

**SYSTEMS-BASED PRACTICE
FAMILY-DRIVEN, YOUTH-GUIDED CARE
Revised January 2020**

**SYSTEMS-BASED PRACTICE FAMILY-DRIVEN, YOUTH-GUIDED CARE
OBJECTIVES***

Knowledge:

- 1) List the “New Rules” for a 21st Century Health Care System endorsed by the Institute of Medicine that specifically support the practice of family-driven, youth-guided care.
- 2) Define family-driven, youth-guided care.
- 3) Explain the guiding principles of family-driven, youth-guided care.
- 4) Discuss the differences between provider-driven and family-driven, youth-guided care.
- 5) Describe the difference between “professional” and “experiential” knowledge, and how they complement one another.
- 6) List examples of family support services.
- 7) List major national and local family/consumer organizations advocating on behalf of youth with mental health needs.
- 8) Describe the component steps of the wraparound process.
- 9) Discuss the role of the child and adolescent psychiatrist in family-driven, youth-guided care, and in advocating for safe, quality care.

Skills:

- 1) Elicit information about youth and family strengths, traditions, and culture in the evaluation process, and be able to use this information to engage the youth and family and develop strong therapeutic relationships.
- 2) Incorporate youth, family and community strengths and culture into formulations and treatment recommendations.
- 3) Demonstrate the ability to work within a wraparound, or team planning process.
- 4) Work with families as partners: include family members in decision-making when providing psychiatric evaluations, creating treatment plans, and prescribing and monitoring psychotropic medication.
- 5) Work with families and family organizations in advocacy and training activities.
- 6) Create treatment plans that are individualized and strengths-based for the particular youth, family and community.

Attitudes:

- 1) Adopt respectful attitudes of “family voice and choice,” “nothing about us without us,” and “no shame, no blame” when working with families.
- 2) Appreciate that youth and family members have strengths that should inform and support treatment goals.
- 3) Appreciate that youth and families have expertise in identifying and prioritizing their needs.
- 4) Embrace a treatment perspective that involves shared decision-making and shared responsibility with youth and family.
- 5) Demonstrate a readiness to advocate for and with the youth and family.

***Appendix 1 describes the systems-based practice competency in the RRC Program Requirements.**

TABLE OF CONTENTS

Overview	3
Knowledge of the Larger Context and System of Health Care	4
Use of Resources within the System to Provide Excellent Patient Care	7
Knowledge of Patient Safety and Advocacy and the Role of the CAP	12
Conclusion	15
Appendix 1	16
Appendix 2	17
Appendix 3	19

OVERVIEW

Family-driven, youth-guided care is a core concept in systems-based practice and is an essential framework for all the child serving systems. Child and adolescent psychiatrists need to understand family-driven, youth-guided care in order to achieve competence in systems-based practice because **the principles of family-driven, youth-guided care are embedded in the system of care (SOC) approach, which has been the major federally funded framework for improving children’s behavioral health over the past 20 years.**² The values and principles of SOC approach underlie family-driven, youth guided care, as will be reviewed.³ Moreover, several key principles of family-driven, youth-guided care are explicitly endorsed by the Institute of Medicine in the “new rules” for a 21st Century Health Care System that informs current federal healthcare reform legislation⁴:

- Care is based on continuous healing relationships
- Care is customized according to (youth and family) needs and values.
- The patient (family of the patient and the youth) is the source of control.
- Knowledge is shared and information flows freely.
- Transparency is necessary.

Family-driven care means families have a primary decision 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. Family-driven care was explicitly identified and highlighted as a core concept in the report of the President’s New Freedom Commission on Mental Health,⁵ which was “designed to advance the community-based service delivery system built on efficiency and demonstrably effective practices.”⁶

The term “family-driven” has been expanded to include “youth-guided” in the document “System of Care Values and Principles Updated,”⁷ in explicit recognition of the importance of the youth’s input and engagement in services he or she receives. Youth-guided means that while youth are minors and have not reached the age to consent for treatment, nevertheless the youth’s voice and choice are essential in helping to determine the care received at both the individual and systems levels. Youth-guided care can be difficult to achieve at the systems level, but has now been explicitly identified as important in federal and state policy. A national organization called Youth Motivating Others through Voices of Experience (Youth MOVE) is supported by the Substance Abuse and Mental Health Services Administration (SAMHSA) in Washington DC,

and in their beginning stages were assisted by the National Federation of Families for Children's Mental Health (FFCMH). There is now a dedicated Family and Youth Section within the American Academy of Child and Adolescent Psychiatry website (<http://www.aacap.org/cs/youth>).

