



Effective Community Responses for Children & Families




POSITIVE SYSTEMS OF CARE:
Stories of Success
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Outline for Presentation

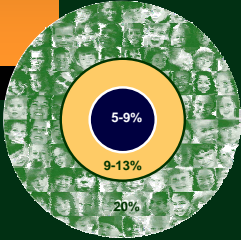


- Scope/Seriousness of Problem
- Three Primary Questions
- Policy/System Responses
- Status of Responses
- Recommendations and Directions for the Future




Seriousness of the Problem

Prevalence of Serious Emotional Disturbance (SED)




Population Proportions (9 to 17 year-olds)


- 5-9% Youth with SED & extreme functional impairment
- 9-13% Youth with SED, with substantial functional impairment
- 20% Youth with any diagnosable disorder



"Recent evidence compiled by the World Health Organization indicates that by the year 2020, childhood neuropsychiatric disorders will rise by over 50% internationally to become one of the five most common causes of morbidity, mortality, and disability among children...no other illnesses damage so many children so seriously."



— Report of the National Advisory Mental Health Council's Workgroup on Child and Adolescent Mental Health Intervention Development and Deployment



"Growing numbers of children are suffering needlessly because their emotional, behavioral, and developmental needs are not being met by those very institutions which were explicitly created to take care of them. It is time that we as a Nation took seriously the task of preventing mental health problems and treating mental illnesses in youth."





— Surgeon General David Satcher, 2000




Characteristics of Children with Serious Emotional Disturbances

- Frequently served in multiple systems
- Variety of diagnoses but most common are ADHD, Oppositional Disorder, and Conduct Disorder
- High rate of co-occurring disorders
- Deficits in intellectual and educational functioning

Characteristics of Children with Serious Emotional Disturbances (continued)


- Deficits in social and adaptive behavior
- Frequently from low income families
- Have often been exposed to violence, and to losses of major people in their life



Characteristics of Children with Serious Emotional Disturbances (continued)


"The major barrier to school readiness for children is often not the lack of appropriate cognitive skills but rather the absence of needed social and emotional skills."

— Florida Commission on Mental Health and Substance Abuse, 2001, p.8.




Characteristics of Children with Serious Emotional Disturbances (continued)

Emotional disturbance is part of an inter-related set of problems that Lisbeth Schorr has called "rotten adolescent outcomes" – including poor school performance, delinquency, early pregnancy, substance abuse, and violence.




Characteristics of Children with Serious Emotional Disturbances (continued)

- National Comorbidity Study shows that "it's clear a substantial part of the drug problem, and the more severe and prolonged drug problem, is in people starting out with emotional problems."
- Median age of onset for mental health disorder was 11 years old and for substance abuse was five to 10 years later.

