

Transformation

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Work Group Report

Transformation Work Group

of the Council on Collaboration and Coordination of the Child, Adolescent,
and Family Branch, Center for Mental Health Services, SAMHSA

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The content of this publication does not necessarily reflect the views, opinions, or policies of CMHS, SAMHSA or DHHS.”

For more information

Bob Friedman, Professor and Chair
Department of Child and Family Studies
Louis de la Parte Florida Mental Health Institute
University of South Florida
(813) 974-4640
friedman@fmhi.usf.edu

Report of the Transformation Work Group

Executive Summary

Approximately one year ago, the Council on Collaboration and Coordination of the Child, Adolescent, and Family Branch, established a Transformation Work Group as part of its effort to improve systems and services for children with mental health challenges and their families. The charge to the Work Group was:

- to examine the operation of the system of care grant program of the branch and recommend strategies for strengthening it;
- to develop recommendations for enhancing the long-term impact of the system of care grant program;
- and to offer recommendations for the use of the system of care grant program to enhance transformation of the system for serving children with mental health challenges in keeping with the report of the President's New Freedom Commission on Mental Health (2003).

The Work Group, as a means of soliciting input, conducted a national survey of key stakeholders in the children's mental health field, conducted individual interviews of key informants, and also conducted focus groups and general forums. Overall, the Work Group concluded that the children's mental health field, with its focus for the past 20 years on the development of data-based and value-based systems of care to serve children with serious mental health needs and their families, has been striving to achieve the type of transformation described by the President's New Freedom Commission on Mental Health. The Work Group concluded that there is much congruence and consistency in the values, principles, and approaches of systems of care and those recommended by the President's New Freedom Commission.

However, the Work Group also concluded that there remains much to do to implement systems of care effectively, to enhance their reach around the country, and for them to function successfully as system transformation mechanisms. The Work Group identified many important areas that need to continue to be emphasized, and offers the following priority recommendations:

- To strengthen the current system of care grant program, there needs to be an increasing emphasis on assisting grant communities in the early stages to develop a vision and clear operational plan of action. Also, the grant program should develop a two-stage process in which grant communities need to demonstrate their accomplishment of a vision, clear operational plan of action, and readiness to move into implementing direct services before receiving funding for direct services;
- To further strengthen the current program, it should be restructured into more of a state-local partnership so that the grant program is aligned with overall state system of care development goals, capacity for developing and supporting systems of care is strengthened at all levels, and the impact of the program is expanded across each state;
- To maximize the long-term impact of the program, there needs to be increased attention to financing issues. Financing policies at all levels need to be examined to ensure that they are aligned with system of care values and

Transformation Work Group

Bob Friedman, Chair
Gary Macbeth, Co-Chair
Gary Blau
Jennifer Clancy
Holly Echo-Hawk
Sandra Keenan
Nancy Koroloff
Brigitte Manteuffel
Lorin McGinnis
Joe Perry
Maria Rodriguez
Carol Schneider
Elaine Slaton

There is much congruence and consistency in the values, principles, and approaches of systems of care and those recommended by the President's New Freedom Commission.

The population of concern for the grant program should be broadened beyond its present focus on children with serious mental health needs and their families.

practices, communities and tribal groups need to be assisted in developing comprehensive financing strategies, and more data on cost-effectiveness needs to be gathered and disseminated;

- In addition, to further maximize the long-term impact of the program there should be strong support of family and youth organizations with the goal of changing power relationships so that professionals and families share power, and form effective partnerships. One specific aspect of this should be providing families with choice both of services and providers;
- To further the transformation efforts, the population of concern for the grant program should be broadened beyond its present focus on children with serious mental health needs and their families. The system of care grant program should invite grant applicants to submit balanced and integrated plans to serve broader populations using population-based, public health approaches, at the same time as the needs of children with serious mental health challenges are being responded to;
- Finally, the system of care grant program and the children's mental health field should increase its focus on resilience and recovery, with the overall goal of providing children with a high quality and independent life in their community. The full implications of a resilience and recovery approach for policy, system development, direct service, and performance measurement should be explored.

Overall, the Work Group believes that these recommendations will not only change services and systems but will help create a culture within every community of caring and support for every child and family, a culture of family-professional partnership and sharing of power, and a culture that supports innovation and continuous learning and improvement.

Report of the Transformation Work Group

Introduction

In the spring of 2004, the Council on Collaboration and Coordination of the Child, Adolescent, and Family Branch created a “Transformation Work Group.” This group was created in the context of the release of the President’s New Freedom Commission report, in the summer of 2003, which called for “transformation” of the mental health system. Another important part of the context for the group was the completion of the first 10 years of operation of the federally-funded Comprehensive Community Mental Health Services for Children and Their Families Program (more simply known as System of Care {SOC} grant program).

This is a grant program that essentially has dual goals. One goal is ensuring the provision of direct services that result in positive outcomes to children with serious mental health needs and their families through a system of care approach, and the second goal is building a strong infrastructure for the achievement of significant, sustainable system change, in accordance with system of care values and principles. The balancing of these dual goals—ensuring the provision of effective direct service, and creating sustainable system change—within a grant program where federal funds are available on a time-limited basis (six years) has been a significant challenge and major tension for many grant communities. The focus on direct services is in many ways a more straight-forward task with which communities are very familiar, while the task of using direct service and other mechanisms to produce *sustainable system change and impact* that extends beyond the length of the federal funding requires more thoughtful and strategic action.

With this background, the mission of the Work Group was to:

- Examine the operation of the SOC grant program and recommend strategies for strengthening it;
- Specifically develop recommendations for enhancing the long-term impact (or legacy) of the SOC grant program;
- Offer recommendations for the use of the SOC grant program to enhance transformation of the system for serving children with mental health needs and their families, in keeping with the values and principles of the President’s New Freedom Commission (New Freedom Commission on Mental Health, 2003).

President’s New Freedom Commission

This mission for the Work Group required first of all an examination of the compatibility of the SOC vision, values and principles, and general practices with those expressed by the President’s New Freedom Commission. This Commission, which addressed both child and adult issues, emphasized very clearly the principles of transformation that it believed to be most important. The New Freedom Commission indicates that, “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.

The task of using direct service and other mechanisms to produce sustainable system change and impact that extends beyond the length of the federal funding requires more thoughtful and strategic action.

The vision, values and principles, and practices of systems of care are compatible with those of the President's New Freedom Commission, and in fact many of these have guided the efforts to improve outcomes for children with mental health challenges and their families for the past 20 years.

- 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" (New Freedom Commission, p. 5).

These principles are overriding and pervasive, and are complemented by six goal areas identified by the Commission:

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.

The Work Group believes that the vision, values and principles, and practices of systems of care are compatible with those of the President's New Freedom Commission, and that in fact many of these have guided the efforts to improve outcomes for children with mental health challenges and their families for the past 20 years. For example, the monograph that served as the foundation for the development of systems of care (Stroul & Friedman, 1986) emphasizes core values and guiding principles that are consistent with the President's New Freedom Commission such as:

- The system of care should be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided;
- The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve;
- Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan;
- The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services;
- Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes (Stroul & Friedman, 1986, p. 17).

The President's New Freedom Commission expresses in very strong words the importance of systems being family-driven, with families exercising choice not only about treatment options but also about providers. Also, as Power points out, "The New Freedom Commission envisions a system in which consumers receive the best possible community-based treatments, services, and supports through individualized plans of care" (Power, 2004, p. 10). These are all concepts that are central to systems of care, have evolved with the growth and maturation of systems of care, and are now being actualized in a number of communities (Friedman, 2004). Efforts to be culturally competent and eliminate racial and ethnic disparities in access to effective care have been and remain strong goals of systems of care (Cross, Bazron, Dennis, & Isaacs, 1989; Hernandez & Isaacs,

1998). Given the evidence that indicates that there is a disparity in access to effective care for children from minority racial and ethnic backgrounds compared to other children, truly eliminating this disparity is transformative in and of itself. (Huang, 2002; U.S. Department of Health and Human Services, 2001).

The President's New Freedom Commission also emphasizes the importance of going beyond the goals of symptom reduction or management, and focusing on resilience, recovery, and a high quality and productive life in the community as ultimate goals for those receiving services. Such goals are consistent with SOC efforts, and have been particularly important to youth and families served in the system; the concepts of resilience and recovery themselves have only sparingly been applied within systems of care, however. The potentially transformative impact of increasing this focus on resilience, recovery, and a satisfying life in the community represents an important contribution of the President's New Freedom Commission. The way in which this can best be conceptualized, framed, and applied for children with mental health challenges and their families has been examined and reported on by another Work Group of the Child, Adolescent, and Family Branch, and a special issue of Focal Point, the newsletter of the Portland State Research and Training Center on Family Support and Children's Mental Health, has discussed this issue (Friesen, 2005; Walker & Friesen, 2005).

Another goal area of the President's New Freedom Commission is the use of new technologies to access mental health care and information. Again, there is no inconsistency between this goal and the goals of systems of care, although the application of this goal is still in very early stages. The President's New Freedom Commission also strongly endorsed the development and application of evidence-based practices. Systems of care have consistently emphasized the importance of effective interventions as well (Stroul & Friedman, 1986; 1996).

The vision, values and principles, and goals of systems of care were first elucidated as part of the National Institute of Mental Health's Child and Adolescent Service System Program (known as CASSP) (Lourie & Hernandez, 2004). They have been carried forward at a federal level through the SOC grant program of the Child, Adolescent and Family Branch of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration. Reviews of state policies indicate that they are also prevalent in formal policy statements of both executive and legislative branches (Davis, Yelton, & Katz-Leavy, 1995; Evans & Armstrong, 2003).