At the level of the individual youth and family, it is necessary for the child and adolescent psychiatrist (CAP) to support youth in obtaining “voice and choice,” which are key elements of active participation and empowerment within the treatment process. CAPs need to have a positive relationship with youth, especially as they get older, in order to develop and maintain a therapeutic alliance in relation to multiple aspects of psychiatric treatment. Even in the presence of parental consent, psychotropic medication is unlikely to be accepted or be helpful if the youth is actively opposed to its use. The CAP needs to engage the youth and learn about the youth's concerns, goals, and priorities. The CAP also needs to elicit youth beliefs, attitudes and concerns about psychotropic medication, with the CAP listening carefully. Only within such a context is it likely that education and a meaningful discussion can ensue, giving rise to the possibility that the youth, either immediately or over time, may agree to a trial of medication or other treatment recommendations. In like manner, youth engagement is essential in determining the overall direction of mental health treatment and developing a specific treatment plan.

Not infrequently, the focus on the youth's dangerous behaviors by the larger system is not accompanied by sufficient attention to the underlying thoughts and feelings of the youth that may have helped shape the behaviors of concern. The CAP is highly qualified and positioned to help youth enhance their capacities to identify their needs and strengths and determine how best to address the needs while building on the strengths.

While family-driven, youth-guided care is embedded in the core competency of systems-based practice, elements of family-driven, youth-guided care as described below are also important in informing competence in additional ACGME core competencies, including patient care, interpersonal and communications skills, and professionalism.

It is strongly recommended that, whenever possible, this module be taught collaboratively with parents and youth in order to model family-professional partnership. Parents and youth with training in family-driven and youth-guided care may be recruited from local family and youth organizations.

In the discussion that follows, key issues to be addressed include the following:

- The definition and guiding principles of “family-driven, youth-guided” care.
- The need for partnership involving professionals with youth and families, based on the concept of complementary expertise (professional expertise vs. lived expertise)
- The definition of and principles for “family support.”
- The nature of the “wraparound” planning process, and how the CAP can promote it.
- Different roles for the CAP in family-driven, youth-guided care, to promote safety in treatment and in the larger system.

I. KNOWLEDGE OF THE LARGER CONTEXT AND SYSTEM OF HEALTH CARE

Family voice determines family-driven, youth-guided care. Families must be central in defining family-driven, youth-guided care. Much of the content for this module is derived from families and taken directly, with permission, from *Shifting Gears: A Curriculum Guide to Family Driven Care*, a CD produced by the Federation of Families for Children's Mental Health (FFCMH).⁸ FFCMH offers the following definition of family-driven care:

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. This includes:

- Choosing supports, services, and providers;
- Setting goals;
- Designing and implementing programs;
- Monitoring outcomes;
- Partnering in funding decisions; and
- Determining the effectiveness of all efforts to promote the mental health and well-being of children and youth.

Guiding Principles of Family-Driven, Youth-Guided Care

- Families and youth are given accurate, understandable, and complete information necessary to set goals and to make choices for improved planning for individual children and their families.
- Families and youth, providers, and administrators embrace the concept of shared decision-making, meaning decisions are made jointly by parents and providers, and there is shared responsibility for outcomes.
- Families and youth are organized collectively to use their knowledge and skills as a force for systems transformation.
- Families and family-run organizations engage in peer support activities to reduce isolation, gather and disseminate accurate information, and strengthen the family voice.
- Families and family-run organizations provide direction for decisions that impact funding for services, treatments, and supports.
- Providers take the initiative to change **treatment decisions** from provider-driven to family-driven.
- Administrators allocate staff, training, support and resources to make family-driven practice work at the point where services and supports are delivered to children, youth, and families.
- Efforts to change community attitudes focus on removing barriers and discrimination created by mental health stigma.
- Communities embrace, value, and celebrate the diverse cultures of their children, youth, and families.

- Everyone who works with children, youth, and families continually advances their own cultural and linguistic responsiveness, as the populations served change over time.

As with cultural competence, the principles of family-driven care should inform all aspects of systems-based practice. Common expressions embraced by families and youth consistent with family-driven, youth-guided care include the following:

- ***Nothing about us without us:***
“Nothing about us without us” means that while professionals must be able to have communication with each other that do not include parents and youth, decisions regarding care planning are not made without direct involvement of the parents and when appropriate, youth.
- ***Youth and family voice and choice:***
In order to truly have “voice” in determining the care they receive, families need the opportunity to choose between different options for care. Developing options for choices in care is an important responsibility of the CAP.
- ***No shame, no blame.***
“No shame, no blame” applies equally to the response of professionals to family members and vice versa. In order to promote and sustain engagement of families and providers, accountability and limit setting must occur without recrimination or blame.

