

FAMILY AND YOUTH MOVEMENT

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History of Mental
Health Services
for Children,
Youth and their
Families in
California

THEN.....



STOCKTON STATE HOSPITAL

- The Stockton Developmental Center began as the first Insane Asylum of California at Stockton.
- Children were placed in hospital wards with adults as no separate accommodations were made available to children in those days.



THEN.....



NAPA STATE HOSPITAL

- Although children were admitted to the same state hospital wards as adults, the percentage was small compared to adult inpatient care.
- When conditions at Stockton and Napa state hospitals became overcrowded funds were appropriated to open a facility exclusively for children in Santa Clara County called the "California Home for the Care and Training of Feeble-minded Children".
- This facility was later moved to Glen Ellen, California, and later became Sonoma State Hospital.



THEN.....

- By the 1950's all five existing state hospitals were over crowded with approximately 1 doctor for every 300 patients
- With de-institutionalization the state hospital model of care changed significantly with the passage of the Short-Doyle act in 1957
- In 1958 37,000 adults and children resided in state hospitals, however this was reduced significantly.
- Unlike adults, children did not become homeless. They were placed in foster care, group homes and residential treatment facilities. Most just did not get the care they needed.
- In 1968 the Lanterman-Petris-Short (LPS) Act further modernized mental health care by establishing standards and legal procedures for involuntary hospitalization

AND NOW.....



- In 1982, Jane Knitzer's "*Unclaimed Children*" described continued nationwide failure to provide services for children and adolescents with serious emotional disturbances.
- Out-of-state placements were high, placements on adult wards still existed and counts of these placements were often unavailable to mental health officials.

NATIONAL INSTITUTE OF MENTAL HEALTH (NIMH) - CHILD AND ADOLESCENT SERVICE SYSTEM PROGRAM (CASSP)

- In 1984, NIMH began funding it's Child and Adolescent Service System Program. (this program was later shifted to SAMHSA)
- The initial cohort of CASSP sites influenced service systems in their states in the intended directions:
 - Toward a more comprehensive system of care
 - Emphasis on community-based treatment
 - Collaborative efforts among state agencies
 - Collaborative efforts among stakeholders
 - Increased involvement by parents and other family members

CALIFORNIA COUNTIES FUNDED BY SAMHSA/CMHS CSOC GRANTS

- SAMHSA began funding California counties in February 1994. The first 5 sites were known as the California 5: Riverside, San Mateo, Santa Cruz, Ventura, and Solano Counties
- SAMHSA funding continued in October 1994: Napa, Sonoma, and Santa Barbara Counties, in October 1997 for San Diego County, in October 1999 for Contra Costa County, again in October 2002 for Glenn County, San Francisco County and Sacramento County. Monterey County was funded in February of 2003.
- Humboldt and Del Norte Counties were funded in 2004 for their Wraparound System of Care along with United Indian Health Services, Inc. in Arcata, California
- SAMHSA continues current funding for Children's Systems of Care in California including Butte County Circle of Care and Los Angeles County 0-5 Program.



MEANWHILE IN CALIFORNIA.....

- Because services were either not available, or difficult to access, parents of children and youth with severe emotional disturbances were often forced to relinquish custody of their children in order to obtain needed mental health services. Relinquishment to either the child welfare system or to the juvenile justice system involves a criminal offense, however, parents often did not have a choice.
- AB 3632, the Special Education Pupils Program, was passed in 1984 to provide a new framework for children's mental health care – this transitioned the responsibility to provide mental health care for special education students from the education system to the mental health system. This new law enabled parents to access appropriate mental health services for their children through the school "Individualized Education Plan" (IEP) for special education students, avoiding custody relinquishment.

CHILDREN'S SYSTEM OF CARE

- The definition of a system of care for children with emotional disorders was first published in 1986 (Stroul & Friedman):
 - *A comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families*
 - Comprehensive, incorporating a broad array of services and supports
 - Individualized
 - Provided in the least restrictive appropriate setting
 - Coordinated both at the system and service delivery levels
 - Involve families and youth as full partners
 - Emphasize early identification and intervention



CHILDREN'S SYSTEM OF CARE (CSOC) IN CALIFORNIA

- In 1984, AB 3920 was passed to create a demonstration pilot program in Ventura County to create a Children's System of Care.
- In 1987, after the early success of the Ventura County pilot, AB 377 (Senator Cathie Wright) was passed to extend funding for the CSOC model in California.
- In 1992, AB 3015 was passed to expand CSOC to other counties in California.
- In 1995, AB 3015 was passed to expand to additional California counties.
- And in 1996, AB 1667 was passed to expand to even more counties.



