



FEDERATION OF FAMILIES

For Children's Mental Health

**A Guide to Achieving the Promise:
*Transforming Mental Health Care in America through Advocacy!***

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FOREWORD

"Achieving the Promise," the final report of the President's New Freedom Commission on Mental Health has stimulated fervent discussions about the status of local, state, and national mental health service systems. To move beyond these deliberations, it is crucial for families, youth and other advocates to convert the Commission's goals and recommendations into actions. This TIP sheet is designed to mount momentum for applying such change. The following pages examine key aspects of the Commission's six goal areas and suggest the opportunities they provide for advocacy initiatives. The purpose of this TIP Sheet is to enlist the support of families, family organizations and advocates to "achieve the promise" of a transformed system. We hope you will use these strategies to make the mental health of children and youth a priority in your community, state, tribe or territory!

INTRODUCTION

Though the second goal of the President's New Freedom Commission on Mental Health calls for care to be consumer and family driven, that goal cannot be fully realized independent of the other five goals. A family driven system calls for all six goals to be achieved with full direction and participation of families. The Commission also calls for a wide scale transformation of the mental health system that is geared to the recovery and resilience of children, and youth with mental health problems and their families.

The Commission makes a strong statement that: "services and supports 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" (P. 5). In the report "Achieving the Promise" the Commission states that a transformed system would:

- Build on the child's and family's strengths, growth and choice, not on pathology, system mandates and eligibility requirements;
- Enable children to be successful in school, and to have friendships, families, and jobs;
- Bring effective services and supports to the child and the family so that each child can fulfill his or her potential;
- Eliminate the discrimination, hostility and unfairness that often prevent children and families from seeking help for mental health problems;
- Detect mental health problems early;
- Ensure that families have choices of the types of services they need;
- Ensure that families are full partners in planning, requesting, delivering and evaluating necessary services and supports;
- Build services around the youth, rather than fitting the youth into the existing services;
- Ensure public funding and private insurance to cover the services and supports needed by each youth and family.

What is the New Freedom Commission?

In 2002, President Bush created the New Freedom Commission on Mental Health. The Commission was responsible for an intensive study of the mental health service system for children, families and adults and to provide recommendations to improve the system. The 15-member appointed Commission, included consumers and family members and completed this task in July 2003. The Commission presented its findings and recommendations in the report, *Achieving the Promise: Transforming Mental Health Care in America*. This Tip Sheet relates to the six goals identified in the report and the promises they hold for children, youth and their families.

Goal 1: Americans Understand that Mental Health is Essential to Overall Health.

The following statistics underscore the importance of Goal 1¹:

- Of the 20% of adults and youth who have a diagnosable mental health problem, half have a serious emotional disorder that hinders functioning in at least two domains of their life.
- Over half of youth with mental health disorders do not complete high school because they drop out or are expelled by harsh disciplinary policies. This is more than youth with any other type of disability.
- 10- 13% of preschoolers (ages 1-6 year old) have emotional/behavioral disorders.
- Among adolescents 15-19 years old, suicide is the 3rd leading cause of death.
- Adolescents from minority groups have the highest rates of suicide attempts and the highest levels of unmet need.

It is clear that we have a public health crisis in children’s mental health. Data of such magnitude demand a national campaign and the mobilization of resources to accomplish the goal of achieving overall health. The Commission report calls for widespread, focused public education activities to inform the public and policy makers about mental disorders and how to seek care. It recommends a **national campaign** to reduce the blame and shame of seeking care and to eliminate discrimination and unwelcoming responses. This new environment would help:

- **Families** access timely, appropriate and effective interventions
- **Communities** reduce isolation and fully include children, youth and their families
- **Practitioners** understand the significance of problems experienced by children and youth, and become better prepared to respond to their needs.

TIPS!

Goal 1 can be used to advocate for:

- Youth and family involvement in the development of a comprehensive state health plan that incorporates mental health.
- Policy makers and funding sources to include children, youth, and families in the development and direction of public education campaigns.
- Public messages that are about children and directed to their families, the systems in which they seek help, and the communities in which they live.
- Suicide prevention programs to be provided in locations where youth live, play, work and seek health care.
- Increased training in prevention and risk recognition for families, care providers, educational staff and juvenile justice workers.

Recommendations for this goal also include a **national strategy for suicide prevention**. The National Strategy for Suicide Prevention² was launched through the combined efforts of advocates, clinicians, researchers and suicide survivors. It lays out a framework for action to prevent suicide and guides development of an array of necessary services and programs. Preventing suicide requires the commitment of individuals, practitioners, organizations and communities to identify youth who are in distress and help them connect with the resources they need. Information about this strategy must reach youth and their families, and the communities in which they live.

