal."

Yes! Jason *can* live at home! He was able to return home due to the multiple cash subsidies, in-home support services, specialized school services and leisure time planning that have been provided. His parents provide the glue that makes this plan work because they will do "whatever it takes" to keep their family together.

This plan of care was developed and supported by the Jefferson Parish Interagency Team and the Jefferson Parish Human Services Authority. For additional information contact: Vicki Scanlan-Leishman, B.C.S.W., M.S., Coordinator of Children's Services, Community Support Services; Jefferson Parish Human Services Authority; Children's Services; 3101 W. Napoleon Avenue, Suite 110; Metairie, Louisiana 70001; (504) 838-5750.

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## WHAT DO FAMILIES THINK ABOUT FAMILY/PROFESSIONAL COLLABORATION?

Parents of children with emotional disorders have often felt excluded by the professionals providing care and treatment for their children. For example, many family members report little involvement in their child's educational plan or not being informed about their child's psychiatric treatment. In recent years, parents and some professionals have called for partnership or collaboration between family members and professionals.

Many authors, both parents and professionals, have suggested what professionals need to do to collaborate with families, but there has been no research asking families what they think. Of all the things that have been suggested about collaboration, what really matters to families? In conjunction with the study to examine some of the ways in which parents express empowerment (See article on page 16) Research and Training Center on Family Support and Children's Mental Health staff also asked parents to rate their relationship with a professional with whom they had worked over the past year. Parents' responses revealed that from their perspective there are four distinct parts of elements to collaboration.

First, it is important that professionals be supportive and understanding in their relationships with family members, that is, include parents in decisionmaking about the child and understand that families have many

obligations in addition to caring for their child with a disorder.

Second, professionals should assist families in the practical aspects of getting services for a child, that is, assist families in finding, coordinating and paying for services when needed.

Third, open and honest communication was identified as an important element of family/professional collaboration.

Fourth, professionals must be willing to involve families in judging how well services are working and be willing to change services based on parental feedback.

In addition to these findings, the study also noted characteristics of professionals and their organizations that are associated with parent/professional collaboration.

The complete paper describing this study is entitled "From Paternalism to Partnership: Family/Professional Collaboration in Children's Mental Health." The paper is in press and will appear in an upcoming issue of *The American Journal of Orthopsychiatry*. A copy of the paper may be obtained from the following: Publications Coordinator, Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751; (503) 725-4040.

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## HOW PARENTS SHOW EMPOWERMENT

In recent years, parents of children with emotional disorders have begun to exercise more influence and control over the services that their children receive. The term that is often used to describe this shift in parents' involvement is *empowerment*. While there has been much discussion of empowerment as an idea, very little research has been devoted to studying it. For this reason, the Research and Training Center on Family Support and Children's Mental Health undertook a study to identify and measure some of the major ways that parents express empowerment. The intent here was to gain a better understanding of empowerment and to develop a method of measuring it that could be used in other studies and evaluations.

The study was conducted through a parent survey that asked about different experiences related to empowerment. Parent organizations in four locations—the District of Columbia, Mississippi, Oregon and Wisconsin—agreed to distribute survey questionnaires to their members. These were organizations for parents whose children have emotional, behavioral or mental disabilities. Questionnaires were also distributed to families who had participated in a previous survey conducted by the Research and Training Center. There were no names or identifying information on the questionnaire. In total, 515 questionnaires (29%) were returned.

The average respondent was a 40 year-old Caucasian female, middle class, high school graduate. The children for whom the parent was receiving services were mostly Caucasian males who averaged 13 years of age. The analysis of parents' responses to the survey identified three distinct types of empowerment.

One type of empowerment concerns handling problems within the family at home. Here, parents feel empowered to the extent that they are generally able to solve problems that arise and are confident in their ability to help their children grow and develop.

Another type of empowerment concerns dealing with the service system—mental health providers, educators, etc.—on behalf of one's own child. Here, empowerment reflects both the belief that parents have a right to make decisions about services and the knowledge about what to do to get better services.