INTERAGENCY ENROLLEE-BASED PROGRAM – CHILDREN’S SYSTEM OF CARE

- CSOC funding was proposed for cuts in the 2002 state budget by Governor Davis.
- United Advocates for Children and Families rallied parents and youth across the state to advocate for continued funding for the CSOC Program.
- Parents and youth testified before budget committees, sent letters and made phone calls.
- Governor Davis reversed the proposed cut and continued the CSOC funding.
- Governor Davis required changes in the CSOC method of evaluation
- Development of new evaluation methods that target individual CSOC client outcomes
- The CSOC Program became the “Interagency Enrollee-Based Program” in 2003.



RESPONDING TO THE CHANGING NEEDS OF CHILDREN AND THEIR FAMILIES IN CALIFORNIA

- Children’s System of Care developed the framework to include families as partners in the care and treatment of their children.
- The Children’s System of Care framework is organized around all of the families’ needs in coordination with multiple systems and agencies.
- “Unclaimed Children” explained the need to develop services that integrated families as partners in their children’s care.
- The California Mental Health Planning Council (CHMPC) was directed by the legislature (1991) to create a master plan for state mental health reform:
 - Client and Family driven mental health system of individual, comprehensive care
- In 2003, the CMHPC updated the master plan:
 - A client-directed approach to services in which all services for children and their families..... guided by individual goals, strengths, concerns, motivation and disabilities.

FAMILY PARTNERSHIP IN CALIFORNIA

- New roles for family members and professionals
- Family involvement at all levels
 - Policy
 - Management
 - Direct Service
- Family programs
 - Support
 - Education
 - Advocacy



THE FAMILY MOVEMENT FOR CHILDREN'S MENTAL HEALTH

- **National Federation of Families for Children's Mental Health** was established in 1989 as a national family-run organization linking more than 120 chapters and state organizations together to focus on the issues of children and youth with emotional, behavioral and mental health needs and their families.



FAMILY MOVEMENT FOR CHILDREN'S MENTAL HEALTH IN CALIFORNIA

- **United Parents** was founded over two decades ago, in 1989, as a family-run organization, on the principle that parents helping parents makes a difference in shaping a better future for our children and our community.



- **Family and Youth Roundtable** was founded in 1998 as a family-run organization, believes that partnering with families and youth and public/private provider agencies will strengthen families, build strong communities and improve outcomes.



FAMILY MOVEMENT FOR CHILDREN'S MENTAL HEALTH IN CALIFORNIA

- **United Advocates for Children and Families** was established in 1992 as the California statewide family-run organization dedicated to improving the quality of life for all children and youth with emotional, behavioral and mental health challenges and to eliminate institutional discrimination and the social stigma attached to these conditions.



FAMILY MOVEMENT FOR CHILDREN'S MENTAL HEALTH IN CALIFORNIA

- In the last several decades, family members of children and youth have gained progressively more central roles in their children's mental health care.
- Each California County who developed a Children's System of Care also developed specialized peer advocacy and support roles for parents of children and youth at all levels of the local county mental health system.
- Many counties developed Family Partnership Programs which were designed to provide peer support to other parents.
- In turn, private provider agencies began to see the success of these peer support roles and began to develop family partnership programs and hire parents within their agencies.
- Children's Wraparound services have family partnership roles embedded within their programs.

FAMILY MOVEMENT FOR CHILDREN'S MENTAL HEALTH IN CALIFORNIA



- In recent years, families have been recognized as full partners, not only in their children's care, but in administrative roles, in management roles, in direct care provider roles, in public policy roles, in legislative advocacy roles and in discussions regarding appropriations.
- Families bring new voice to support public policy makers to create constant pressure for improvement in the children's mental health arena.
- Families bring the persistence to examine every program and redesign them around children in the context of their families.

FAMILY-DRIVEN SERVICES

- **Definition of “Family Driven”**
- Family driven services exist when the beliefs, opinions, and preferences of every child, youth and their family/caregiver are a deciding determinant in service planning on the individual level; are a significant determinant in program development and implementation at the agency level; and are integral to legislation and appropriation at the policy level.
- Children, youth and their family/caregiver make the decisions about their own care and participate in developing and implementing strategies for mental health system improvement.