The need for family-driven, youth-guided care is well summarized by the following statement from the FFCMH⁸:

Families, youth consumers, and family oriented practitioners echo the findings and recommendations of the (President’s New Freedom) Commission. They know that outcomes are better when families have a key voice in decision-making.

Families know what works for them. Therefore, it makes sense that they drive service delivery decisions. Their experience is holistic. In other words, they do not have a mental health part, a child welfare part, a juvenile justice part, and so forth. Families focus on the concrete challenges that they face all day and every day. Families also know their strengths and their limitations. Families know the difficulties they face. Families can see change in how they or their child are doing on a daily basis. They know how a program, agency, or system works (or doesn’t work) for them. Most importantly, without family comfort and buy-in, children and youth won’t participate in services. Also, family voices are listened to by politicians and public officials. Their passion and persistence are necessary to transform mental health services.

The question arises for **CAPs** and for other mental health professionals working with families: What does family-driven, youth-guided care look like in actual practice, and how are the principles of collaboration and reciprocity operationalized? Appendix 2 identifies appropriate

expectations for parents in their interactions with mental health professionals, and appropriate expectations for mental health professionals in relation to parents, which in combination help create and sustain a context of mutual respect and reciprocity.

There are significant differences between a *provider-driven* and a *family-driven* system.⁹ These differences are significant enough to constitute a paradigm shift in service delivery. The table below contrasts provider-driven and family-driven care according to key system parameters.

Paradigm Shift in Service Delivery Systems for Children and Youth with Emotional Disturbance

	Provider-Driven	Family-Driven
Source of Solutions	Professionals and agencies	Child, family, and their support team
Relationship	Child and family viewed as a dependent client expected to carry out instructions	Partner/collaborator in decision-making, service provision, and accountability
Orientation	Isolating and “fixing” a problem viewed as residing in the child or family	Ecological approach enabling the child and family to do better in the community
Assessment	Deficit oriented	Strengths based
Planning	Based on agency resources	Individualized for each child and family
Access to Services	Limited by agency’s menus, funding streams, and staffing schedules	Comprehensive and provided when and where the child and family require
Outcomes	Based on agency function and symptom relief	Based on quality of life and desires of child and family

II. USE OF RESOURCES WITHIN THE SYSTEM TO PROVIDE EXCELLENT PATIENT CARE

A. “Professional” and “Experiential” Expertise Complement Each Other: Partnerships between Child and Adolescent Psychiatrists and Family Members

Family members, both parents and youth, have strengths that can guide and support desired treatment goals. It is important to recognize the value of “experiential expertise” as a complement to the more commonly recognized “professional expertise” when working with families as partners in service planning and delivery.

Professional expertise comes from formal education and training including scientific sources such as research, books and articles, as well as clinical experience.

Experiential expertise comes from the lived experience of the youth and family. It informs the treatment process on what it is like to live in this specific family and with this specific youth, in this specific community. Experiential expertise also encompasses the

first-hand knowledge that family members have about their strengths and past successes, their belief systems and culture, their priorities, and specific needs that might not be known by someone external to the family.

Child and adolescent psychiatrists should gather information about youth and family strengths, traditions, and culture in the evaluation and treatment process.

Knowledge of this information is essential in order to develop an individualized, strengths-based formulation and care plan and to promote optimal youth and family partnership in treatment.

Family and youth voice is also important at the system level, not just the individual youth and family service level. In a system of care that is truly family-driven and youth-guided, family members, including youth participate as members on oversight and policy making bodies. Family-run organizations offer leadership training for parents and family members to understand and fully engage in policy making roles. Family/consumer organizations provide multiple resources for supporting child mental health treatment at the youth and family level, as well as research and advocacy at the systems level.

B. Family Support

Family support may be provided by a community, county, state or specific service system, and may also be provided by a family-run organization. The availability of family support can enable a family to persevere during a challenging time, become more informed about the challenge at hand and how to address it, and in general feel supported by others. As a result, families and youth are better able to participate actively in treatment and work as partners with providers.