¹ Details from New Freedom Commission 2003

²www.mentalhealth.samhsa.gov/suicideprevention

Goal 2: Mental Health Care is Consumer and Family Driven.

The Commission calls for a change in the power relationships in the system, elevating the voice and choice of consumers and families. Transformation is dependent on consumers and families acquiring more influence over decisions that affect them individually and that affect the system's overall policies and practices. Families of children with serious emotional disorders know the impact of their child's disorder, experience a high burden of care, and are more personally invested in their successful recovery than anyone else.³ The Commission promotes a family-driven system in which the family's needs and preferences drive the practice, policy and financing decisions that affect them.

Goal 2 puts families in the "driver's seat,"⁴ highlighting family-driven care. Following the Commission's lead, the Federation and the Child, Adolescent and Family Branch of the Center for Mental Health Services have defined "family-driven care" and identified the principles and characteristics for its implementation. According to the definition, "*Family-driven* means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation." Within Goal 2 are several recommendations of critical importance to children, youth and their families.

- **An Individualized Single Plan of Care** is essential for achieving cohesive, continuous, and coordinated services among systems. Children who need multiple services and supports benefit most when services are coordinated and care management and funding are uninterrupted. The Commission recommends legislation for a customized approach called, "Money Follows the Individual" Rebalancing. This demonstration program would allow the Centers for Medicare and Medicaid Services (CMS) to create flexible financing for long-term services and supports. Funds would support the most appropriate and preferred services based on individual need, regardless of where they are delivered.
- **A Broader Array of Services and Supports** will help children, youth, and their families get what they need. While out patient care, residential treatment, and medication management have offered hope for families, it is important to develop and fund additional options. Consumers and families must have a say in the types of services and supports most helpful to them.
- **A Comprehensive State Mental Health Plan** can reduce confusion and address service and financing challenges for children and their families by bringing the multiple service systems together. As states convene this cross-system planning process, families, youth and advocates must be involved to share their experiences in accessing appropriate services and navigating multiple systems, and promote their recommendations for improvement.
- **Protect and Enhance the Rights of People with Mental Illnesses** calls for eliminating the conditions under which parents must relinquish custody so that their children can get mental health treatment. The Commission emphatically calls for federal, state and local governments to work together with provider, family and advocacy organizations such as the Federation of Families for Children's Mental Health to eliminate this cruel practice.

TIPS!

Goal 2 can be used to:

- Advocate for families to determine what family-driven care looks like.
- Organize support for the political action necessary for creating policies and funding that promote family-driven care.
- Guide all systems to adopt policies that support families as full participants in decision making about service delivery and system development.
- Tell policy makers in all systems the challenges families face.
- Encourage states to re-allocate funds that currently pay for inappropriate services toward family-driven and more effective treatment.
- Support legislation and policies that allow families to buy-in to public financing, such as Medicaid when they have no other means of paying for their child's mental health care.

³ Shonkoff and Phillips, 2000

⁴ Osher, 2003

Goal 3: Disparities in Mental Health Services are Eliminated.

Unequal treatment persists for many youth, including those who represent ethnic and racial diversity and those who live in rural and geographically remote areas. The following findings may provide more insight into the significance of this goal:

- Black and Latino youth are less likely to receive specialty mental health care or medications than the general population seeking these supports⁵.
- African American and Latino children have the highest rates of unmet need.⁶
- Asian American and Latino female teens have highest rates of depression with 1 in 5 Latina older adolescents making a suicide attempt.⁷
- Adolescents living in rural areas have a higher rate of suicide than their urban counterparts.⁸
- There is a significantly higher rate of suicide among Native American youth.⁹
- Youth of color continue to be overrepresented in juvenile justice and child welfare with high rates of mental health needs.¹⁰

The Commission calls for eliminating disparities in access, treatment and outcomes for youth who are culturally diverse. Demographic data about the children and youth who receive services from all systems are available to the public. Families and advocates can analyze this data to discover the specific pattern of disparities in individual institutions and their programs, for each local community agency or statewide.

TIPS!

Goal 3 can be used to:

- Advance the collective education, experiences and messages of families with diverse experiences to influence public will.
- Advocate for data regarding disparities that can be effectively used to inform decision-making and service development.
- Institute cultural competence standards in public service contracts, including those for education, juvenile justice and health care services.
- Highlight inequities and promote and model public endorsement of solutions.
- Advocate for outcomes that are clearly defined and culturally significant to the population being served.
- Promote and support the transformation necessary to meet the specific needs of minority and rural populations.
- Promote outreach to and provide incentives for ethnically and racially diverse people seeking to serve children, youth and families.