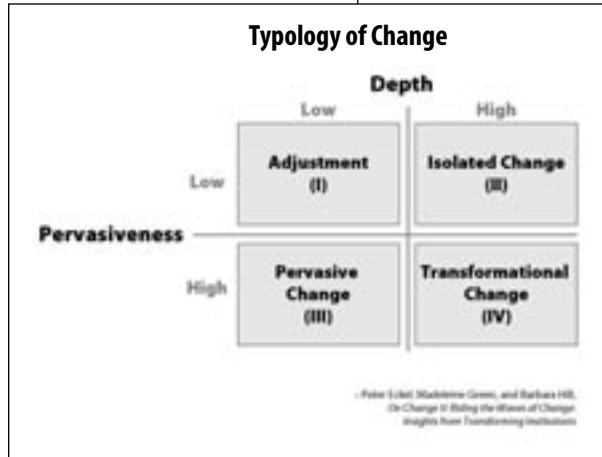
In many ways, therefore, not only is there great consistency between the approach being taken within systems of care to better provide mental health services, and the approach taken by the President's New Freedom Commission, but the children's mental health field has been working for 20 years to actualize this approach. While there has been substantial progress made over the past 20 years, there is no doubt that there is much that remains to be done, and the report and recommendations of the President's New Freedom Commission provide impetus for making progress at an even faster pace in the years to come.

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Concept of Transformation

The Transformation Work Group reviewed a two-dimensional typology of change, developed by Eckel, Green, and Hill (2001) (see Figure 1). Within this typology, transformational change is identified as that which is both pervasive and deep. The Work Group clearly supports the focus on change that is pervasive in reaching into every community in the United States, and goes beyond superficial changes to effect meaningful changes in policy and practice.



As part of its initial work, the Work Group proposed an overall long-term goal for the SOC grant program of bringing about changes so that *all children with serious emotional disturbances and their families have access to effective care that results in positive outcomes in accordance with system of care principles and values, and those of the President's New Freedom Commission.*

It is noteworthy that this long-term goal for the SOC grant program focuses on young people with *serious* mental health needs and their families. This has been the priority focus of public mental health systems since the initiation of CASSP in 1984, and remains the priority focus of the SOC grant program. One of the issues considered by the Work Group is whether this priority focus should be

changed, and, if so, how it should be changed. Recommendations concerning this will be presented later.

It is also noteworthy that the Work Group does not view a transformed system in which system of care values and principles are applied broadly and deeply as a final “destination.” Rather, the Work Group would like to see systems that are committed to continuous, ongoing improvement through regular input from various stakeholders and review of data on overall system performance. In keeping with the work of systems theorists such as Plsek (2001) and Senge (1990), and the work of administrators and researchers in the public and private sector (Collins, 2001; Giuliani, 2002), the Work Group embraces a vision of a system in which there is ongoing learning for purposes of sustaining positive results and continually improving the system’s success in meeting its goals. Consistent with this, Senge defines learning organizations as “...organizations where people continually expand their capacity to create the results they truly desire, where new and expansive patterns of thinking are nurtured, where collective aspiration is set free, and where people are continually learning to see the whole together” (Senge, 1990, p. 3). This is consistent with the transformation equation, as presented by Power, which consists of vision plus belief plus action multiplied by continuous quality improvement (Power, 2005).

Lessons from Other Fields

The Work Group was committed to a broad-based approach to learning about system change and transformation. This included looking not only at the children’s mental health field but also at lessons from research and field experiences in other governmental and corporate systems, organizations, and movements. This was done through a selective review of the literature as well as consultation with experts from other fields, such as developmental disabilities, adult mental health, education, and hospice.

Particularly helpful in the review was material from the Institute of Medicine's recent report on re-designing the 21st century health care system (Institute of Medicine, 2001).

In this report, the Institute of Medicine calls for a common purpose. This purpose would be that, "all health care organizations, professional groups, and private and public purchasers should adopt as their explicit purpose to continually reduce the burden of illness, injury, and disability, and to improve the health and functioning of the people of the United States" (Institute of Medicine, 2001, p. 39). Both in the original report, and in the report of the first "Crossing the Quality Chasm Summit," there is a strong call for six guiding aims in the health care system. Health care should be:

- Safe
- Effective
- Patient-centered
- Timely
- Efficient
- Equitable

While each of these principles has applicability to children's mental health, it is particularly notable that the Institute of Medicine calls for:

- a patient-centered system in which care is given that is responsive to patient preferences, needs, and values;
- and care that does not vary in quality because of personal characteristics such as gender or ethnicity, or socio-economic status.

In elaborating upon these, the Institute of Medicine indicates that care should be customized based on patient needs and values, and that "patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them" (Institute of Medicine, 2001, p. 8).

Another strong emphasis of the Institute of Medicine report is that care should be based on the best available scientific knowledge. Further, it is pointed out that "all organizations...can improve their performance only by incorporating care process and outcome measures into their daily work. Use of such measures makes it possible to understand the degree to which performance is consistent with best practices, and the extent to which patients are being helped" (Institute of Medicine, 2001, p. 12). This focus on data-based decision support systems is a strong emphasis within systems of care and the President's New Freedom Commission as well.

The Work Group engaged in consultation with leaders from other systems, and review of material from other systems. These consultations and reviews indicate that system change and transformation in various systems involve many of the same factors, often coming together in different ways to bring about positive change (Israel, Van Dyke, & Friedman, 2005). Some of the most common factors appear to be:

- The development and/or identification of a new approach to service/treatment that is based on clear values and principles, more effective or more humane than existing approaches, and no more costly—an excellent exam-

Care should be customized based on patient needs and values, and "patients should be given the necessary information and the opportunity to exercise the degree of control they choose over health care decisions that affect them."

— Institute of Medicine, 2001

Transformation means identifying, leveraging, and even creating new underlying principles for the way things are done while also identifying and leveraging new sources of power. It is therefore both a change in principles, and a change in the distribution of power.

ple of this is the move to hospice care in the past 20 years in this country;

- Strong support and push from consumers and/or family members, as in the developmental disabilities field, adult mental health, and hospice movement, often taking the form of new, strong, visible coalitions that cut across traditional boundaries;
- A crisis within the system, brought about by public examples of ineffective treatment if not maltreatment, often exacerbated by scarcity of resources, and frequently leading to legal or legislative action;
- A successful effort to take an innovative approach and bring it to scale.

As this report moves into its recommendations stage, these findings about the interactive and often cumulative impact of innovative service development, strong advocacy and coalition-building, demonstrations of cost-effectiveness, crisis, and potential for going to scale will be considered again.

Both the Substance Abuse and Mental Health Services Administration (2005), and Mazade (2005) emphasize an important point made by Cebrowski (2002). According to Cebrowski, transformation means identifying, leveraging, and even creating new underlying principles for the way things are done while also identifying and leveraging new sources of power. It is therefore both a change in principles, and a change in the distribution of power. Hogan (2005), who served as Chair of the President's New Freedom Commission, emphasizes that transformation is a series of linked actions at many levels that add up to dramatic change, and that it is a change in processes and not just programs.

In describing a major system transformation effort currently underway in New Mexico, Hyde (2005) talks about the importance of building social capital, creating a cultural change, establishing strong partnerships, and managing change well. She also emphasizes the importance of consumer and family support, being able to describe the transformation in a clear and easily understandable way, and keeping an eye on the cost. She indicates that one must, "put it in economic terms; it's about the money!" It is noteworthy that as part of the system transformation effort in New Mexico, the state was divided into six local collaboratives. Five of these collaboratives are regionally based while the sixth incorporates the Native American population throughout the state. In New Mexico, responsiveness to the Native American population was considered to be so important that a separate collaborative was created.

In 2001, a meeting was held of states that had addressed children's mental health through special state commissions, and a summary of the conclusions and recommendations from those state reports was prepared (Friedman, 2002). It is noteworthy that while each of the states reported some progress, each also identified major needs for change. The Commissions were consistent in their support for system of care values, as described briefly earlier (Stroul & Friedman, 1986). However, they sought a greater emphasis on prevention and earlier intervention, using risk and resilience models, improved collaboration across service sectors, and clearer accountability at local and state levels for the well-being of children overall, and for their mental health status, in particular.

With this background, the next sections will describe the methods used by the Work Group, the findings, and the recommendations in response to the three primary questions.

Method

The Work Group was committed to a participatory process of data collection and recommendation development in which representatives of various stakeholder groups had an opportunity to provide input. The Work Group itself includes individuals who work at the federal, state, and local level, both family and youth participation, and individuals from various research, technical assistance, and social marketing organizations. It also includes participation from several different racial and ethnic groups.

The Work Group, in an effort to get input on the three major questions described earlier, developed a web-based survey that was distributed in the fall, 2004, to 423 individuals from the following groups:

1. Past and present directors of system of care grants;
2. Past and present family leaders of system of care grants;
3. The Advisory Group to the national evaluation of the grant program;
4. State directors of children's mental health;
5. Members of the National Alliance of Multi-Ethnic Behavioral Health Associations;
6. Family network grantees;
7. Local chapters of the Federation of Families for Children's Mental Health;
8. Staff of the Child, Adolescent, and Family Branch of the Center for Mental Health Services;
9. Circle of Care grantees;
10. Members of the CCC.

The survey was available in both English and Spanish.

In addition, individual interviews were conducted with eight representatives of key national organizations, such as the National Mental Health Association, National Alliance for the Mentally Ill, and Child Welfare League of America. Research reports from the national evaluation of the system of care grant program were reviewed as well as other research documents related to systems of care.

Results of the survey, interviews, and literature review were discussed at an all-day Work Group meeting in December, 2004, and a preliminary report was developed. This report was then shared in February, 2005, at the meeting of system of care grantees with the following groups: a focus group of youth; members of the CCC; state directors of children's mental health; and other attendees of the conference who attended a session specifically on this topic. Since that time, the Work Group has been reviewing the input that was received, continuing to examine relevant literature, and seeking consultation from individuals with experience in bringing about large-scale changes in the children's mental health and other systems.