Family support within family-driven, youth-guided care is defined as follows⁸:

Family support is a constellation of formal and informal services and tangible goods that are defined and determined by families. It is “whatever it takes” for a family to care for and live with a child or adolescent who has an emotional, behavioral or mental disorder. It also includes supports needed to assist families to maintain close involvement with their children who are in out-of-home placement and to help families when their children are ready to return home.

The table below identifies some of the common family support services and supports that can make a significant difference in the lives of youth and families. Note the broad range of family support identified, some of which involves education, peer support, concrete services, and an overall orientation towards flexibility and individualized care.

FAMILY SUPPORT SERVICES INCLUDE BUT ARE NOT LIMITED TO THE FOLLOWING COMPONENTS
Family self-help, support, and advocacy groups and organizations
Information and referral
Education that will support families to become active, informed decision-makers on behalf of their family and their child
Advocacy with and behalf of the family, if needed
Capacity to individualize, provide flexible support services, and meet unplanned needs quickly and responsibly
In-home and out-of-home respite care, with an emphasis on neighborhood and community participation for the child, and conceptualized not as a clinical services but as a support for the whole family
Cash assistance: “flexible funding”
Assistance with family survival needs (housing, food, transportation, home maintenance, etc.)
Other supports as determined by the family

The services listed above need to be supported by specific principles. These principles are consistent with the family-driven, youth-guided principles discussed above, which also comprise system of care principles.

PRINCIPLES FOR FAMILY SUPPORT
Decisions must be based on a family’s preferences, choices, and values rather than administrative expediencies.
Families must be recognized as the primary resources and decision-makers for their child.
Families must have access to a flexible, affordable, individualized array of supports, services and material items that provide “whatever it takes” to maintain the family unit.
The family’s strengths, including the social networks and informal support already available to and within the family, should be the foundation upon which new supports are designed or provided. Furthermore, if the family wishes it, family support services should help to expand and strengthen the informal resources available to the family.
Support services must be culturally and geographically sensitive and able to meet the diverse needs of families.
Family supports must be affordable, well-coordinated, accessible, and available to all families who need them, when and how they need them.

Family supports are promoted and sustained by family organizations, and also by communities and local systems of care. Major family/consumer organizations, with national presence and local chapters, are in Appendix 3, along with their web sites. They are sources of considerable information for both professionals and family members. Family supports include parent peer support providers, youth peer support providers and adult or consumer peer support providers. Parent peer support providers are parents who have lived experience with raising a child with serious mental health challenges. Youth peer support providers are young adults who preferably have lived experience with having serious mental health challenges. Adult or consumer peer support providers are adults who have lived experience with serious mental health challenges.

C. Care Planning for Children and Youth with Mental Illness

A common practice in children's mental health is to develop mental health care plans for children and youth with a mental illness who have several healthcare and/or other child-serving professionals working with them and their families. A care plan explains the supports provided by each of those professionals and when treatment should be provided. The care plan also includes what to do in a crisis or to prevent further deterioration.

D. Wraparound Process

The principles of family-driven, youth-guided care are operationalized by the **wraparound process**. This is an approach to care planning for youth with more complex behavioral health needs and their families that prioritizes family voice and the use of natural supports (i.e., nonprofessionals who support the family such as extended family, friends, church members, etc.), and not just traditional professional services in the process.

Federal Medicaid (Centers for Medicare and Medicaid, CMS) supports reimbursement specifically for high fidelity wraparound, referred to as "intensive care coordination" by CMS, along with other "intensive home and community-based services," such as in-home therapy and youth mobile crisis intervention. Eligibility for in-home services and for the wraparound team planning process service is based on medical necessity, as defined by the child or adolescent having a "serious emotional disturbance" (SED), which briefly is defined as having a DSM diagnosis and serious functional impairment in two or more domains (home, school or community that has lasted a year or more, or would be expected to last for at least a year without intervention. While other forms of this service planning exist, they all rest on the priority given to family "voice and choice."⁸

Family and youth/child perspectives are intentionally elicited and prioritized during all phases of the wraparound process. Planning is grounded in family members' perspectives, and the team strives to provide options and choices such that the plan reflects family values and preferences.

The youth and family care planning team, or wraparound process, involves developing a team of people with complementary strengths who are committed to improving the mental health of the identified youth. The team is facilitated by a care coordinator who has had training specific to supporting wraparound service planning. This planning process, which can effectively complement the use of traditional community-based providers and evidence-based treatments for addressing mental health challenges, involves a four-stage process: 1) engagement and team preparation; 2) initial team meeting and plan development; 3) meeting follow-up and ongoing plan implementation; and 4) transition. Care coordinators and family partners should work with at most 10-14 wraparound teams at a time, given the intensive nature of this model of serviced planning.

