

Creating Informed Choice for Families:

The Link Between Individualized Care, Data-Based and Value-Based Systems of Care, and Evidence-Based Practice



May 7, 2004

"Family Strengths Conference"
Research and Training Center on Family Support and Children's Mental Health
Portland State University
Portland, Oregon

Robert M. Friedman, Ph.D.
Professor and Chair
Department of Child and Family Studies
Louis de la Parte Florida Mental Health Institute
University of South Florida
Tampa, Florida
friedman@lmhi.usf.edu



Transforming Systems and Services for Children with Mental Health Challenges and their Families

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?



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.



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.



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



Role of System of Care

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





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




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

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




Individualized Care (Continued)



Consistent with President's New Freedom Commission

- "In a transformed mental health system, a diagnosis of a serious mental illness or a serious emotional disturbance will set in motion a well-planned, coordinated array of services and treatments defined in a single plan of care" (p. 8)
- The individualized plan of care...will include treatments, supports, and other assistance to enable consumers to better integrate into their communities" (p. 8)
- "Creative programs will be developed to respond to the needs and preferences of consumers and families, as reflected in their individualized plan of care" (p. 8)




Choice


- The right thing to do but often a neglected thing
- An evidence-based process in and of itself

Choice (Continued)

“A consistent finding in the research is that when given choices as part of an intervention, children show a decrease in inappropriate behavior and/or an increase in appropriate behavior”



(Kern et al., 2001)




Choice (Continued)



“The effectiveness of behavioral interventions is highly dependent on parent (and teacher) cooperation, enthusiasm, motivation, and sustained effort”

(Hoza, 2001)

Choice (Continued)

- Access
- Voice
- Ownership

Choice (Continued)



“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”

President's New Freedom Commission (p. 27)




Choice (Continued)

Choice of service providers should be available as well as choice of services and supports

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



USF
UNIVERSITY OF SOUTH FLORIDA

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



USF
UNIVERSITY OF SOUTH FLORIDA

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



USF
UNIVERSITY OF SOUTH FLORIDA

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.



USF
UNIVERSITY OF SOUTH FLORIDA

Improving Quality and Cost-Effectiveness of Care

A Sampling of Strategies

- Strengthen capability of professionals through training, coaching, supervision
- Provide expanded range of services
- Strengthen integration between systems and agencies at the service and/or system level
- Provide more individualized care



USF
UNIVERSITY OF SOUTH FLORIDA

Improving Quality and Cost-Effectiveness of Care (continued)

A Sampling of Strategies

- Expand provider network
- Provide informed choice of services and providers to families
- Implement continuous quality improvement procedures
- Apply treatment guidelines/standards
- Provide more flexible funding and funding mechanisms to support individualized and comprehensive service plans



USF
UNIVERSITY OF SOUTH FLORIDA

Improving Quality and Cost-Effectiveness of Care (continued)



A Sampling of Strategies (continued)

- Expand use of natural supports
- Apply evidence-based programs
- Identify active agents of change in effective interventions and provide training/coaching in them
- Apply system of care values/principles such as partnerships with families, focus on strengths, and cultural competence
- Identify practices that are ineffective and cease doing them




Evidenced-Based Practices



Practices that have met a particular set of stringent research criteria, indicating that they have been demonstrated to be effective in relation to some other practice – essentially they have passed a particular threshold

Evidence-Based Practices

What They Are Not and What They Should Be



- They should not be viewed as an alternative approach to systems of care and individualized care
- They should be a complement and enhancement to systems of care and individualized care*

Evidence-Based Practices

What They Are Not and What They Should Be



- They should not be an alternative to child and family choice
- They should provide important information to children and families, and to entire treatment planning teams, so that informed choices can be made*

Evidence-Based Practices

What They Are Not and What They Should Be



- They should not be the only choice, or always the best choice, for improving outcomes in a community system
- They are one alternative approach to improving outcomes that should be considered by community stakeholders along with other alternatives*

Evidence-Based Practices

What They Are Not and What They Should Be



- They should not be an effort to establish one-size fits all interventions that can be applied to all populations under varying conditions
- They should be an attempt to look contextually at interventions, taking into consideration such factors as characteristics of the population to be served, the community, and the system*

Evidence-Based Practices

What They Are Not and What They Should Be



- They should not be an attempt to stifle innovation and adaptation
- They should encourage innovation and adaptation, and the careful study of field-based interventions that have not had the resources or opportunity for careful evaluation*