The Work Group was committed to a participatory process of data collection and recommendation development in which representatives of various stakeholder groups had an opportunity to provide input.

The three strategies that received the largest number of endorsements were:

- *Reform financing of services and supports for children with emotional disturbances and their families*
- *Build local and state capacity for developing systems of care*
- *Provide strong evidence of the effectiveness of systems of care to influence policy/funding decisions*

Findings

A summary of the results from the transformation survey distributed by the Work Group is available in Appendix A. In addition to this summary, the Work Group reviewed each response to the open-ended questions, and a listing of those responses is available upon request.

The survey was completed by 150 people, representing 35% of the 423 people who received the survey. Of the respondents, 42% identified themselves as being program or system administrators, and 19% identified themselves as being a family member of a child with emotional disturbance. In addition, 29% indicated that they had multiple roles in the field, e.g., family member and provider, or administrator and family member.

The first question of the survey talked about the overall long-term goal of the system of care grant program. The survey asked:

Broadly speaking, the overall goal of the program is to transform the children's mental health system so that all children with serious emotional disturbances and their families have access to effective care that results in positive outcomes in accordance with system of care principles and values, and the President's Commission. Is this the right program goal for this point in time?

This goal was identified as being the right goal by 92% of the respondents. Individuals who indicated that this was not the right goal were asked to provide other suggestions to augment or replace this goal. The predominant response of the 8% who did not feel that this was the right goal was to call for an expansion of the population of concern beyond "children with serious emotional disturbances and their families," and/or to call for a greater focus on prevention and early intervention.

The next three questions presented the respondents with a list of potential strategies for achieving this long-term goal. First the respondents were asked to rate the importance of each of the potential strategies on a four-point Likert scale, then to rate the difficulty of implementing the responses on a four-point scale, and then to identify the three most important strategies. This last question elicited more variability in response than did the first question, where all strategies were rated as highly important. The three strategies that received the largest number of endorsements to this last question were:

- Reform financing of services and supports for children with emotional disturbances and their families—63%;
- Build local and state capacity for developing systems of care—38%;
- Provide strong evidence of the effectiveness of systems of care to influence policy/funding decisions by state & local governments & Congress—38%.

The financing strategy was overwhelmingly selected as the most important strategy, particularly by administrators who included it in their list of the three most important strategies 83% of the time compared to 57% for families. Despite this difference, both groups included the financing strategy in their list of top three strategies more often than they included any other strategy. Family members placed greater emphasis than did administrators on supporting advocacy activities of important stakeholders, creating a public and professional education program, and reforming professional training.

Three strategies were rated as either “moderately difficult” or “very difficult” by more than two-thirds of the respondents. They were:

- Reform financing of services and supports for children with emotional disturbances and their families—90%;
- Build local and state capacity for developing systems of care—78%;
- Reform professional training & human resource development efforts—67%.

It is noteworthy that two of the three strategies rated as most important were also rated as most difficult. This highlights the challenge facing the children’s mental health field.

The responses to the remainder of the questions are included in Appendix A. The next section, rather than repeating these responses, seeks to integrate the information obtained from the web-based survey, from interviews with individual leaders in the field, from a focus group with youth who have been involved in the system, from open meetings specifically designed to solicit input, from material reviewed by the Work Group, and from in person and telephone discussions conducted by the Work Group. It seeks to provide answers to each of the three main questions, recognizing that the same strategies may be applicable to more than one question.

Question 1: Examine the operation of the system of care grant program and recommend strategies for strengthening it?

The Work Group recognized that many communities and tribal groups have seized upon the opportunity of the system of care grant program to make profound changes in how they serve children with serious mental health needs and their families. The Work Group reviewed reports provided through the national evaluation, conducted by ORC/Macro and its partners, reviewed the responses to the survey, and considered the information provided in various meetings.

Based on this information, a general concern emerged that while communities, in their grant applications, seem to be able to adequately express the general vision of the grant program, and discuss system of care values and principles, there was not as much indication of careful thinking about specific short-term and long-term goals, and strategies and actions to achieve the goals. This seems to be hampering the success of communities overall, and particularly their success in using the program as a vehicle for bringing about long-term change in their community. Overall, communities seem to be more effective in achieving the direct service goals of the program than in achieving the system change goals.

There was a consensus of the Work Group that the early stages of a grant are the key stages in helping a community set a direction, and think strategically about how to go about achieving both the direct service and system change goals. The Work Group believed that there was a need to both strengthen accountability during these early stages, and enhance assistance so that communities would be more likely to develop and implement a careful and thoughtful goal-oriented plan.

Related to this, the Work Group expressed the view that system of care communities would benefit from doing a better job of bringing together into an integrated, cohesive whole, the processes of:

- developing clear goals;
- developing a theory of change and translating this theory into action;

A general concern emerged that while communities, in their grant applications, seem to be able to adequately express the general vision of the grant program, and discuss system of care values and principles, there was not as much indication of careful thinking about specific short-term and long-term goals, and strategies and actions to achieve the goals.

There was a consensus of the Work Group that the early stages of a grant are the key stages in helping a community set a direction.

There needs to be both more accountability for development of careful plans and theories of change, and more assistance in doing so.

- developing and implementing a continuous quality improvement and performance measurement system;
- developing a governance and management system which promotes accountability, and clear and efficient decision-making.

The importance of these processes was highlighted in information presented to the Work Group. Their importance is also reflected in the earlier reference to Cebrowski (2002), who emphasizes the value of clear thinking about the principles behind the way things are done, and Hogan (2005), who emphasizes that transformation is a change in processes and not just programs.

The Work Group recognized that commendable efforts had been made to address these issues, such as adding a planning year for each grantee, and requiring that logic models be developed. However, the Work Group believes that there needs to be both more accountability for development of careful plans and theories of change, and more assistance in doing so. Potential strategies for doing this that were identified included the establishment of a two-stage process of project review, in which grantees would undergo a second review to determine the adequacy of their initial planning before receiving funding for implementation of their services; the front-loading of TA at the beginning of grants to assist with this; the establishment of “readiness” criteria to help evaluate the planning efforts of communities; an increased focus in TA on financing policies and strategies; and a greater emphasis in the grant review process on theories of change and continuous quality improvement processes. One option for accomplishing a readiness review is through the required federal site visits, which can be used to determine when a site has met the criteria to move from planning to implementation. The Work Group believes that through a more rigorous process of review with higher expectations for concrete plans and strategies, accompanied by more intensive TA, significant improvements can be achieved in the performance of grantee communities.

The Work Group also believes that it is important for local communities to be knowledgeable about state-level policy that affects their ability to successfully serve children with serious mental health challenges and their families in a manner that is consistent with system of care values and principles. Two goals for the grant program are to sustain services and system changes beyond federal funding, and to extend the successful service delivery and system change strategies to other parts of the state. To meet these goals, community grant sites must work closely with state officials, and be integral to larger state reform agendas in children’s services. It was proposed to the Work Group that in grant applications, applicants should be required to address the relationship between proposed local system of care activities, and state policy, and that applicants should be required as well to build in a strong partnership with the state. Further, grant applicants should be required to demonstrate in the original proposal and at later times how the community system of care will be integral to an overall state strategy for using the positive outcomes of the grant for sustaining the local changes, and replicating them in other areas of the state. These are recommendations that the Work Group strongly endorses, and that are consistent with the strong endorsement in the national survey of the importance of building state, local, and tribal capacity.

It is also noted that there is often a large discrepancy between good intentions and ideas, and the *implementation* of those intentions and ideas. Often times there is far more time and attention devoted to the development of a plan than

to the nitty gritty but critical work of implementing the plan properly. Part of the TA should be to help communities understand and apply the growing body of knowledge related to implementation (Fixsen, Naoom, Blase, Friedman, & Wallace, 2005), and part of the readiness review process should look at plans for implementation of the ideas that have been developed.

The Work Group recognized that there are actions that could be taken at the state and federal level that would improve the ability of grant communities to achieve their goals. These include changes in financing and other policies so that they are better aligned with the values, principles, and practices of systems of care, and the needs of the children and families who are served, promoting more collaboration across service sectors, and providing support for family and youth organizations. The Work Group certainly supports the importance of actions at all levels of government but wishes to emphasize that local communities have much opportunity to build into their own plans and strategies a strong emphasis on:

- examining funding policy and seeking to best align it with the needs of the children and families;
- supporting strong family and youth voice at the policy, program, and practice level, and providing family choice of services and providers as called for by the President's New Freedom Commission
- engaging partners from other service sectors in a collaborative effort;
- truly being responsive to children and families from diverse racial and ethnic backgrounds, and ensuring that cultural competence is integrated into all aspects of system development and implementation;
- establishing workforce development procedures that will result in improved capacity for serving children and families in a manner consistent with system of care values and principles.

In summary, in response to the first question addressed by the Work Group, there are two primary recommendations. First, it is recommended that there be increased accountability and technical assistance in the early stages of a grant to help communities translate their vision into a practical, meaningful set of goals, theory of change, implementation plan, and set of continuous improvement processes. Readiness criteria should be established to help guide communities and to help assess their progress and ultimate readiness to move from a planning to a direct service stage, and it is suggested that the readiness reviews be conducted as part of federal site visits. It is recognized that there is no single way to go about achieving the program goals, and that communities have to approach their grants in a manner that takes into account their own local context. However, for this reason it is essential that there be a strong continuous quality improvement and performance measurement system that will allow local stakeholders, in a transparent way, to assess their level of performance and make changes as needed.

Second, it is recommended that the grant program include a stronger state and local partnership for the purpose of enhancing the capacity to support, and sustain the system of care in the grant community, and to expand its impact throughout the state. The existence of such a partnership should have to be demonstrated in grant applications, with appropriate resources committed to supporting this partnership. It should also be the subject of technical assistance throughout the proposal, and should be part of the readiness criteria used to determine when (or "if") a community is ready to move from a planning stage to a direct service stage.