A third type of empowerment concerns influencing the service system and the community to improve services for all children with emotional disorders. This is political empowerment in the sense that efforts here are not only made on behalf of one's own child but on behalf of all children.

Not all parents show each type of empowerment; for example, most parents are not especially active in the community or politics. However, the study did show that it is meaningful to distinguish between these different types of empowerment. Moreover, it resulted in a questionnaire that can be used in other studies, thereby helping researchers to learn more about this important topic.

The complete paper describing this study is entitled "Measuring Empowerment in Families Whose Children Have Emotional Disabilities: A Brief Questionnaire" and is available in *Rehabilitation Psychology*, Volume 37, Number 2, 1992, pages 305-321. A copy may be obtained by contacting the following: Publications Coordinator, Research and Training Center on Family Support and Children's Mental Health, Portland State University, P.O. Box 751, Portland, Oregon 97207-0751; (503) 725-4040.

### HAVING OUR SAY

*This column features responses to questions posed to readers. In this issue we feature responses from participants at the April 1994 Building on Family Strengths children's mental health conference to the question: "What was the most useful information that you gained from this conference?"*

- Family strengths were emphasized over and over and over! It was a healing atmosphere to be in and very comforting!!
  - That I was validated by strangers.
  - It was encouraging to see that a lot more parent/professional collaboration is going on around the country than I had realized. I got specific ideas for educational outreach to teachers and clergy and new things to think about related to stress and social support research.
  - How important parent advocates are and how they can work with the "service givers"—not against!
  - Many presentations are really "pushing the envelope" of radical models, utilizing families as case managers, etc.
- The theme of the conference was clearly embodied in the design of the days, the workshops and sessions.
- I discovered I don't like research.



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## NOTES & COMMENTS

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### NAMI CAN Summer Convention Scheduled

The National Alliance for the Mentally Ill-Child and Family Network (NAMI CAN) helps families with children who have serious brain disorders or mental illness by providing support, information, and advocacy. The purpose of the organization is to promote improved systems of care for children and adolescents with these disorders. The organization's annual convention, entitled *Changes, Challenges and Choices* is scheduled for July 6 & 7, 1994 at the San Antonio Convention Center in San Antonio, Texas. The NAMI CAN sessions will be followed by the annual National Alliance for the Mentally Ill conference on July 7-10, 1994.

Gary DeCarolis, chief of the Child, Adolescent and Family Branch, Division of Demonstration Programs, Center for Mental Health Services, United States Department of Health and Human Services, will describe the role the Center for Mental Health Services plays in developing services for children who have serious brain disorders and their families. Steven Pliska, of the University of Texas Health Science Center, will discuss his research with children who have attention deficit hyperactivity disorder and will suggest strategies for working with these children in classroom settings. Psychologist Diane Marsh, author of *Families and Mental Illness: New Directions in Family Practice* and the sister of an adult who has a mental illness, will address the topic "Siblings: The Forgotten Family Members." North Dakota teacher and consultant Bonnie Berryman's presentation will offer strategies for educating youth in school about neurobiological disorders. Ms. Berryman will provide lesson plans and instructional materials for conducting inservice trainings for teachers. A presentation by the program coordinator for Parents for Behaviorally Different Children in Albuquerque, New Mexico—Delfy Roach—will examine successful strategies for reaching out to minority families.

NAMI CAN offers a number of resources to educate families, organizations, and the general public regarding the nature of serious brain disorders and mental illness. They provide lists of helpful publications and organizations for parents with children who have serious brain disorders or mental illness, a series of medical information brochures that include up-to-date information on a wide variety of mental illnesses and treatment modalities, and numerous publications, videos, and other education tools. NAMI CAN also publishes a newsletter.

For conference registration or for further general information contact: NAMI CAN, 2101 Wilson Blvd., Suite

302, Arlington, Virginia 22201; (703) 524-7600 or (800) 950-NAMI; or Sara Gonzalez at (512) 883-6125 for additional information on the NAMI CAN conference program.