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FAMILY-DRIVEN SERVICES

- **Defining Characteristics of the Definition of Family Driven Include:**
- Children, youth and their families/caregivers are responsible for making care plan decisions based on partnership with their provider's.
- Care plans are clearly related to the child, youth and family/caregiver beliefs, opinions and preferences.
- Children, youth and their families/caregivers are respected and valued.
- The adverse effects of mental health stigma including shame, guilt and blame are understood and mitigated.
- Parents and other family/caregiver members receive easily understood information on emotional disorders, the process for obtaining prompt access to needed mental health screening, assessments and care, entitlements to care, and legal rights and protections.
- Services and supports build on child, youth and family/caregiver strengths.
- Children, youth and their families/caregivers are offered easily understood information necessary to be full and credible participants in service planning.
- Communication with children, youth and their families/caregivers is clear and honest.

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EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT (EPSDT)

- The Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit has been a requirement of the federal Medicaid program since its inception in 1966. Under this program, states are required to inform eligible beneficiaries from birth through age 21 of the services available to them. In 1993, a group of California-based attorneys filed a lawsuit against the state, charging that the state was not complying with federal law. The courts agreed, and the EPSDT mental health benefit implemented as a result of this lawsuit increased the availability of funds for Medi-Cal specialty mental health services provided to eligible children and adolescents.



EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT (EPSDT)

- Prior to the EPSDT program, the demand for children's mental health services outweighed the resources available, bringing to light the number of children who go un-served, often resulting in hospitalization and group care placements for children.
- The EPSDT program allowed a new group of Medi-Cal eligible children access needed mental health services while remaining in their homes and communities.
- Under the new funding, services greatly expanded, became available for individual and family therapy, intensive services and a Wraparound approach to care to be provided in a community or home setting, allowing the child to stay at home with their families.
- With early screening and diagnosis, many of the mental health needs of children can be confronted without the added stress of leaving their home and creating a more unbalanced environment.
- EPSDT has changed the mental health delivery system for children and their families, however, this funding source does not meet the need for children who do not qualify for this entitlement.

HEALTHY FAMILIES

- The California Healthy Families Program began in July of 1998, in response to the Children's Health Insurance Program, approved by Congress in 1997. One year later, 145,000 children were enrolled and by September 2003, 690,000 had enrolled.
- As a Healthy Families Program member, children have access to mental health services through their health plan. If specialty mental health services are needed, the Healthy Families Program Serious Emotional Disturbance (SED) benefit may be available as well. This Healthy Families SED benefit is offered only through local mental health departments.



ADVOCACY FOR CHILDREN'S MENTAL HEALTH SERVICES

- In 1998, the *Emily Q. v. Bonta* lawsuit was filed arguing that children in mental institutions and group homes could be better served by offering one-to-one behavior aides to provide services to children in their homes and communities. In 2001 the federal court agreed and ordered the state and counties to provide Therapeutic Behavioral Services (TBS) through the Medi-Cal program. This affects 25,000 children in California.
- In 2003, a class action lawsuit was filed, *Katie A. v. Bonta*, challenging the long standing practice of confining foster children with mental health problems in hospitals and large group homes instead of providing services that would enable them to stay in their homes and communities. In 2003, the lawsuit against Los Angeles County was settled and included the expansion of Wraparound services and evidence-based practices instead of institutionalization for foster children.



MENTAL HEALTH SERVICES ACT

- Families of children and youth participated in the development of Proposition 63 along with other California stakeholders.
- Families of children and youth participated in the campaign for Proposition 63 by gathering signatures, donating to the campaign, and encouraging their families, neighbors and communities to vote yes on the proposition.
- In 2004 the Mental Health Services Act was passed. The passage of the MHSA was intended to enable the provision of comprehensive community mental health services to children and youth with serious emotional disturbance in accordance with the Children's System of Care standards for those youth who do not qualify for services under one of the existing entitlement programs.



UNCLAIMED CHILDREN REVISITED – A CALIFORNIA STUDY (MAY 2010)

- The California Case Study represents a major component of Unclaimed Children Revisited. It was a multi-method, multi-level study that included 11 California Counties.
- Findings:
 - Approximately 6% of California's school-age children have mental health problems, however, less than 2% are utilizing county mental health services.
 - Mental health system leaders report struggles to provide services to children and youth of color even though Hispanics/Latinos make up the largest racial/ethnic group in California.
 - System leaders recognized the importance of family and youth driven services, although, the philosophy is not fully embedded across all counties, although, progress is being made, progress varies by county and within the county.
 - Though California has made strides in implementing prevention and early intervention, challenges include low resources, service capacity, and lack of systemic priority in providing PEI services

WHY DO CHILDREN AND YOUTH NEED MENTAL HEALTH SERVICES FUNDED BY THE MHSA?