The Wraparound Planning Process:

1a. Engagement and Team Preparation: Pre-meeting preparation of the family

- Initial engagement and mutual orientation as well as safety planning by the family with a care coordinator and, when available, a parent per support provider and a youth peer support provider.
- Culture, strengths and needs discovery, and development of a vision for the youth and family for how they will know that their situation is better.
- Review team meeting format, including “no shame, no blame.” Discuss concerns and positive previous experiences with providers. Discuss how to handle sensitive information.
- Establishment of the priorities the youth and family have regarding needs or problems to address first.
- Addressing of any crisis in need of immediate attention, when applicable.

1b. Engagement and Team Preparation: Pre-meeting preparation of all other team members

- Get a sense of provider hopes and concerns for their work with the family.
- Communicate the importance of the family’s desire to have them participate.
- Discuss the format, especially regarding “no shame, no blame.”
- Ask for a summary of history and other information on the child’s status ahead of time, with family informed consent.
- Review options for input by team members, even if direct participation is not possible.
- Information regarding the youth and family may be discussed without the presence of the youth or family, but no decisions regarding the treatment plan/plan of care can be made without the participation of the family/legal guardian.
- Preliminary conversations between professionals can help them sort out their own interface issues without further burdening the family when the team meeting occurs.

2. Initial Team Meeting and Plan Development

- Family members identify the domains to be addressed (e.g. housing, employment, legal, transportation, school, emotional, behavioral, etc.).
- Needs and strengths in the youth, family and community for the domain chosen are identified.
- Input from team members unable to attend is included.
- Options are generated to meet the needs, ideally building on strengths.
- A plan of care is developed, settling on the best options and identifying *who* will do *what* by *when*.

3. Meeting Follow-Up and Ongoing Plan Implementation

- Care coordinator is responsible for tracking outcomes from the plan of care and supporting accountability.
- If progress is not made, the assumption is that the plan of care needs to be revised, not that the youth or family or provider is to blame.
- The youth and family team continues to meet, frequency weekly to monthly until the family's vision is achieved or the family chooses to withdraw.
- The team should follow the youth through different levels of care to provide continuity (IOM "rule" that prioritizes continuous healing relationships).

4. Transition

- When the vision of the family and the team plan have been achieved, the team supports a transition to the family maintaining future care coordination, to include natural supports as well as formal services.
- The transition process, with ample preparation for the family, leads to the cessation of wraparound, with a clear plan for continued family functioning in place.

An organizational infrastructure is necessary to support the youth and family team/wraparound care planning process. This infrastructure includes the following:

- Training, coaching, and supervision for wraparound staff, including the care coordinator.
- Administrative support including flexible funds to help support costs in the plan of care that insurance will not cover (e.g. respite care, transportation costs, etc.) and data tracking for continuous quality improvement.
- Support by the leadership of various child-serving systems, so that system representatives can participate in the wraparound process.

High fidelity wraparound has become established as an evidence-based practice by the influential Washington State Institute for Public Policy. To date, there have been nine controlled published studies of wraparound, seven of which found consistent and significant outcomes in favor of wraparound compared to control groups across outcomes domains—most prominently reduced use of residential placement, improvement of symptoms, decreased recidivism, and improved community and school functioning.¹⁰ Furthermore, Snyder et al.¹¹ found in their study of youth with serious emotional disturbances in Georgia that there was a reduction of \$1,130 in monthly health care spending in the treatment group as compared to the control group the year after the youth completed the wraparound process. These spending reductions were the result of decreases in mental health inpatient spending and general outpatient spending. For more information and materials on high fidelity wraparound go to the National Wraparound Initiative web site at www.rtc.pdx.edu/nwi.

III. KNOWLEDGE OF PATIENT SAFETY AND ADVOCACY AND THE ROLE OF THE CAP

Knowledge of patient safety and advocacy are two competencies stressed within the general competency of Systems-Based Practice. “Rule” 6 in the IOM *Crossing the Quality Chasm* states “Safety is a system property,” meaning that the Hippocratic Oath “Above all else, do no harm,” belongs not just to the individual physician, but to the system of care as a whole.⁴ In what follows, challenges to patient safety and quality are identified, and key roles of the CAP in advocacy and the promotion of safety and quality are discussed.