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### Training Institutes on Systems of Care for Children Planned for June 1994

An important upcoming event will provide an intensive training opportunity for a wide range of participants. The biannual Child and Adolescent Service System Program (CASSP) Training Institutes are scheduled for June 19-23, 1994 and will be held in Traverse City, Michigan at the Grand Traverse Resort.

The response to the 1992 Training Institutes, held in Colorado, was overwhelming and confirmed an extraordinary level of interest in training related to the development of systems of care. To meet this need, the 1994 Training Institutes are entitled *Developing Local Systems of Care for Children and Adolescents with Severe Emotional Disturbances*. The Institutes will offer an opportunity to obtain in-depth, practical information on how to develop, organize, and operate comprehensive, coordinated, community-based systems of care for children and their families. The faculty will be comprised primarily of representatives of communities that have made substantial progress toward developing systems of care, and participants will be able to choose Institutes presenting different approaches to system development.

The Institutes are designed for a variety of individuals including state and local administrators, planners, providers, parents, and advocates. A primary target group consists of agency administrators, managers, providers, and parents from local areas, representing mental health and other child-serving agencies. These individuals, ideally attending as a team, are the ones who can take the knowledge and skills developed at the Institutes and begin to apply it in their home communities. This training can be an invaluable experience for a community planning a system improvement initiative.

The Institutes are sponsored by the CASSP Technical Assistance Center at Georgetown University and are funded by the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, Department of Health and Human Services. For more information contact: CASSP Technical Assistance Center, 2233 Wisconsin Avenue, N.W., Washington, D.C. 20007; (202) 338-1831.

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## NOTES & COMMENTS

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### Seventh Annual Children's Mental Health Research Conference Held

The Research and Training Center for Children's Mental Health held its seventh annual research conference, *A System of Care for Children's Mental Health: Expanding the Research Base*, February 28-March 1, 1994 at the Hyatt Regency Westshore in Tampa, Florida. Over 530 participants had the opportunity to select from among 127 paper presentations and symposia and over 40 poster presentations. Researchers, policymakers, providers, consumers and family members attended from 37 states and Canada.

An opening presentation featured a panel that included participants from the President's Work Group on Mental Health chaired by Tipper Gore. Panelists Judith Katz-Leavy, Beth Stroul, Sybil Goldman, Sheila Pires and Chris Koyanagi described President Clinton's plan for health care reform including who would be served, how systems of care would be implemented without disrupting services and how children will be effected. Sybil Goldman of the Child and Adolescent Service System Program (CASSP) Technical Assistance Center at Georgetown University emphasized, "The Clinton plan is the only proposal that details a mental health benefit and articulates public policy goals."

Former first lady Rosalynn Carter received standing ovations as she presented her views on health care reform and its impact on mental health services. She advised the Clinton Administration on its health care reform plan. In the area of mental health services, Mrs. Carter believes health care reform should address prevention, early intervention and follow-up services. The former first lady said, "People are treated for a physical illness until they are well and the same standards should apply in treating mental illness." Mrs. Carter was the first annual Gwen Iding Distinguished Lecture Series speaker at the yearly meeting.

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### Federation of Families for Children's Mental Health Holds Fifth Annual Conference

Five hundred family members and professionals attended *Diversity, Direction and Dedication*, the fifth annual Federation of Families for Children's Mental Health's national conference. Held in Arlington, Virginia on November 12-14, 1993, sessions were presented by many state organizations and covered topics such as organizing families in an urban multicultural neighborhood, respite care, rural systems of care, diversity in support groups, parents

on boards or committees, adoption, custody issues and parent/professional partnerships.

Conference attendees heard an update on the Annie E. Casey Foundation's Mental Health Initiative for Urban Children Project. That initiative has provided grant money to communities in six states to develop healthier neighborhoods, families and children.