Often times there is far more time and attention devoted to the development of a plan than to the nitty gritty but critical work of implementing the plan properly.

Question 2: Develop recommendations for enhancing the long-term impact (legacy) of the system of care grant program?

It should first be noted that this question is not framed to focus exclusively on the degree to which grant communities sustain their system of care after grant funds have expired. Rather, it is focused on the overall *long-term impact* of the system of care grant program across the country, including the impact on communities and tribes that have not and are not likely to ever receive a system of care grant simply because it is not likely that the program will ever be able to directly fund every community and tribe. This question essentially deals with the issue of the legacy of this demonstration program. Although it is hoped and expected that the SOC grant program will continue on for many more years, the issue of its long-term impact and legacy should be addressed now so that strategic actions can be taken to help achieve them. It is recognized that Question 2, concerning long-term impact, clearly overlaps in focus both with Question 1 and Question 3.

There were a number of inter-related recommendations discussed by the Work Group which relate strongly to enhancing the long-term impact. These are:

- Achieve changes in financing policies to support system of care values, principles, and practices;
- Strengthen the voice of families and youth at the policy, program, and practice level;
- Gather together the best data on the cost-effectiveness of systems of care to use as tools in sustaining and expanding them;
- Build strong partnerships with key stakeholders from other service sectors and work to infuse system of care values and principles in other systems;
- Enhance state, local, and tribal capacity to develop effective systems of care;
- Identify and implement strategies for effectively reaching out to children and families who have historically been underserved or inappropriately served, including children from racial and ethnic minority backgrounds, children living in poverty, and gay, lesbian, bisexual, and transgender children, and providing culturally and linguistically competent services to them;
- Gather data on an ongoing basis on system performance, create a community culture focused on measurement of performance, and continue to be open to new ideas for system improvement;
- Enhance professional training and workforce development, including developing large and diverse provider networks that are capable of providing the most effective interventions so that families can have meaningful choice of services and providers;
- Enhance marketing of system of care values, principles, and of the entire concept, developing and delivering clear and easily understandable messages about children's mental health and systems of care, and building both on successes, and the tragic consequences of failing to provide effective systems and services;
- Develop, test, and apply effective practice-level interventions for children and families.

As indicated earlier, Hogan (2005) has said that to achieve transformation there is a need for linked actions, large and small, at many levels. This set of items should be viewed as an inter-related collection of components in which the cumulative impact of addressing them is greater than the sum of the whole. They reflect the recommendations for enhancing the long-term impact that the Work Group has heard, and are consistent with strategies that have worked in bringing about changes in other service systems.

There are special challenges here, though. For example, as valuable as it may be to demonstrate cost-effectiveness of interventions, it is often difficult within a demonstration program that provides new funding to communities to be able to demonstrate this. However, there are examples of cost-effective interventions, such as wraparound and multi-systemic therapy, within the children's mental health field, and information about these examples need to be synthesized and widely disseminated in a manner that reaches out to key policy-making audiences. Similarly, while changing professional training is a slow process, a number of communities have significantly enhanced their provider network, bringing in more minority providers in the process, and therefore created more accountability at the provider level and more choice for families. While the development and implementation of performance measurement procedures is sometimes viewed as an extra cost that takes away from direct services, several states and communities have now developed strong models that can benefit the entire field. While there is characteristically professional resistance to shifting power from professionals to families and youth, there is greater support for this than there has ever been, not only in children's mental health but in related fields such as adult mental health, developmental disabilities, and general health, and there is a strong call for this from the President's New Freedom Commission.

The Work Group identifies two particular areas of focus here that seem especially critical to maximizing the long-term impact. The selection of two areas is not intended to diminish the importance of any of the other areas that have been mentioned.

First, the Work Group concludes that the general issue of financing is of extreme importance if the long-term goals of the program are to be accomplished. This was the item that clearly was most strongly endorsed by respondents to the national survey. It is recommended that there be an increased focus in technical assistance on the development of comprehensive financing plans that are consistent with system of care values and principles and local theories of change, that at the federal level there be an accumulation of the best evidence on cost-effectiveness of new interventions and on the dissemination and marketing of these findings to all audiences but especially key funders and policy-makers, and that there be an ongoing effort at the federal level to modify policies so that they are best aligned with system of care values and practices.

Second, the Work Group concludes that long-term impact and system transformation absolutely requires strong family and youth involvement in all levels of the system, and strong professional—family partnerships in which power and authority is genuinely shared. This is not only the right thing to do but a review of change efforts in other systems only reinforces the notion that major change requires strong family and consumer leadership and support. Such a focus on shared power and authority between professionals and families is relatively easy to achieve when all parties are in agreement. However, it is a sign of a healthy

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Long-term impact and system transformation absolutely requires strong family and youth involvement in all levels of the system, and strong professional-family partnerships in which power and authority is genuinely shared.

It is recommended that starting from their grant proposals, applicants be required to demonstrate how families and youth will be involved as meaningful partners in the system, and to commit appropriate resources to support this effort.

The teenagers and young adults who participated in the focus group conducted by the Work Group emphasized their dissatisfaction with the term “emotional disturbances.”

partnership when parties are strong enough and independent enough to disagree, and then to work out a resolution of the disagreement while maintaining a strong overall partnership. The children’s mental health field must strive to reach this point where power is genuinely shared, where respectful disagreement is not out of the ordinary, and where constructive conflict resolution procedures are used when disagreements occur.

It is recommended that starting from their grant proposals, applicants be required to demonstrate how families and youth will be involved as meaningful partners in the system, and to commit appropriate resources to support this effort. It is recommended that a priority be on the use of additional resources to strengthen family organizations, many of which operate with only minimally adequate resources, and to continue to provide them with strong technical assistance so that a true sharing of power at all levels can be achieved. Such family organizations should include leadership and membership that is diverse and reflective of the general community population. It is also recommended, consistent with the President’s New Freedom Commission and the Institute of Medicine, that grantees be required to provide families and youth with the opportunity to exercise informed choice both of services and supports, and of providers.

It should be noted, additionally, that the teenagers and young adults who participated in the focus group conducted by the Work Group emphasized their dissatisfaction with the term “emotional disturbances.” In keeping with that, this report has used the term “mental health needs.” It is recommended that the issue of language be re-examined so that terms which reduce stigma can replace those that are more stigmatizing.

Question 3: Offer recommendations for how the system of care grant program can be used to achieve system transformation in accordance with the recommendations of the President’s New Freedom Commission.

As noted earlier, the values, principles, and practices of systems of care are very consistent with those recommended by the President’s New Freedom Commission. To a large extent this reflects the fact that the manner in which children with serious mental health needs and their families are served has been undergoing transformation for the past 20 years, since the initiation of the Child and Adolescent Service System Program. This does not mean that large-scale changes are not needed. Such changes are clearly needed given the difficulty in implementing the vision of systems of care as it has been presented, and in increasing its reach across the country. It does mean, however, that these changes represent a continuation of the efforts that have been ongoing for the past 20 years to increase access to effective data-based and value-based systems of care for all children and families in need. Such systems must continue to strive to provide comprehensive and individualized plans of care, to provide culturally and linguistically competent services, to provide families with informed choice of effective and evidence-based services and to engage them as system partners, to emphasize services in the home and community, to align financing policies with the needs of children and families, to engage partners from multiple service sectors, and to get out the message about the importance of mental health, the value of new approaches, and the great price that is paid when effective services and systems are not available.

The system of care grant program, and all efforts to develop systems of care must be viewed as vehicles of transformation. Family and youth organizations in

particular must be strengthened because of their vital role in ensuring that the right things will be done and sustained over time. At the federal government level, there must be effective partnerships across service sectors as a message to state and local policy-makers about the importance of such partnerships, and as a strategy for getting to the point where existing resources can be used more effectively.

There are two important recommendations in the President's New Freedom Commission and in the information provided to the Work Group that require additional attention. The President's New Freedom Commission made a strong call for early identification of problems, and ready access to services. The Work Group, both in the responses to the survey, and in its meetings with stakeholders, heard about the importance of prevention, early identification, and early intervention. This is consistent with the system of care philosophy as originally expressed (Stroul & Friedman, 1986). However, for a variety of reasons systems of care have focused their almost exclusive attention on those with the most serious needs, and have devoted far less attention to prevention, early identification, and early intervention. A notable exception to this was the Urban Child Mental Health Initiative of the Annie E. Casey Foundation in the early to mid 1990s (Gutierrez-Mayka & Contreras-Neira, 1998) which sought to improve outcomes for all children in a small group of high poverty neighborhoods.

As part of the move toward large-scale system change, it is clear that a greater focus needs to be devoted to prevention, early identification, and early intervention. The Subcommittee on Children and Families of the President's New Freedom Commission has clearly indicated that, "Prevention, early identification and intervention offer the best opportunity to maximize the likelihood of positive outcomes, yet many children and families must wait until their problems have reached serious or crisis proportions before they can receive help" (Huang et al., in press). The Subcommittee recommends "the establishment of an infrastructure at the federal and state levels, and in every community in America, to plan, coordinate and support the development of preventive, early identification, and early intervention services" (Huang et al., in press). Such an effort would clearly need to place a greater focus on young children than has typically been the case in children's mental health, and must cross narrow categorical lines. It should embrace population-based public health approaches, should build on knowledge about risk and protective factors, and should include broad-based coalitions from a wide variety of service sectors as well as business, government, the faith community, primary health care, and the volunteer sector. In true system of care fashion, there should be "no wrong door" to enter a system. If there is genuine system integration, then whatever door a child or family enters should provide access to the supports and services that are needed.