The implications of economic, geographic, ethnic, linguistic, racial, and cultural diversity of youth and families must be addressed in each one of the Commission's goals. For example, the anti-stigma and national suicide prevention plans described in Goal 1 need to have specific "messages" geared for diverse populations and in various languages. The messages and the messengers who carry them must be carefully chosen to insure they are either universal or geared to specific segments of the population. The State plan described in Goal 2 must address disparities in access to effective services and in outcomes achieved for youth of color and youth in rural areas and designate performance measures that show how well programs are meeting the needs of these populations.

⁵ Kelleher, 2000

⁶ Ringel & Sturm, 2001

⁷ Commonwealth Fund, 1997; NGA, 2005

⁸ IOM, 2002

⁹ ibid

¹⁰ Gibbs and Huang, 2003; Teplin, 2002

Goal 4: Early Mental Health Screening, Assessment, and Referral to Services Are Common Practice.

The Commission calls for a national focus on **screening, assessment and early intervention**. According to the Commission, the national focus will accomplish two things. It will build on coordination mechanisms already in place, such as Part C of the Individuals with Disabilities Education Act (IDEA); and it will expand the coordination of services for children ages 3 through 21 for those who qualify for services under Part B of IDEA, thus building capacity for improved and increased services in communities.

The earlier the recognition of a problem and the earlier intervention is introduced, the better the likelihood of helping the child and preventing more serious problems.¹¹ When thinking about Goal 4, consider the following:

- A promising intervention consisting of depression screening and intervention considerably lowered rates of suicide attempts.
- Appropriate interventions, including academic help, can promote successful educational experiences for youth with emotional and behavioral disorders.
- Brief screening for depression in pediatric settings increases the recognition of early signs of mental health problems and leads to appropriate assessments.
- Screening calls attention to concerns, provides support for preventive interventions such as parent education, parent support, and social skills practice.¹²

Timely and appropriate screening for emotional and behavioral disorders is a tool for helping families make decisions about whether to seek further assessment or treatment. Screening is not an end goal itself. It is the first step in a process that can lead to additional services if they are necessary and helps families better understand their child's development, giving them an opportunity to talk with professionals and seek further information and help if they wish.

Detecting the need for mental health interventions early on is as critical as detecting primary health needs like vision and hearing. Parental consent should be required for all screening, assessment and early intervention services. Results should be kept confidential and provided only to the child's parents.

A coordinated, national approach to these issues will help eliminate social and emotional barriers to learning and will promote success in school and in other community settings for all children. Successful early identification requires collaboration between parents and all the providers who serve them and their child.

TIPS!

Goal 4 can be used to:

- Advocate for the funding & development of appropriate and effective services.
- Ensure that screening occurs in natural settings such as schools and health clinics.
- Include "social and emotional check-ups" in primary health care.
- Institute methods for timely inclusion of youth and families in all decision-making and information sharing.
- Increase workforce and family involvement skills of people treating young children and their families.
- Train primary health providers to screen for and recognize early signs of emotional and behavioral issues and to offer referrals for accessing professional evaluations and appropriate interventions.

¹¹ Webster and Taylor, 2001

¹² New Freedom Commission, 2003

Goal 5: Excellent Mental Health Care is Delivered and Research is Accelerated.

There are two parts to this goal. The first recognizes that the quality of mental health care provided to children and youth is generally lacking and could be significantly improved. The second looks to an acceleration of research to insure better treatments, interventions, services, and supports are available.

The quality of mental health care depends on the availability of a well trained and culturally competent workforce that is deployed strategically throughout the country so **excellent mental health care** is delivered to every child no matter where they live or their family's ability to pay for mental health care.

Acceleration of research to define effective prevention and treatment interventions for emotional and behavioral disorders in children is intended to shrink the 15-17 year gap between research and the development of new, effective treatments and their implementation. This timeframe equates to a complete "childhood", a fact that makes the force for this acceleration even more compelling! There is an immediate urgency to the work of developing effective treatments for children, youth and their families.

TIPS!

This goal can also be used to:

- Advocate for research about mental health treatments, services, and supports for children, youth, and families.
- Hold providers accountable for effective care and the commitment to use effective interventions.
- Shape the research agenda; just as care must be family-driven, research must address the questions of priority to families. Families can use this goal to advocate for research that is defined by their needs, concerns and priorities.
- Promote family-driven research and encourage researchers to partner with families on studies of service effectiveness.
- Distribute research results to families in useable form.

TIPS!