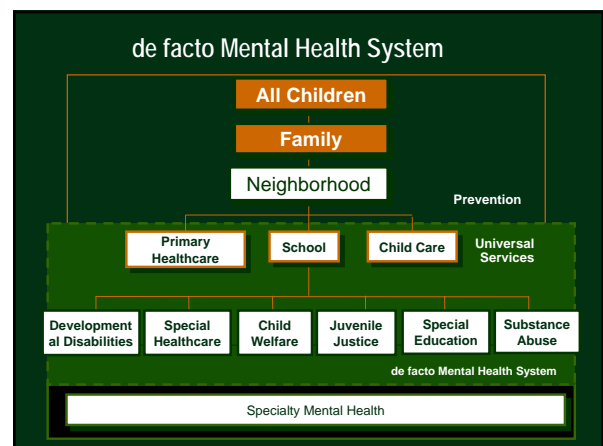


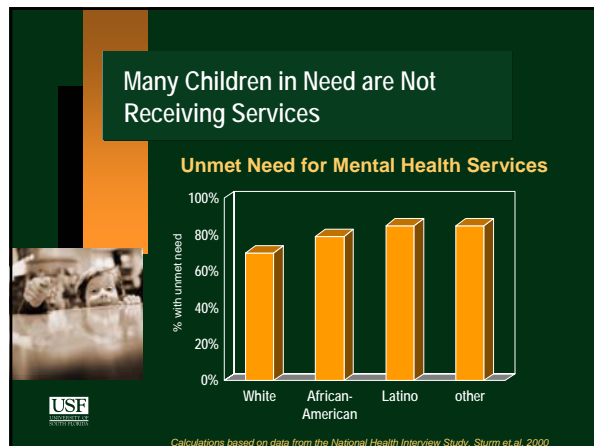
Impact in Adulthood

"Early-onset psychiatric disorders have been associated with subsequent truncated educational attainment, higher risk of teenage childbearing, higher risk of early marriage, lower probability of later marriage, and lower family income."



— From National Comorbidity Study





Three Basic Questions

- How can we improve access to care for those in need?
- How can we improve quality and effectiveness of care?
- How can we improve the mental health status and well-being of all children?

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Improving Quality and Effectiveness of Care

- Major approach since the mid 1980s has been through the development and implementation of community-based systems of care based on a set of principles and values, and the best available research.

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What is a System of Care?"

- A system of care is 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 adolescents with severe emotional disturbances and their families.

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What System Conditions Led to Development of Systems of Care?

- Inadequate range of services and supports
- Failure to individualize services
- Fragmentation of system when children and families had multi-system needs
- Children with special needs are in many systems
- Lack of clear values/principles for system
- Lack of clarity about population of concern
- Inadequate accountability
- Lack of adequate responsiveness to cultural differences

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Role of System of Care

- To provide access to effective services for a large and diverse population within a specified community



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Key Principles/Values of a System of Care

- Based on needs of child and family
- Promotes partnerships between families and professionals
- Involves collaboration between multiple agencies and service sectors
- Involves provision of individualized supports and services based on strengths and needs in multiple domains
- Promotes culturally responsive supports and services
- Includes system of ongoing evaluation and accountability



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What Should a System of Care be Based Upon?

- A vision, and set of values, and principles developed and agreed upon by community stakeholders;
- A clear definition of the population to be served and a thorough understanding of the population to be served;
- A set of goals and desired outcomes, also developed and agreed upon by community stakeholders;
- Best available evidence on effectiveness of system mechanisms, and services
- A theory of change that makes explicit the link between interventions (at the system, organization, program, provider, and child/family levels) and desired outcomes



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Findings and Recommendations from the President's Commission



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"Successfully transforming the mental health service delivery system rests on two principles:

- First, services and treatments must be consumer and family centered, geared to give consumers real and meaningful choices about treatment options and providers—not oriented to the requirements of bureaucracies.
- Second, care must focus on increasing consumers' ability to successfully cope with life's challenges, on facilitating recovery, and on building resilience, not just on managing symptoms.



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- p. 5

"Consumers and family members will have access to timely and accurate information that promotes learning, self-monitoring and accountability...when a serious mental illness or a serious emotional disturbance is first diagnosed, the health care provider—in full partnership with consumers and families—will develop an individualized plan of care for managing the illness. This partnership of personalized care means basically choosing who, what, and how appropriate health care will be provided

- Choosing which mental health care professionals are on the team,
- Sharing in decision making, and
- Having the option to agree or disagree with the treatment plan.



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Goal 2

"Consumers and families told the Commission that having hope and the opportunity to regain control of their lives was vital to their recovery. Indeed, emerging research has validated that hope and self-determination are important factors contributing to recovery."