The important challenge in doing this, as discussed by the Work Group, is to not neglect those with the most serious need while attention is being focused on prevention and early intervention. There must be a balance established in the emphasis on each group. Similarly, given that systems of care were established partly in response to a fragmented service system with narrow categorical programs, such an effort to enhance population-based preventive efforts must figure out how to integrate this with other existing efforts rather than creating yet another narrow categorical program. One model for doing this that the Work Group identified is the application of Positive Behavioral Support efforts in many schools across the country (Carr, Dunlap, Horner, et al., 2002; Kincaid & Fox,

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As part of the move toward large-scale system change, it is clear that a greater focus needs to be devoted to prevention, early identification, and early intervention.

It is recommended that the focus of the system of care grant program be expanded to allow and encourage communities and tribal groups to propose integrated approaches to serving children whose problems may fall along a continuum of severity, and their families.

2002). Positive behavioral support provides, in an integrated way, interventions at three levels: the entire school, those with mild problems or at risk, and those with severe problems. This approach emphasizes that to only address individual problems while not trying to strengthen the overall school culture and environment is likely to be futile. An example of successful primary care and behavioral health partnerships is medical home models that provide many important benefits for families including a single point of contact to address all primary care needs, screening for mental health needs and substance abuse issues with all family members, referral to program services, preventive education, and linkages to care coordination for families with serious or complex needs.

Approaches such as positive behavior support are ecological in nature, recognizing that the behavior of individuals is a function both of their own characteristics and the characteristics of the environments in which they find themselves. As part of transformation efforts, it is important that this be recognized and emphasized, and be translated into strong community development and family support efforts that go hand in hand with direct services to individual children and families.

It is recommended that the focus of the system of care grant program be expanded to allow and encourage communities and tribal groups to propose integrated approaches to serving children whose problems may fall along a continuum of severity, and their families. If change in the Congressional language authorizing this grant program is needed to achieve this change, then the Work Group would endorse such a change. An expanded approach not only has the potential of reaching more children in a more effective way but also of normalizing the mental health challenges that so many children face in one way or another at some point in time. The Work Group recognizes that other service sectors also face now, or have faced, the challenge of expanding their focus beyond those with the most serious challenges. The Work Group recommends that there be further research to identify strategies for achieving such an expansion in an integrated way at the direct service, system, and policy levels, and for creating and supporting community, tribal, and state infrastructures that focus on the mental health needs of children across the continuum of severity.

The President's New Freedom Commission also calls for a strong emphasis on a recovery and resilience-oriented system. SAMHSA emphasizes as a goal providing individuals with a life in the community, including the social, recreational, and vocational domains as well as housing and transportation. The Institute of Medicine's report on transforming health care includes as part of its goal the reduction of burden due to illness, disability, and injuries. A consistent theme is a focus not solely on symptom reduction or elimination of a disorder or illness. Rather the focus is heavily on the developing of skills, coping strategies, and supports to promote as high a quality of life, and as independent a life as possible in the community. Such an emphasis has important implications for service delivery, for planning efforts, and for evaluation efforts. These are all very positive and consistent with the message that families and youth have been giving for years. It is consistent with the strength-based approach of systems of care, and with the general thrust of system of care work for the past 20 years. Given that, it is easy for the system of care world to overlook the importance of this emphasis from the President's New Freedom Commission. This would be a mistake. This Work Group certainly endorses the focus on practical skills and supports to promote a high quality of life in the community,

and recommends that the implications of this for direct services, for community planning, for community partners, and for evaluation be fully explored. Friesen (2005) indicates that, “the value that we found through a review of resilience knowledge and in key elements of recovery suggests that these ideas should have a more central place in our work to transform the mental health system across the life span. The effect, we think, should be to move them out of the background and into the spotlight” (2005, p. 8). The Work Group shares this view and recommends that the specific implications of this for system development, direct service, performance measurement, and evaluation be further examined.

Summary

In summary, the Work Group is convinced that the children’s mental health field, with its focus on data-based and value-based systems of care, has not only been on the right track for the past 20 years but is very much consistent with the values and principles of the President’s New Freedom Commission. The main challenges, if substantial and sustained change is to occur, are to implement systems of care for children with serious mental health needs and their families more effectively, increase their reach so that all children in need have access to them regardless of how they enter the system, and at the same time move to implement the recommendation to increase systemic and comprehensive efforts to prevent problems and promote good mental health.

More specifically, the Work Group recommends that to strengthen the system of care grant program there needs to be an increasing emphasis on the early stages after a grant is awarded. Communities need to be provided with increased assistance in translating their vision into a clear theory of change with a strong implementation plan and performance measurement procedures, and the grant program needs to be restructured so that communities are accountable for doing this before receiving funding for implementation of services. The grant program also needs to be re-structured into more of a state—local partnership so that capacity for developing and supporting systems of care is strengthened at all levels, and the impact of the program can be expanded across each state.

At the same time a comprehensive plan needs to be developed to help maximize the long-term impact of the system of care grant program, not only in funded communities but across the country. This plan needs to build into a cohesive, integrated whole a focus on many issues but particularly on changes in financing policies so that they are aligned with the needs of children and families, the development of comprehensive financing strategies at the local and state levels, gathering and marketing the best data on cost-effectiveness of new interventions, and strengthening family and youth voice at state and local levels, and at both the direct service and policy/planning level.

In support of efforts to maximize impact and achieve significant change, the system of care grant program should expand its focus to include a greater emphasis on children with less severe mental health needs whose problems, if left unaddressed, are likely to become more severe. There is a need to apply population-based public health approaches to prevent problems from occurring, and intervene early where problems have already occurred. This must be done in a manner that is integrated with ongoing efforts to serve children with the most severe challenges. Further, the system of care field needs to strengthen its focus on resilience and recovery, and the overall goal for children of providing them with a high quality and independent life in their community.

The main challenges, if substantial and sustained change is to occur, are to implement systems of care more effectively, increase their reach so that all children in need have access to them regardless of how they enter the system, and at the same time move to implement the recommendation to increase systemic and comprehensive efforts to prevent problems and promote good mental health.

The system of care grant program, and all efforts to build systems of care, with their strong focus on enhancing the power of families and youth, can be viewed as efforts not only to change systems but to change cultures—to create in every community a culture of caring and support for every child and family, a culture of family-professional partnership, and a culture that supports innovation and continuous learning. Systems of care have had many successes—the next challenge is to build upon these successes, to learn from the struggles, and to use this new knowledge and strong commitment to bring about even more large-scale system and culture change so that all children can live high-quality and productive lives in their communities.

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Appendix

Transformation Survey Summary of Results



Background

In the spring of 2004, the Council of Collaboration and Communication created a “Transformation Work Group.” The mission of this Work Group is to develop recommendations for strengthening the Comprehensive Community Mental Health Services Program for Children and Their Families, and to determine how that program can best contribute to transforming the children’s mental health system in keeping with the recommendations of the President’s New Freedom Commission on Mental Health.

The Work Group consists of Bob Friedman, Chair; Gary MacBeth, Vice-Chair; Gary Blau, Jennifer Clancy, Holly Echo-Hawk, Brigitte Manteuffel, Joe Perry, and Carol Schneider. As part of its effort to achieve its mission, the Work Group sought to get input from a large and diverse group of constituents of the grant program. To do this, the Research and Training Center for Children’s Mental Health of the University of South Florida developed a survey for the Work Group. The purpose of this report is to present preliminary findings

Method

The survey was primarily web-based; however, respondents were given additional options of printing off a hard copy of the survey and mailing or faxing a hard copy back to the RTC. Both the electronic version that was distributed and the hard copy version included an option to complete the survey in Spanish. The survey consisted of questions that called for quantitative ratings by the respondents, and questions that were more open-ended and required narrative responses. For those questions that were open-ended, the team at the Research and Training Center developed coding categories, reviewed each response, and placed it within the appropriate category. The main effort of this review was to identify dominant themes from the narrative responses.

The survey, which was reviewed by the CCC and approved by the Work Group, was distributed on Oct 27, 2004 and respondents were encouraged to complete the survey by mid-November. Reminders were sent out to encourage respondents to complete the survey and responses were accepted until the end of November. Members of the following groups were asked to complete the survey:

1. Past and present directors of system of care grants;
2. Past and present family leaders of system of care grants;
3. The Advisory Group to the national evaluation of the grant program (the first three categories included 179 individuals);
4. State directors of children’s mental health (n=54);
5. Members of the National Alliance of Multi-Ethnic Behavioral Health Associations (n=5);
6. Family network grantees (n=43);
7. Local chapters of the Federation of Families for Children’s Mental Health (n=145);

8. Staff of the Child, Adolescent, and Family Branch of the Center for Mental Health Services (n=10);
9. Circle of Care grantees (n=7);
10. Members of the CCC (n=23).

Surveys were distributed by individuals who already had a relationship with the organization to whom the survey was to be distributed wherever possible. For example, ORC Macro distributed the surveys to the Advisory Group for the national evaluation, and to directors and family leaders of the system of care grants. The National Technical Assistance Center at Georgetown University distributed the surveys to state directors of children's mental health. The United Advocates for Children of California, which provides technical assistance to family network grantees, distributed the surveys to this group, and the central office of the Federation of Families distributed surveys to local chapters. The National Indian Child Welfare Association, which provides technical assistance to circle of care grantees, distributed surveys to that group.

Results

The total number of invitations to complete the survey was 463. Due to an overlap of members between groups, estimated to be at least 40 (9%), the total number of potential respondents is 423. A total of 150 people responded to at least the first question of the survey (35% of the 423 asked to complete the survey). Depending on the particular question, approximately 111 responded to the remaining questions. All respondents used the English version of the survey and the majority of respondents (92%, n=138) used the web-based version while only 12 (8%) returned a hard copy of the completed survey.