The annual "Claiming Children" award went to Evelyn Williams of Mississippi for her "outstanding efforts on behalf of children with emotional/behavioral/mental disorders and their families." Judy Katz-Leavy, of the Center for Mental Health Services, received the "Professional of the Year" award.

New officers were installed. Jane Walker of Maryland succeeded outgoing President Creasa Reed. Al Duchnowski and Kathy Berg, both of Tampa, Florida, serve as - respectively - vice president and secretary. Velva Spriggs of Washington, D.C. is the Federation's treasurer.

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### New Publications Available Through Research and Training Center's Resource Service

Two new publications are available through the Research and Training Center's Resource Service. The development of 15 statewide family organizations funded by the Child and Adolescent Service System Program during the 1990-91 and 1991-92 fiscal years is documented in *Family Advocacy Organizations: Advances in Support and System Reform*. This publication describes the three principal roles that parent coordinators often fill; identifies the interorganizational issues that may arise among family organization projects that have a sponsoring organization; examines the developmental process of statewide family organizations that choose to develop independently from a sponsoring organization; and identifies areas for further research and training.

A detailed account of the procedures followed in conducting a survey of families with children with emotional disabilities is provided in *Family Caregiving for Children With a Serious Emotional Disability. Phase One: Technical Report*. The family caregiving model employed in the survey is reviewed. A literature review that led to the formulation of the family caregiving model is included, as is a complete copy of the final questionnaire, and a description of the data collection and analysis procedures and findings.

Ordering information is provided on page 19.

# Research and Training Center Resource Materials

- Annotated Bibliography. Collaboration Between Professionals and Families of Children with Serious Emotional Disorders.* Contains 136 entries addressing family-professional collaboration, establishing collaborative relationships, collaboration in early intervention and education, advocacy, and empowerment. \$6.00.
- Annotated Bibliography. Parents of Emotionally Handicapped Children: Needs, Resources, and Relationships with Professionals.* Covers relationships between professionals and parents, parent self-help, support groups, parent participation. \$7.50.
- 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.
- 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.
- Building a Conceptual Model of Family Response to a Child's Chronic Illness or Disability.* Proposes comprehensive model of family caregiving based on literature review. Causal antecedents, mediating processes and adaptational outcomes of family coping considered. \$5.50.
- Changing Roles, Changing Relationships: Parent-Professional Collaboration on Behalf of Children With Emotional Disabilities.* Monograph examines barriers to collaboration, elements of successful collaboration, strategies for parents and professionals to promote collaborative working relationships, checklists for collaboration, suggested resources. \$4.50.
- Child Advocacy Annotated Bibliography.* Includes selected articles, books, anthology entries and conference papers. \$9.00.
- Choices for Treatment: Methods, Models, and Programs of Intervention for Children With Emotional Disabilities and Their Families. An Annotated Bibliography.* Literature on the range of therapeutic interventions used with children and adolescents with emotional disabilities is described. Includes innovative strategies and programs. \$6.50.
- Developing and Maintaining Mutual Aid Groups for Parents and Other Family Members: An Annotated Bibliography.* Topics addressed include organization and development of parent support groups and self-help organizations, professionals' roles in self-help groups, parent empowerment in group leadership, and group advocacy. \$7.50.
- Families as Allies Conference Proceedings: Parent-Professional Collaboration Toward Improving Services for Seriously Emotionally Handicapped Children and Their Families.* April 1986. Delegates from thirteen western states. Includes: agenda, presentation transcriptions, recommendations, worksheets, and evaluations. \$9.50.
- NEW!** *Family Advocacy Organizations: Advances in Support and System Reform.* Describes and evaluates the development of statewide parent organizations in 15 states. \$8.50.
- NEW!** *Family Caregiving for Children with a Serious Emotional Disability.* Summarizes a family caregiving model employed in survey of families with children with emotional disabilities. Includes review, questionnaire, data collection and analysis procedures and findings. \$8.00.
- Family Research and Demonstration Symposium Report.* Summarizes recommendations from 1992 meeting for developing family research and demonstration agenda in areas of parent-professional collaboration and training systems, family support and advocacy, multicultural competence, and financing. \$7.00.
- 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.
- Glossary of Acronyms, Laws, and Terms for Parents Whose Children Have Emotional Handicaps.* Glossary excerpted from *Taking Charge*. Approximately 150 acronyms, laws, and words and phrases commonly encountered are explained. \$3.00.
- 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.
- 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.
- Making the System Work: An Advocacy Workshop for Parents.* A trainers' guide for a one-day workshop 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.
- The Multnomah County CAPS Project: An Effort to Coordinate Service Delivery for Children and Youth Considered Seriously Emotionally Disturbed.* Process evaluation of an interagency collaborative effort. The planning process is documented and recommendations are offered. \$7.00.
- National Directory of Organizations Serving Parents of Children and Youth with Emotional and Behavioral Disorders, Third Edition.* Includes 612 entries describing organizations that offer support, education, referral, advocacy, and other assistance to parents. \$12.00.
- Next Steps: A National Family Agenda for Children Who Have Emotional Disorders Conference Proceedings.* December 1988. Includes: development of parent organizations, building coalitions, family support services, access to educational services, custody relinquishment, case management. \$6.00.
- Next Steps: A National Family Agenda for Children Who Have Emotional Disorders (booklet).* Briefly summarizes Next Steps Conference and recommendations made by work groups. Designed for use in educating administrators, policymakers and advocates about children's mental health issues. Single copy: \$2.50. Five Copies: \$7.00
- Organizations for Parents of Children Who Have Serious Emotional Disorders: Report of a National Study.* Results of study of 207 organizations for parents of children with serious emotional disorders. Organizations' activities, program operation issues, training programs described. \$4.00.
- Parent-Professional Collaboration Content in Professional Education Programs: A Research Report.* Results of nationwide survey of professional programs that involve parent-professional collaboration. Includes descriptions of individual programs. \$5.00.
- Parents' Voices: A Few Speak for Many (videotape).* 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: A Key Ingredient of Family Support.* Conference proceedings. October 1989. Includes speeches and panel presentations on topics such as starting respite programs, financing services, building advocacy, and rural respite care. \$5.50.
- Respite Care: An Annotated Bibliography.* Issues discussed include: the rationale for respite services, family needs, program development, respite provider training, funding, and program evaluation. \$7.00.