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"In particular, community-based treatment options for children and youth with serious emotional disorders must be expanded...segregating these children from their families and communities can impede effective treatment. Emerging evidence shows that a major Federal program to establish comprehensive, community-based systems of care for children with serious emotional disturbances has successfully reduced costly out-of-state placements and generated positive clinical and functional outcomes"



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Six Goal Areas

1. Understand that mental health is essential to overall health
2. Mental health care is consumer & family driven
3. Disparities in mental health services are eliminated
4. Early mental health screening, assessment, and referral to services in multiple settings across the life-span are common practice
5. Excellent mental health care is delivered and research is accelerated
6. Technology is used to access mental health care and information



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From CASSP to the Present

First Stage of Transformation of the Children's Mental Health System

- Identifying children with serious emotional disturbances and their families as the priority population;
- Redefining the role of families at all levels;
- Expanding the range of services and developing highly individualized treatment plans;



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From CASSP to the Present

First Stage of Transformation of the Children's Mental Health System (continued)

- Developing culturally competent outreach, intervention, and research practices;
- Building partnerships between service sectors with different mandates;
- Moving from deficits to strengths;
- Moving from symptom reduction to functioning in the community.



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Translating the Vision into Reality

- How are we doing?
- What have we learned?
- How can we apply our lessons learned in the next stage of system transformation?



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From State Mental Health Commissions

- Areas of progress in every state;
- But overall dissatisfaction with efforts to address the mental health needs of children and their families;
- Consistent emphasis on the importance of the values and principles of systems of care;
- Increased emphasis on prevention, based on models of risk and protective factors;
- Greater attention to planning, accountability, and responsibility.

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– Friedman, 2002

Implementation

- Since the vision of system of care was created, there is an increased recognition of complexity and difficulty of implementing values and principles, and achieving change both at the service level and at the system level.

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Implementation

It is one thing to say with the prophet Amos, "Let justice roll down like mighty waters," and quite another to work out the irrigation system.

– William Sloane Coffin,
Social activist and clergyman

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Implementation

"The solution is not to abandon our current work but to do it better, with more sophistication and from a more strategic vantage point...we need to be sure to invest in a continuous cycle of tracking our work, distilling lessons, applying new information, and learning as we go."

– Kubisch et al., 2002

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Policy Directions for Improving Outcomes and Access Within Systems of Care

- Focus on theories of change and implementation at system and practice level;
- Emphasis on issues related to provider networks and human resource development;
- Clearer accountability;
- Performance measurement;
- Evidence-based practices.

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Data-Based Systems of Care

- Involves the systematic collection of data on system performance and outcome for purposes of improving system functioning
- Involves creating a culture that promotes data-based accountability



Data-Based Systems of Care (Continued)

- Utilization and improvement-focused
- Combination of in-depth and aggregate information
- Use of both qualitative and quantitative information
- Focus on a few key measures
- Feedback loop to all participants
- An intervention itself...not just a measurement



Differentiating Between Data-Based Systems of Care and Evidence-Based Practices

- Data-based systems of care involve collecting data in the present time, and in one's own community for purposes of assessing how the system is performing and identifying areas in need of improvement
- Evidence-based practice refers to interventions that have met a specific criteria of effectiveness at some other time and in some other place

Relationship Between Data-Based Systems of Care and Evidence-Based Practices

Data on system performance helps guide system stakeholders to determine if they need to make changes. It should come before efforts to make change. If the need for change is identified, then stakeholders should examine alternative approaches to making change.

Individualized Care

- Based on a belief in the uniqueness of each individual and family
- Research findings show tremendous diversity in the strengths and needs of children with mental health challenges and their families
- A long-held belief carried to previously unimaginable levels during the past 20 years




Individualized Care (Continued)

- Developed through a team-process, often called "wraparound," involving child and parents, important other individuals in natural support system, care coordinator, and other key representatives of service system
- Based on strengths, needs, culture, and choices of child and family, in partnership with team




Individualized Care (Continued)

- Enhanced by creative and participatory team process, and facilitated by availability of flexible funding, broad range of services, and extensive provider network
- The application of system of care principles and values at the child and family level