Role Identification. Respondents were asked to provide information about their role in children's mental health. They were given a list of roles and asked to select as many roles as applied. The following table summarizes the roles of the respondents.

| Role | N | %N | (% selected role) |
|---|-----|------|-------------------|
| Family member of a child with emotional disturbance | 22 | 15% | 19% |
| Program or system administrator | 49 | 33% | 42% |
| Researcher or evaluator | 5 | 3% | 4% |
| Provider of services | 2 | 1% | 2% |
| Provider of technical assistance/consultation | 3 | 2% | 3% |
| Youth receiving services | 0 | 0% | 0% |
| Other | 2 | 1% | 2% |
| Multiple roles selected | 34 | 23% | 29% |
| No role selected | 33 | 22% | — |
| Total | 150 | 100% | |

Level at Which Respondents are Involved (n=119). Respondents were asked at what level of government their primary involvement had been. They were allowed to select as many levels as applicable. The next table presents the results, indicating that about 74% have some involvement at the local level, 63% have at least some involvement at the state level, and 30% have involvement at the national level.

| Level | n | %n |
|--------------------------|-----|------|
| Local | 32 | 27% |
| State | 18 | 15% |
| National | 9 | 8% |
| Local / State | 34 | 29% |
| State / National | 5 | 4% |
| Local / National | 3 | 3% |
| Local / State / National | 18 | 15% |
| Total | 119 | 101% |

State Identification (n=112). Respondents were asked to identify the state that was their primary residence or place of work. They were also instructed to select the choice of “All” if their primary work was national in scope. Of the 150 respondents, 112 (75%) of the participants answered this question, representing 38 different states. 12 respondents indicated that their work was national in scope instead of identifying a particular state. New York was the state most often selected, representing 21% (24) of all who responded to this question.

| State | % | n | State | % | n | State | % | n | State | % | n |
|----------|-------|----|-------|------|---|-------|-------|----|-------|------|---|
| National | 10.6% | 12 | ID | 2.7% | 3 | MO | 1.8% | 2 | PA | 2.7% | 3 |
| AL | 0.0% | 0 | IL | 2.7% | 3 | MT | 0.9% | 1 | RI | 0.9% | 1 |
| AK | 2.7% | 3 | IN | 3.5% | 4 | NE | 1.8% | 2 | SC | 0.9% | 1 |
| AZ | 0.9% | 1 | IA | 0.9% | 1 | NV | 1.8% | 2 | SD | 0.0% | 0 |
| AR | 0.0% | 0 | KS | 0.0% | 0 | NH | 0.9% | 1 | TN | 0.0% | 0 |
| CA | 0.9% | 1 | KY | 1.8% | 2 | NJ | 0.0% | 0 | TX | 2.7% | 3 |
| CO | 1.8% | 2 | LA | 0.9% | 1 | NM | 0.9% | 1 | UT | 2.7% | 3 |
| CT | 1.8% | 2 | ME | 0.9% | 1 | NY | 21.2% | 24 | VT | 0.9% | 1 |
| DE | 0.9% | 1 | MD | 1.8% | 2 | NC | 0.0% | 0 | VA | 0.0% | 0 |
| DC | 0.0% | 0 | MA | 0.9% | 1 | ND | 0.9% | 1 | WA | 0.9% | 1 |
| FL | 4.4% | 5 | MI | 0.0% | 0 | NH | 0.0% | 0 | WV | 0.9% | 1 |
| GA | 1.8% | 2 | MN | 1.8% | 2 | OK | 6.2% | 7 | WI | 0.0% | 0 |
| HI | 1.8% | 2 | MS | 1.8% | 2 | OR | 0.9% | 1 | WY | 3.5% | 4 |

Section 1: Appropriateness of the Goal (n=150)

The first question of the survey talked about the overall long-term goal of the system of care grant program, as perceived by the respondents. *This section deals with the overall long-term goals of the Community Mental Health Services Program for Children and Their Families. Our beginning premise is that, broadly speaking, the overall goal of the program is to transform the children's mental health system so that all children with serious emotional disturbances and their families have access to effective care that results in positive outcomes in accordance with system-of-care principles and values, and the President's Commission.*

Is this the right program goal for this point in time? (n=150)

Yes 92% (138)

No 8% (12)

Other Goals (n=86). Are there other long-term goals that you would suggest to augment this goal or to replace it? For example, should the program focus on a broader population? Please list your suggestions briefly below.

Dominant Themes

The dominant themes in this section included the ideas that the population of interest to the grant should be expanded, increased emphasis should be placed on prevention and intervention efforts, and a greater focus should be placed on transforming current interventions, particularly through increased family participation. Approximately one-third of all responses were concerned with the themes of expanding the population and emphasizing prevention and early intervention; approximately one third of the responses were concerned with changing the philosophy or approach to mental health treatment. Respondents specifically indicated a need to include children other than those with a serious emotional disturbance in the program. There was also a strong emphasis on expanding intervention efforts to more explicitly focus on prevention and intervention efforts in an attempt to reduce the size of the SED population and to limit the harm done by failing to diagnose and treat disorders in a prodromal stage. Responses that indicated a need to expand the population of interest tended to co-occur with responses indicating a need to focus on prevention and intervention. Many of the responses regarding transforming mental health treatment addressed the need for greater family involvement in care choices and for the development of more family-focused services. Family involvement suggestions included the need to develop interventions providing family support, education, and in-home services, and doing so in a way that respects and understands families and their cultures.

Less frequent themes, in descending order of frequency, included the need for information to be disseminated to the public or families regarding mental illness or principles of SOC, the need to disseminate such information to professionals and pre-professionals, concerns about the funding of mental health services, and the need for collaboration across systems. Less than ten percent of all responses included any or all of the last three themes.

Dissenting Themes

About twenty percent of all responses included at least one element that did not fit the coding scheme developed. This included three responses indicating the need to continue to limit the population of interest to children and youth with SED. Two respondents indicated that it was premature to broaden the focus to other populations before achieving the grant goals for the current population.

Section 2: Rating of Strategies

In this section, the focus was on securing input about the strategies that were most likely to result in achievement of the long-term goals, in the view of the respondents. Twelve strategies were listed. Respondents were asked to rate these strategies in three different ways: (1) by importance (on a 4-point scale); (2) by difficulty of implementation (also on a 4-point scale) and; (3) by top three in importance. After rating the strategies, respondents were asked if there were any others strategies that should be considered. The complete listing of the strategies and their average ratings is included at the end of the narrative. This table also shows the ratings given by individuals whose primary role was judged to be a family member, an administrator, or all others not included in the first two categories.

Importance of Strategies (n=138). Given the general goal stated above in Section I, there are many possible strategies for achieving it. These strategies are not mutually exclusive. In the first column below, please rate how important you believe each listed strategy is to achieving the broad goal.

On the 4-point scale, all 12 factors received a rating that ranged from 3.2 to 3.8. The strategies that were rated as “very important” by 70% or more of respondents were:

- Reform financing of services and supports for children with emotional disturbances and their families;
- Build local and state capacity for developing systems of care;
- Promote systems-of-care practices and values, such as individualized care, cultural competence, and family choice, throughout other child-serving systems;
- Support advocacy activities of important stakeholders such as family organizations, youth organizations, minority mental health organizations, and state directors of children’s mental health;
- Provide strong evidence of the effectiveness of systems-of-care to influence policy/funding decisions by state and local governments and Congress.

However, all strategies were clearly rated as important. Administrators gave ratings of greater importance than family members did to building local and state capacity, and developing and testing effective practice-level interventions. Family members gave higher ratings than administrators on creating a public and professional education program, and supporting advocacy activities of important stakeholders.

Difficulty of Implementation (n=128). Given the general goal stated above in Section I, there are many possible strategies for achieving it. These strategies are not mutually exclusive. Please rate how difficult you believe it is to successfully implement the strategy.

Respondents were asked to rate how difficult each of the twelve strategies would be to implement. A four-point scale was used, with 1 being not difficult, 2 being somewhat difficult, 3 being moderately difficult, and 4 being very difficult. The range of scores was from a low of 2.4 to a high of 3.6, indicating that overall difficulty ranges from “somewhat difficult” to “very difficult” to implement. The following strategies were rated as either “moderately difficult” or “very difficult” by more than 67% of the respondents.

- Reform financing of services and supports for children with emotional disturbances and their families (90%);
- Build local and state capacity for developing systems of care (78%);
- Reform professional training & human resource development efforts (67%);

It is noteworthy that two of the three strategies viewed as most difficult were also among those rated as the most important strategies identified above. The three strategies rated as least difficult to implement were supporting advocacy activities of important stakeholders, supporting a learning laboratory, and promoting system of care practices and values throughout other child-serving systems. The differences between family members and administrators in ratings of difficulty were minimal, except for the strategy of establishing systems of care on a community-by-community basis by continuing the present approach to distributing grants. Family members rated this as less difficult than did administrators.

Three Most Important (n=128). Given the same strategies as in the previous two questions, please check the three that you believe are the most important for achieving the goals of the program.

This question proved to get more variability in response than did the first question, where all strategies were rated as highly important. The three strategies that received the largest number of endorsements to this question were:

- Reform financing of services and supports for children with emotional disturbances and their families 63% (n=81)
- Build local and state capacity for developing systems of care 38% (n=49)
- Provide strong evidence of the effectiveness of systems of care to influence policy/funding decisions by state & local governments & Congress 38% (n=48)

These three strategies all appeared in the previous question concerning importance in which they were rated first, second, and fifth in level of importance. Less than 42 people endorsed the remaining strategies. The financing strategy was overwhelmingly selected as the most important strategy, particularly by administrators who included it in their list of three most important strategies 83% of the time, compared to 57% for families. Administrators also listed providing strong evidence of the effectiveness of systems of care, and building state and local capacity as more important than did family members. Family members placed greater emphasis on supporting advocacy activities of important stakeholders, creating a public and professional education program, and reforming professional

training more highly than did administrators. It is noteworthy that while both family members and administrators rated reforming financing as their number one item, there were more differences between groups in response to this question than either of the other two questions.