Evidence-Based Practices

What They Are Not and What They Should Be

- They should not be an effort to emphasize one approach to research to the exclusion of others
- They should be an effort to encourage a culture within a system of care that focuses on a variety of data-based approaches*

Evidence-Based Practices

What They Are Not and What They Should Be

Data-Based Approaches Should:



- Balance concerns with internal validity with concerns with external validity*
- Look in depth at intervention processes, seek to identify active agents of change, and provide theory to guide action*
- Use the best research design available for a particular situation*
- Gather data from multiple perspectives*
- Learn from natural experiments and local practices that don't have the opportunity or resources to use the most rigorous research designs*




Evidence-Based Practices

What They Are Not and What They Should Be

- They should not be an attempt to anoint particular interventions as "the answer" to particular needs
- They should recognize that knowledge is not static, and that interventions must be studied and understood in a context*

At Their Best, Evidence-Based Practices...

- Can permit families, and entire child and family teams to make more informed choices
- Can provide community stakeholders with an important option as they seek to improve outcomes
- Can complement the values and principles, and possibly enhance the outcomes of systems of care
- Contribute to a culture of performance measurement, and accountability
- THESE ARE IMPORTANT GAINS!!!**




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)

USF
UNIVERSITY OF SOUTH FLORIDA

Barriers to Integration of Systems of Care, Individualized Care, and Evidence-Based Practices

- Research requirements for description of intervention vs. system requirements for flexibility
- Accountability
- Populations served
- Attitudes and interests



USF
UNIVERSITY OF SOUTH FLORIDA

Directions for the Future

The basic foundation must be data-based and value-based systems of care that promote individualized care, and child and family choice – unless community stakeholders are clear about their goals, their theory of change, their values, and how well their system is functioning, they are not in a position to bring about system enhancements and improvements



USF
UNIVERSITY OF SOUTH FLORIDA

Directions for the Future (Continued)

Research and program development must continue on all strategies for improving outcomes for children with mental health challenges and their families, with a particular emphasis on studying interventions that are developed in *real world* settings with populations of children and families who are *representative* of those served in systems of care



USF
UNIVERSITY OF SOUTH FLORIDA

Directions for the Future (Continued)

System of care stakeholders, and developers of evidence-based interventions must come together to develop strategies for overcoming the barriers to effective integration of the different approaches



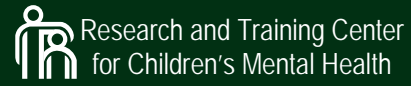
USF
UNIVERSITY OF SOUTH FLORIDA

References

- Burns, B. J. (2000). Prevention, early intervention, and community-based services. In U. S. Public Health Service, *Report of the Surgeon General's Conference on Children's Mental Health: A National Agenda*. Washington, DC: pp. 35-36.
- Burns, B. J., Hoagwood, K., & Mrazek, P. J. (1999). Effective treatments for mental disorders in children and adolescents. *Clinical Child and Family Psychology Review*, 2, 199-254.
- Greenberg, M. (2001). Research-based programs and lessons of implementation. In Bruner, C., Greenberg, M., Guy, C., Little, M., Weiss, H., & Schorr, L. (Eds.), *Funding What Works: Exploring the Role of Research on Effective Programs and Practices in Government Decision-Making*. Des Moines, Iowa: National Center for Service Integration Clearinghouse and the Center for Schools and Communities, pp. 7-16.
- Hoza, B. (2001). Psychosocial treatment issues in the MTA: A reply to Greene and Ablon. *Journal of Clinical Child Psychology*, 30, 126-130
- Kern, L., Mantegna, M. E., Vorndran, C. M., Bailin, C. M., & Hilt, A. (2001). Choice of task sequence to reduce problem behaviors. *Journal of Positive Behavioral Interventions*, 3, 3-10.

References

- New Freedom Commission on Mental Health (2003). *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. U.S. Department of Health and Human Services, Rockville, Md.
- Schorr, L. B. (1995). New approaches to evaluation: Helping Sister Mary Paul, Geoff Canada, and Otis Johnson while convincing Pat Moynihan, Newt Gingrich and the American public. Presentation at the Second Annual Research/Evaluation Conference, Annie E. Casey Foundation, Baltimore.
- Thomlison, B. (2003). Characteristics of evidence-based child maltreatment interventions. *Child Welfare, 82*, 541-576.
- Worthington, J., Hernandez, M., Friedman, B., & Uzzell, D. (2001). *Systems of Care: Promising Practices in Children's Mental Health, 2001 Series, Volume II*. Washington, DC: Center for Effective Collaboration and Practice, American Institutes for Research.



<http://rtckids.fmhi.usf.edu>