Active Agents of Change/Components of Service Effectiveness

Those elements or components of interventions which contribute to positive outcomes – the same active agents of change may be present in different forms or structures within different interventions




Active Agents of Change/Components of Service Effectiveness (Continued)

The very characteristics that are likely to make services effective – they are comprehensive, individualized and flexible – make them more difficult to describe and to evaluate

(Schorr, 1995)




Active Agents of Change/Components of Service Effectiveness (Continued)

"...the effectiveness of services, no matter what they are, may hinge less on the particular type of service than on how, when, and why families or caregivers are engaged in the delivery of care...it is becoming increasingly clear that family engagement is a key component not only of participation in care, but also in the effective implementation of it"

(Burns, Hoagwood, & Mrazek, 1999)




Active Agents of Change/Components of Service Effectiveness (Continued)

"Not all the studies show that the improvements resulted from the intervention specifically. Family engagement may play a stronger role in outcomes than the actual intervention program"

(Thomlison, 2003)




Active Agents of Change/Components of Service Effectiveness (Continued)

"Strong bonds between families and providers appeared to be critical, whether the providers were case managers, therapists, parent advocates, or other staff. These bonds had their beginning in the engagement process... providers built trust and confidence by listening carefully to what families identified as their primary needs and treated family members as full partners in the treatment process, focusing on their strengths rather than on their deficits"

(Worthington, Hernandez, Friedman, & Uzzell, 2001)




Active Agents of Change/Components of Service Effectiveness (Continued)



- Comprehensive, flexible, and responsive to the needs of participants
- View children in the context of broader ecologies—families, schools, neighborhoods, churches, and communities
- Link with other systems of support and intervention to ensure they can produce and sustain their impacts over time

(Greenberg, 2002)



Active Agents of Change/Components of Service Effectiveness (Continued)



- Operated by people with a commitment and intensity to their work and a clear sense of mission
- Based upon quality staff with effective models of training and ongoing technical assistance



Community-Based Interventions with an Evidence-Base



- Function as service components in a system of care and adhere to system of care values
- Are provided in the community, homes, schools, and neighborhoods, not in an office
- With exception of multisystemic therapy and sometimes case management, direct care providers are not formally clinically trained
- Their external validity is greatly enhanced because they were developed and studied in the field with real-world child and family clients

(Burns, 2000)



Improving the Mental Health Status and Well-Being of All Children

Critical for our Future

- Children's Sub-Committee Report of President's Commission
- Recommendations of state mental health commissions



Strategies for Achieving this Goal



- Apply population-based, public health approach;
- Increased focus on young children and early identification;
- Public and professional education;



Strategies for Achieving this Goal (continued)



- Reduce community risk factors and increase community protective factors;
- Increased focus on prevention and resilience overall;
- Increase access to care and availability of supports and services;
- Ongoing data collection of mental health status and well-being of children.



Two-Part Crisis

1. Deteriorating mental and behavioral health of children in this country;
2. We are viewing this primarily from the standpoint of psychopathology, and not examining the environmental/community conditions that contribute to it.



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— Commission on Children at Risk, 2003

Two-Part Crisis (continued)

Importance of positive social connections and social capital in contributing to overall health and well-being



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Directions for the Future

- The primary goal must be to promote productive, successful community integration – living, learning, working and playing in the community, and contributing to the community.

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Directions for the Future (continued)

- The basic foundation must be *data-based and value-based systems of care that promote individualized care and incorporate effective practice*
- The multi-level, multi-sector nature of the system must be recognized and there must be developed integrated planning and accountability mechanisms



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Directions for the Future (continued)

If long-term progress is to be made, there must be a greater emphasis on population-based approaches, including:

- Promoting resilience through strengthening protective factors and reducing risk factors;
- Developing and implementing comprehensive, integrated plans for promotion of well-being of children and their families;
- Increased support of young children and their families, and early identification;
- Support of approaches that promote social/emotional development along with academic/educational attainment.



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