Goal 5 can be used to:

- Support personnel training programs that prepare individuals to work in children's mental health. Training programs should develop skills for working in partnership with families and in accordance with the values and principles of systems of care.
- Advocate for expansion of systems of care.
- Advocate for parity and the Family Opportunity Act. (www.congress.gov)
- Promote the expansion and use of telemedicine to enable high quality specialist to serve children in remote areas.

For many children's emotional and behavioral problems, there are interventions or combinations of interventions that have been shown to be effective or promising. Children, youth and families are entitled to the best interventions available. So they can be good consumers who make well-informed decisions about their care.

There are many intervention, services, and supports that families and providers have found to be helpful that have not been the subject of rigorous research. Research about the effectiveness of specific mental health interventions including clear descriptions of the population(s) that can and cannot benefit from them is needed.

Goal 6: Technology is Used to Access Mental Health Care and Information.

Family Access to Information and Support is integral to a system of family-driven care. Families want and need relevant and cutting-edge information about diagnoses, symptoms, treatments and supportive services relevant to their child's mental health. Conversely, and equally important, families seeking care would like technology to assist others in being better able to effectively and efficiently serve them.

However, this information is often difficult to access in a timely manner. The Commission proposes technology information and support that gives families (1) ready access to information about best practice models, scientific research, relevant health information, and available services and supports and (2) a personal electronic health record that integrates behavioral health data from multiple systems and sources to support decision-making regarding their child's care. Electronic data systems and enhanced communication between informed family members and behavioral health care providers can lead to better decisions and treatment planning for children.

This goal also recommends use of technology to *deliver* care. Through tele-health care, people are able to receive services that would otherwise be unavailable or unaffordable. A study of Arkansas' Rural Hospital Telehealth Project found that 41 percent of patients who use telemedicine services would not have been able to see a doctor because of doctor shortage and travel costs.¹³

Technology permits local providers ready access to vital health information from one another and from state, regional and inter/national experts. With a patient's informed consent and when high standards of confidentiality are maintained, on the spot exchange of information and expertise enhances treatment decisions. The capacity to reach beyond local expertise also permits health care providers to support their customers in a language they understand, in a manner that reflects their culture and respects their choice.

Technology supported services reduce the amount of time spent on travel, in waiting rooms, and away from school and work. They can eliminate costly travel and lengthy stays away from home to seek specialized services. Youth who are unable to physically attend school can participate with the aid of technology.

Growth in the use of technology will help us access specialized treatment despite a shortage of health care providers; increase productivity in the workplace; prevent provider burnout; and provide cost savings for customers!

TIPS!

Goal 6 can be used to:

- **Determine that information for families be made available in multiple formats (written, audio, video teleconferences) to accommodate the various needs of families.**
- **Provide families and family-run organizations with access to cutting edge technology, including internet access to web based training and information.**
- **Fund family-run organizations to prepare and disseminate critical information to families in useful and usable formats.**
- **Increase timely access to peer support, resiliency building and recovery strategies.**
- **Insist that electronic medical records are maintained in the strictest confidentiality.**
- **Advocate for resources to establish or improve telemedicine availability.**
- **Expand tele-options for workplace, school and day care settings.**

¹³ 2005 ATA annual meeting

CONCLUSION

The New Freedom Commission report provides a critical tool for advocacy! It gives us a unique and important opportunity to achieve public endorsement to propel changes in mental health care - an arena that is often hidden from most Americans. Through a set of six goals and 19 specific policy recommendations, the Commission calls for an overhaul of the system, including its values, organizational structure, and its use of human and fiscal resources. With the backing of a presidential Commission, families and other advocates have a chance to capture the attention of national, state and local leaders.

Nationally, key stakeholders have embraced the report and are using it to frame their advocacy efforts, including:

- The Substance Abuse Mental Health Services Administration (SAMHSA), along with 19 other federal agencies, has created the Federal Action Agenda to implement first steps in transformation. To learn more, visit http://www.samhsa.gov/Matrix/matrix_mh.aspx
- The Campaign for Mental Health Reform, a coalition of 16 national mental health advocacy groups including the Federation of Families for Children's Mental Health, has issued *EMERGENCY RESPONSE: A Roadmap for Federal Action on America's Mental Health Crisis*. This document is available at www.mhreform.org.

TIP!

- **The transformation that is vital for serving children and youth will only occur through the leadership and advocacy of families!**

Families have had and will continue to have a vital role in these and other advocacy efforts. Families repeatedly testified before the Commission. Their voices were heard and their ideas incorporated into recommendations to change "business as usual." The report acknowledges that families are key to transformation!



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