More listings and order form on reverse side 



- Respite Care: A Monograph.* Monograph describes: types of respite care programs, recruitment and training of providers, benefits of respite services to families, respite care policy and future policy directions, and a summary of funding sources. \$4.50.
- Statewide Parent Organization Demonstration Project Final Report.* Describes and evaluates the development of statewide parent organizations in five states. \$5.00.
- Taking Charge: A Handbook for Parents Whose Children Have Emotional Handicaps.* Addresses issues such as parents' feelings about themselves and their children, labels and diagnoses, and legal issues. Second edition includes post-traumatic stress disorder and mood disorders such as childhood depression and bipolar disorder. \$7.00 .
- Therapeutic Case Advocacy Trainers' 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.
- Therapeutic Case Advocacy Workers' Handbook.* Companion to the *Therapeutic Case Advocacy Trainers' Guide.* Explains the Therapeutic Case Advocacy model, structure of task groups, group process issues, evaluations. \$4.50.

- Transition Policies Affecting Services to Youth With Serious Emotional Disabilities.* Examines how state level transition policies can facilitate transitions from the child service system to the adult service system. Elements of a comprehensive transition policy are described. Transition policies from seventeen states are included. \$8.50.
- 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.
- Youth in Transition: A Description of Selected Programs Serving Adolescents With Emotional Disabilities.* Descriptions of existing youth transition programs provided. Residential treatment, hospital and school based, case management, and multi-service agency transition programs are included. \$6.50.
- List of Other Publications Available Through the Research and Training Center.* Free.

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