- 300,000 children and youth who need mental health services in California do not receive them. (CMHPC)
- Elimination of state funding for children's mental health programs:
 - Governor Schwarzenegger eliminated the Children's System of Care funding from the state budget.
 - Governor Schwarzenegger eliminated the AB 3632 mandate for children's mental health services, although this program has been plagued with funding problems for several years.
- County mental health programs for children's services have historically been grossly under-funded.
- The state has increased the county's share of cost for the EPSDT mandate program from 5% to 10%.

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WHY DO CHILDREN AND YOUTH NEED MENTAL HEALTH SERVICES FUNDED BY THE MHSA?

- Mental health problems (mild to severe) affect 1 in 5 children and adolescents
- Half of all lifetime cases of mental illness begin by age 14 and, on average, the delay between the onset of mental illness and treatment is 8 - 10 years (NIMH 2005)
- The National Health and Nutritional Examination Survey found that 13 percent of children ages 8-15 had at least one mental disorder, a rate comparable to diabetes, asthma and other childhood diseases
- Suicide is the 3rd leading cause of death for 15-24 year olds



WHY DO CHILDREN AND YOUTH NEED MENTAL HEALTH SERVICES FUNDED BY THE MHSA?

- Estimates indicate that less than 1 in 5 children receive the appropriate needed treatment
- There is not adequate financial support for quality services to prevent and treat mental health problems of children and youth:
 - In 2007, 3.1 million youths (12.5 percent of 12 to 17 year olds) received treatment for problems with behavior or emotional disturbances in specialty mental health settings



WHAT WILL MHSA DO FOR CHILDREN, YOUTH AND THEIR FAMILIES?

- Promised to protect all existing funding and entitlements to care for children and youth.
- Promised to establish new funding for services delivered under the Children's System of Care.
- Promised to increase the potential for Wraparound services and training in each California County.
- Establish new prevention and early intervention programs.
- Provide additional funds to deal with the shortage of qualified mental health professionals.
- Allocate funds to each county to develop innovative programs designed to improve outcomes and meet the needs of underserved children and youth.



WHY ARE FAMILY MEMBERS OF CHILDREN SUPPORTING THE USE OF MHSA FUNDING FOR CHILDREN AND YOUTH?

- MHSA has the potential to transform the service delivery system for children and youth.
- MHSA could be a catalyst for expanding Children's System of Care
- Improve the quality of life and optimize outcomes families and their children by including cultural values, beliefs and strengths, family-driven care, early care and treatment, integrated and comprehensive community based services, effective practices, and individualized plans in service delivery.
- "Super Size" phenomena: Families want to ensure that the "Super Size" phenomena does not plague MHSA implementation. They want effective care with accountability.
- Families want their children to receive services in their own communities.
- They want their transition age children to receive services in a way that makes sense.
- They want their children to receive effective, evidence-based practices that will improve outcomes for their children.

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KEY IMPLEMENTATION RECOMMENDATIONS FROM CALIFORNIA FAMILY MEMBERS

- California Children's System of Care
- Evidence-Based Practice and Best Practice Approaches
- Family Driven Services
- Family Partnership Programs
- Stigma and Discrimination
- Resiliency



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EVIDENCE-BASED PRACTICES AND BEST PRACTICE APPROACH TO CARE

- Families want and deserve the most effective mental health treatment approaches and they must be available with the continuum of services available to children.
- Research has shown some practices to be either in-effective or harmful. These practices should not be funded.
- Evidence-based practice and best practice approaches to care are complementary to the Children's System of Care model.
- Families want and deserve accountability for the care and treatment their children receive, in the most appropriate setting, in their own communities.



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EVIDENCE-BASED PRACTICE AND BEST PRACTICE APPROACH TO CARE

- **Recommendations:**
 - Dedicate resources for the training and implementation of evidence-based practice approaches for children and youth that include the values of the MHSA and the CSOC model.
 - Include an array of evidence-based practice approaches to care for children and youth in every California community.
 - Ensure that the practices chosen are delivered with high fidelity and model-adherence for the best outcomes.
 - Ensure data collection for accountability.
 - Given California demographics, high priority should be placed on research related to the effectiveness of evidence-based practice approaches for the treatment of children from racially, culturally, and linguistically diverse backgrounds.
 - Dedicate resources so that county and private providers can create program evaluation designs that investigate differences in outcomes for children of color.
 - California has significant and unacceptable disparities in access to and provision of quality mental health services to diverse populations of children. Ensure that the selection of a treatment practice is based on mutual decision making between informed clients and their providers.