Other Strategies (n=44). Now that you have rated the strategies we listed, are there any other strategies we should consider to achieve the goals of the program?

After rating the categories for importance and difficulty, most of the narrative responses that followed added specifically to one of the twelve categories from the survey. A couple of responses noted a need to reform other systems such as Child Welfare, Juvenile Justice, and Education. In addition, a number of respondents made suggestions for changes to the current grant process.

Section 3: Actions or Changes (n=112)

Please describe the three to five actions or changes to be taken in the next few years that you believe would be most important to the long-term success of the Program and why. This could include structural changes (e.g., definition of the population of concern, size and/or length of the grant, legislative language, etc.) or shifts in strategy (e.g., increasing attention paid to particular program components or strategies, strengthening existing partnerships and/or developing new partnerships, modifying evaluation approaches, etc.)

Dominant Themes

Frequently occurring themes in response to this question included the idea that funding should change, that cross-agency collaboration should be expanded, that families should be more centrally involved, and that evaluation and data collection procedures and dissemination should change. More than a third of all responses included suggestions for modifying funding for the grant recipients or for state or local mental health services in general. Predominant among the ideas for revision included the ideas that sustainability of services and programs should be a core concern of the program, that funds should be more flexible and available for blending from multiple sources, and that Medicaid funding should be expanded as in the case of the Medicaid waiver for home and community-based services, shored-up, or expanded to include a larger population of persons. Respondents also had strong opinions about the need for increased cross-agency collaboration. They voiced the view that federal agencies should model cross-agency collaboration, create cross-agency SOC grants, and emphasize federal and state agency collaboration. Regarding family involvement, survey respondents generally indicated a need for a greater level of support for family involvement at all levels of policy development and service delivery, and for greater technical and financial support for family organizations. Finally, in terms of data and evaluation, suggestions included the need for culturally relevant evaluation procedures, for meaningful and consistent data collected from grantees, and to provide evidence of the effectiveness of SOC.

About ten percent of responses included discussion of the need to increase technical assistance to grantees, to emphasize prevention and early intervention, to broaden the population of interest, to educate professionals and pre-professionals about SOC and EBPs, and to educate legislators and reform mental health policy.

Dissenting Themes

About one-quarter of all responses included elements that were not included in the themes described above. These included the idea that a new program is needed, that targeted systems of care should not be called “mental health systems of care,” that community readiness should be addressed when considering the implementation of SOC principles, and that culturally relevant practices should not be negated simply because they don’t meet standards for evidenced-based practice.

Section 4: Changes and Innovations (n=91)

What changes or innovations have you introduced, heard about, or seen through the grant program that you believe have the greatest possibility of achieving system transformation?

Dominant Themes

In this section a number of respondents indicated innovations that they have seen, as well as innovations that they would like to see. The innovation most frequently endorsed as systems-changing included educating, involving and empowering families. Respondents talked about giving families a voice in selecting treatment, being involved in all levels of decision-making, and placing funds for care in the hands of families. There was also discussion of the power of broader community involvement, of grassroots efforts to promote a responsive mental health system. Survey respondents indicated that family and community involvement in the process was more likely to result in culturally competent and family-driven care, which was seen as preferable to the traditional provider or medically-driven model of care. Other diverse themes were also endorsed, including the idea of making concerted efforts to impact legislation and policy, the advent of wraparound services, and the inclusion of a Latino voice in community mental health service development. One respondent mentioned the need to maintain the practices that have been put into place in order to institutionalize SOC values.

Dissenting Themes

A small minority of respondents indicated that the grant program had not introduced meaningful or innovative, potentially transformative system changes. One individual responded, “Nothing. The Federal level does not enforce the terms of the contracts. Families ultimately have a new label on an old system and keep on getting taken advantage of by the system. As long as the dollars go to the government agencies, they will do with it as they please which doesn’t necessarily follow the SOC model.” Another respondent stated, “None. I think the program has become an obstacle because community [sic] are not prepared and merely parrot parts such as parent involvement, wraparound that are not part of a well thought system of care and associated strategy.”

Section 5: Actions Within the Child, Adolescent, and Family Branch (*n*=93)

Up to now, questions have addressed the Community Mental Health Services Program for Children and Their Families. In addition to this Program, what other actions should the Child, Adolescent, and Family Branch take to transform the children's mental health system into a system that provides access to effective care based on systems-of-care principles and values, and the President's Commission? Please list your recommendations below, providing as much description and rationale as you would like.

Dominant Themes

The responses to this question reflected a strong emphasis on increased collaboration across systems, specifically at the federal level. The responses also demonstrated a broad range of funding concerns, including a desire to see more blending and braiding of the resources at the federal and state level, as well as increased flexibility in the use of the available resources. Other common responses addressed the following topics: the need for increased family involvement, efforts to increase awareness and understanding of mental health issues, recommendations to modify the grant process, and suggestions to enhance the impact of technical assistance efforts.

Dissenting Themes

A couple of respondents expressed specific concerns distinct from the dominant themes. One respondent stated, "I think depending on the family to take action is not a realistic view. This takes time and many families need intervention for crisis stabilization." In addition, it was noted that, "providing ideas for access does not assure that all will be alright." One respondent expressed concern about the process that is used to choose who will attend particular events, such as the last Medicaid-Mental Health summit. Finally, several individuals responded that they did not currently have additional recommendations for the program.

Section 6: Transformation to Better Serve Children with ED (*n*=101)

Now, please think beyond just the Child, Adolescent, and Family Branch. What actions have the greatest potential for achieving large-scale and lasting transformation in our nation's ability to better serve children with emotional disturbances and their families?

Dominant Themes

The responses to this question reflected a strong emphasis on increased collaboration across systems, specifically at the federal level, state level, and among the local child-serving entities, such as education, mental health, child welfare, juvenile justice, and primary care physicians. The responses also reflected a broad range of funding concerns, including a desire to see more blending and braiding of the resources available at the federal and state level, more funding to ensure family support and involvement, and a desire to "establish insurance parity for mental health and substance abuse." Furthermore, the responses addressed the need to focus on

prevention and intervention, efforts to reduce stigma, and the promotion of evidence-based practices. Finally, a number of recommendations utilized educational strategies to achieve transformation by enhancing awareness and understanding of children with emotional disturbances at the high school, professional school, and professional development levels.

Dissenting Themes

One respondent noted the need for alternatives to traditional health services for youth and families. Another respondent stated, “get rid of a reliance on behaviorist psychology and all the measurements that go with that orientation.” Another respondent suggested, “stop thinking of children’s mental health and substance abuse services as versions of adult programs for younger people.” Finally, one respondent indicated, “stop attacking parents and kids who have special needs.”

Section 7: Transformation to Prevent Emotional Disturbance (n=100)

Please continue to think “big picture.” What actions have the greatest potential for achieving large-scale and lasting transformation in our nation’s ability to prevent emotional disturbances?

Dominant Themes

The responses to this question emphasized the need to educate the community (as well as students, educational personnel, parents, medical personnel, law enforcement, and stakeholders) to increase awareness of the signs and impact of mental illness, as well as prevention strategies. In addition, responses reflected a need to educate the community to reduce the stigma associated with mental illness. Many responses specifically addressed the need to focus on prevention efforts and an overall shift to a focus on wellness and routine early assessments integrated into a variety of child serving settings such as day care centers, schools, medical settings, and recreation settings. Furthermore, a number of concerns about funding were expressed, ranging from recommendations for additional funding for specific needs to changing how funding occurs, including recommendations to change private insurance and Medicaid to allow for prevention and wellness activities. Again, the theme of increased collaboration across systems was well represented among the responses to this question. Finally, respondents noted broad needs to reform aspects of the health care system, the educational system, the child welfare system, the juvenile justice system, and the economic realities that negatively impact children and families. One respondent specifically endorsed the current strategy and course of action.

Dissenting Themes

One respondent suggested that the greatest possibility for achieving large-scale and lasting transformation would be achieved by “increasing compassion,” while another respondent suggested abolishing SAMHSA. Another respondent recommended transforming “mental health into a cognitive approach to working with children and families.”

Section 9: Comments (n=50)

Do you have any other comments that you would like to make to assist the Work Group? What questions were missing from this survey?

This last question asked for any other comments to the Work Group that would assist the group or provide questions that should have been asked in the survey. Of the 50 comments, the most common response was a thank you. A complete listing of comments is available upon request.

Summary

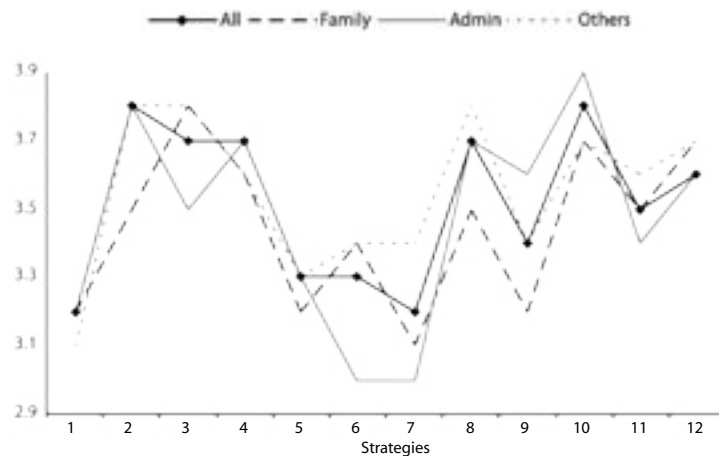
The survey elicited responses from about 35% of the sample. The respondents were a diverse group and seemed to agree most strongly on the overall long-term goal for the system of care grant program, and the need to emphasize changes in financing policies and strategies. Other consistent themes were the need to strengthen family participation, including more choice for families, and the importance of securing broad cross-sector partnerships. There was significant sentiment expressed for broadening the focus of the system of care grant program to go beyond just children with serious emotional disturbances and their families, and strong interest as well in increasing support for important stakeholder groups, increasing professional and public education, and gathering data to support the effectiveness of systems of care. While there was some strong criticisms expressed of the current program by a few respondents, the overall sentiment was that while changes were needed, the efforts were generally moving in the right direction.

Mean of Importance of Strategy (n=138)

Please rate how important you believe each listed strategy is to achieving the broad goal.

1=Not Important, 2=Somewhat Important, 3=Moderately Important, 4=Very Important

| Strategy | All 138 | 16% | 36% | 49% |
|---|------------|--------------|-------------|--------------|
| | | Family 22 | Admin 49 | Others 67 |
| 1. establish systems of care on a community-by-community basis by continuing the present approach to distributing grants | 3.2 0.8 | 3.2 0.9 | 3.2 0.9 | 3.1 0.8 |
| 2. build local and state capacity for developing systems of care | 3.8 0.6 | 3.5 0.9 | 3.8 0.4 | 3.8 0.5 |
| 3. support advocacy activities of important stakeholders such as family organizations, youth organizations, minority mental health organizations, & state directors of children's mental health | 3.7 0.6 | 3.8 0.7 | 3.5 0.7 | 3.8 0.5 |
| 4. provide strong evidence of the effectiveness of systems-of-care to influence policy/funding decisions by state and local governments and Congress | 3.7 0.6 | 3.6 0.8 | 3.7 0.4 | 3.6 0.6 |
| 5. support a learning laboratory, continuously expanding our knowledge of how to implement effective systems of care | 3.3 0.8 | 3.2 0.9 | 3.3 0.7 | 3.3 0.8 |
| 6. create a public and professional education program, helping to gain ongoing support from all stakeholders | 3.3 0.8 | 3.4 1.0 | 3.0 0.7 | 3.4 0.7 |
| 7. define a model of partnership between local, tribal, state, and federal government | 3.2 0.9 | 3.1 1.0 | 3.0 0.9 | 3.4 0.8 |
| 8. promote systems-of-care practices and values, such as individualized care, cultural competence, and family choice, throughout other child-serving systems | 3.7 0.6 | 3.5 0.8 | 3.7 0.6 | 3.8 0.5 |
| 9. develop/test effective practice-level interventions for children and families | 3.4 0.8 | 3.2 0.8 | 3.6 0.6 | 3.4 0.8 |
| 10. reform financing of services and supports for children with emotional disturbances and their families | 3.8 0.5 | 3.7 0.7 | 3.9 0.3 | 3.7 0.6 |
| 11. reform professional training and human resource development efforts | 3.5 0.7 | 3.5 0.7 | 3.4 0.7 | 3.6 0.7 |
| 12. expand public health approaches related to prevention of emotional disturbances and early identification | 3.6 0.6 | 3.7 0.7 | 3.6 0.5 | 3.7 0.7 |

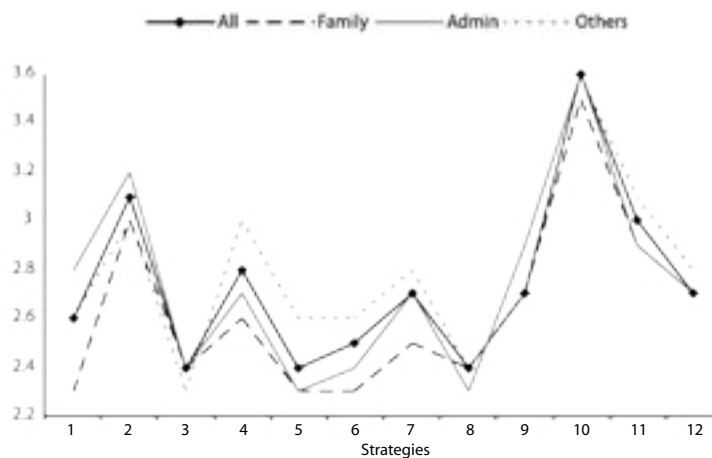


Mean of Difficulty to Implement Strategy (n=128)

Please rate how important you believe each listed strategy is to achieving the broad goal.

1=Not Difficult, 2=Somewhat Difficult, 3=Moderately Difficult, 4=Very Difficult

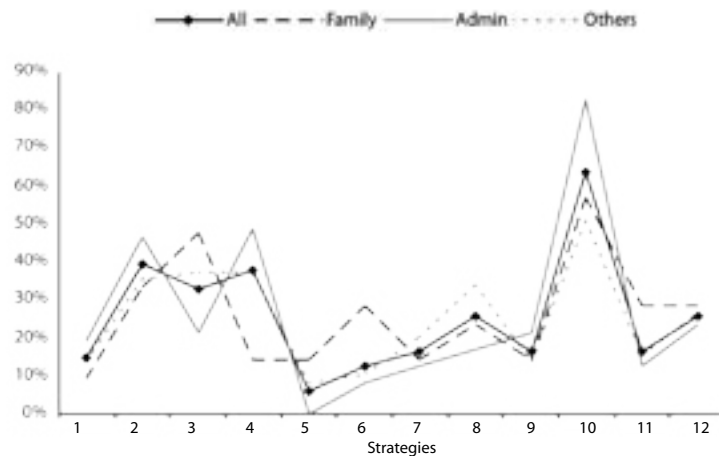
| Strategy | All 128 | 17% | 37% | 46% |
|---|------------|--------------|-------------|--------------|
| | | Family 22 | Admin 47 | Others 59 |
| 1. establish systems of care on a community-by-community basis by continuing the present approach to distributing grants | 2.6 1.0 | 2.3 0.8 | 2.8 0.9 | 2.6 1.0 |
| 2. build local and state capacity for developing systems of care | 3.1 0.8 | 3.0 0.9 | 3.2 0.6 | 3.0 0.8 |
| 3. support advocacy activities of important stakeholders such as family organizations, youth organizations, minority mental health organizations, & state directors of children's mental health | 2.4 1.0 | 2.4 1.2 | 2.4 1.0 | 2.3 1.0 |
| 4. provide strong evidence of the effectiveness of systems-of-care to influence policy/funding decisions by state and local governments and Congress | 2.8 1.0 | 2.6 1.0 | 2.7 1.0 | 3.0 1.0 |
| 5. support a learning laboratory, continuously expanding our knowledge of how to implement effective systems of care | 2.4 0.9 | 2.3 1.0 | 2.3 0.8 | 2.6 1.0 |
| 6. create a public and professional education program, helping to gain ongoing support from all stakeholders | 2.5 0.9 | 2.3 0.8 | 2.4 0.9 | 2.6 1.0 |
| 7. define a model of partnership between local, tribal, state, and federal government | 2.7 1.0 | 2.5 1.0 | 2.7 0.9 | 2.8 1.0 |
| 8. promote systems-of-care practices and values, such as individualized care, cultural competence, and family choice, throughout other child-serving systems | 2.4 1.0 | 2.4 1.2 | 2.3 0.9 | 2.4 1.0 |
| 9. develop/test effective practice-level interventions for children and families | 2.7 0.8 | 2.7 0.8 | 2.9 0.8 | 2.7 0.9 |
| 10. reform financing of services and supports for children with emotional disturbances and their families | 3.6 0.7 | 3.5 0.9 | 3.6 0.6 | 3.6 0.7 |
| 11. reform professional training and human resource development efforts | 3.0 1.0 | 2.9 1.0 | 2.9 1.0 | 3.1 1.0 |
| 12. expand public health approaches related to prevention of emotional disturbances and early identification | 2.7 0.8 | 2.7 0.8 | 2.7 0.7 | 2.8 0.8 |



Three Most Important Strategies (n=127)

Percentage who selected strategy as one of their top three

| Strategy | All 128 | Family 21 | Admin 47 | Others 59 |
|---|------------|--------------|-------------|--------------|
| 1. establish systems of care on a community-by-community basis by continuing the present approach to distributing grants | 15.0% | 9.5% | 19.1% | 13.6% |
| 2. build local and state capacity for developing systems of care | 39.4% | 33.3% | 46.8% | 35.6% |
| 3. support advocacy activities of important stakeholders such as family organizations, youth organizations, minority mental health organizations, & state directors of children's mental health | 33.1% | 47.6% | 21.3% | 37.3% |
| 4. provide strong evidence of the effectiveness of systems-of-care to influence policy/funding decisions by state and local governments and Congress | 37.8% | 14.3% | 48.9% | 37.3% |
| 5. support a learning laboratory, continuously expanding our knowledge of how to implement effective systems of care | 6.3% | 14.3% | 0.0% | 8.5% |
| 6. create a public and professional education program, helping to gain ongoing support from all stakeholders | 12.6% | 28.6% | 8.5% | 10.2% |
| 7. define a model of partnership between local, tribal, state, and federal government | 16.5% | 14.3% | 12.8% | 20.3% |
| 8. promote systems-of-care practices and values, such as individualized care, cultural competence, and family choice, throughout other child-serving systems | 26.0% | 23.8% | 17.0% | 33.9% |
| 9. develop/test effective practice-level interventions for children and families | 16.5% | 14.3% | 21.3% | 13.6% |
| 10. reform financing of services and supports for children with emotional disturbances and their families | 63.8% | 57.1% | 83.0% | 50.8% |
| 11. reform professional training and human resource development efforts | 16.5% | 28.6% | 12.8% | 15.3% |
| 12. expand public health approaches related to prevention of emotional disturbances and early identification | 26.0% | 28.6% | 23.4% | 27.1% |



Transformation Work Group
of the Council on Collaboration and
Coordination of the Child, Adolescent, and
Family Branch, Center for Mental Health Services,
SAMHSA