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FAMILY-DRIVEN SERVICES

- California defined family-driven services by implementing a participatory process that included a broad stakeholder group of youth, families, advocates, counties, and private providers.
 - “Family driven services exist when the beliefs, opinions, and preferences of every child, youth, and their family/caregiver are a deciding determinant in service planning at the individual level, are a significant determinant in program development and implementation at the agency level, and are integral to legislation and appropriation at the policy level”.
- Recommendation:
 - All public children’s mental health services should be family-driven, as defined by California mental health stakeholders.



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FAMILY PARTNERSHIP PROGRAMS

- Family partnership programs have been developed in response to significant obstacles faced by families in general, and families of color in particular, to accessing quality care for their children.
- The defining feature of family partnership programs is that they are governed and operated by families of children and youth who have emotional, behavioral, and mental health conditions, who have received services in the past, or are currently receiving services.
- Family partnership programs can offer a range of different practices and activities that transform children’s mental health systems and improve outcomes for children and their families.

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FAMILY PARTNERSHIP PROGRAMS

■ Recommendations:

- Every California county should fund a family partnership program or local family organization.
- The statewide family organization should be utilized to provide training and technical assistance to the local family programs and organization to both build the capacity of the organization as well as to support the skill development of family member staff within the local family organizations.



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STIGMA AND DISCRIMINATION AWARENESS



- Institutional discrimination and stigma related to mental health conditions undermines effective access to and use of mental health treatment in the community.
- Stigma and discrimination is pervasive not only in the broader community, but among mental health providers and is a barrier to quality, effective care
- Recommendations:
 - Every mental health agency and program develop projects/ programs to discuss stigma and discrimination and social justice issues

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STIGMA AND DISCRIMINATION AWARENESS

- Family members of children and youth with emotional, behavioral and mental health problems face the stigma of being blamed for “*poor parenting*”. They are frequently blamed by their own family, the school, mental health professionals, and community leaders for causing the problems their children face.
- This blaming incites a multitude of problems, such as a poor access to needed services, the wrong services offered and delivered, placement in institutions and foster care settings, and unnecessary conflict added to the family (if the parent would get help the child will be okay).
- This also causes parents to feel unnecessary guilt and shame for their the problems within their family, leading to isolation from friends, family and community.



STIGMA AND DISCRIMINATION AWARENESS

■ Recommendations Continued:

- Public mental health agencies and professional organizations should take the lead in reviewing their policies, professional codes of conduct, and practices and make appropriate changes to eliminate policies and practices contributing to institutional racism, stigma and the resulting discrimination related to mental health illness.
- Client and family organizations should be primary providers in training aimed at eliminating stigma and discrimination among mental health workers.
- Sharing experiences and documentation of instances of stigma and discrimination will help us understand that mental illness does not define one's life.
- General public information campaigns



RESILIENCY

- **Resilience is complex:**
- Resiliency requires optimism and hope.
- Resiliency can be developed, it is strength-based, and it involves avoiding negative consequences associated with specific risky behaviors and adversity in general.
- Resiliency is the ability to balance stressful events personally, in the family, in school, with a peer group and in the community.
- Resiliency requires protective factors -
 - Protective factors are important in understanding child and youth behavior. They are believed to operate in the following three ways: decreasing the impact of risk factors, interrupting risk factor patterns, and preventing risk factors from emerging. They include such things as engaging in spiritual activities, having problem-solving skills, and having good relationships with family members, with teachers, with peers and in the community.



RESILIENCY

- Many family members are uncomfortable using the concept of *recovery* with children and youth, expressing their belief that the term is confusing, that it implies a medical-illness orientation to treatment for emotional and behavioral disorders, and that it lacks a developmental perspective.
- Most family members agree that the concept of recovery, as developed within the adult mental health field, cannot be imported “as is” into the children’s mental health field.



RESILIENCY

■ Recommendations:



- Improving the circumstances in a child and family's life by identifying protective factors and developmental assets that lead to resiliency become the central focus of the child's care plan.
- Providers should increase their understanding of the complex nature of resiliency, to better able identify particular factors, processes, and environmental elements that may be changed.
- In developing a care plan for a child and family, a provider should look toward building resiliency as an overarching goal.

THANK YOU

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