A. The Role of the CAP in Modeling Collaboration and Promoting System Coherence

Families of youth with severe emotional disturbances (SED) are very often interacting with multiple individuals and service systems concurrently. Coordinated, respectful and collaborative communication between system partners can promote youth and family hopefulness and investment in service and support participation. This is accomplished through first-person language, taking a partnership approach with youth and families in treatment, recognizing the expertise and strengths of youth and families as part of the intervention process. Conversely, systems that do not communicate adequately or communicate in a conflicted and contradictory manner can exacerbate family stress, often ending up causing harm.

CAPs have a leadership responsibility to model collaborative, respectful interactions with other involved system partners. In addition, whenever possible, the CAP can also help involved system representatives move toward a common understanding of the youth and family, so that the care plan is cohesive and coherent. In this way, the CAP helps to reduce system-induced stress while enhancing a sense of mastery for youth and family to experience a sense of mastery, leading to increased family hopefulness and trust.

B. The Role of the CAP in Educating Youth and Family about the Disorder, the Psychiatric Care, and the Larger System

When confronted by emotional and psychiatric disorders in their children, parents often experience intense confusion, anxiety, fear, and often grief. They lack adequate or appropriate information to understand mental health problems and to obtain appropriate, effective services.¹² Under such circumstances, problems may go unaddressed for an extended period of time, and opportunities for early intervention may be lost. In addition, as the severity of the challenges increase, family discouragement, blaming, and isolation within and outside the family may occur.

CAPs have an advocacy responsibility to educate youth and families regarding the psychiatric disorder, recommended psychiatric care, and the larger system, so that knowledge is acquired, along with a greater awareness of options and support, as well as how to take an active role in treatment and effectively navigate the system. To be family-driven in your approach means to provide the family with the information and options so

they may choose the path that best fits their family. CAPs inform, discuss pros and cons of the options and assist them in weighing these options. In addition to general discussion, the CAP should provide access to other sources of information including the internet, handouts and other printed material, and contact information for family organizations in order to promote shared decision making with the youth and family. CAPs should look especially for opportunities to engage in advocacy in partnership with caregivers and youth.

C. The Role of the CAP in Promoting Continuity of Relationships for the Youth with the Family

The first rule of *Crossing the Quality Chasm* is: “Care is based on continuous healing relationships.” Although conflict may at times occur within a family, the parents or legal guardians have an essential role in maintaining the well-being of the youth and promoting his or her emotional growth and healing. Conversely, disrupted attachments, as occurs with multiple out-of-home placements, can be harmful to the health of the youth. Short-term emergency responses, such as repeated hospitalizations or acute residential treatment, while at times necessary for safety, must be balanced against the potential for long-term harm caused by disrupted attachments between the youth and parents, further exacerbated by the disruption of community-based relationships with providers that follows out-of-home placement. Another important issue is the family involvement in treatment with youth of transition age for many reasons including their historical knowledge but also because the family is frequently the default safety net for their youth/young adult. It is vital that the CAP have this discussion with the youth/young adult regarding the possible ways for family members or parents to be included in treatment.

Therefore, the CAP can play an important role in supporting the capacity of family and community-based services and supports to promote the healing of the youth, to maximize the impact of continuous healing relationships embedded within the family and community-based providers and natural supports.

D. The Role of the CAP in Ensuring a Full Array of Services for Youth

Even though it may often be in the best interest of youth to remain with their family in the community, therapeutic out-of-home placements – including specialized foster care, acute psychiatric inpatient, or mental health residential treatment – do provide a safety net for youth at risk and their families. There can be pressure on state and federal health and human service agencies to promote expansion of intensive home and community-based services at the expense of maintaining support for therapeutic out-of-home placement necessary for the safety net. The “Building Bridges Summit” convened by the Substance Abuse and Mental Health Services Administration (SAMHSA) to look at the role of residential and hospital care in the system of care, highlights the need for these levels of care to become more closely aligned with the recommendations of the President’s New Freedom Commission on Mental Health report and promote active youth and family participation in care.⁵ More information on the Building Bridges

Initiative is available at:

<http://www.tapartnership.org/docs/presentations/socMeetingSummer2011/day1/Workshop%2030-%20The%20National%20Building%20Bridges%20Initiative/The%20National%20Building%20Bridges%20Initiative.pdf>.

Given the ongoing importance of residential and hospital care, **CAPs can advocate for the continued availability of these out-of-home options as a necessary resource within the SOC. The CAP can also help these levels of care embrace the same family-driven, youth-guided philosophy that increasingly characterizes community-based care.**

E. The Role of the CAP in Ensuring Youth and Family Voice and Choice

Perhaps the greatest risk of treatment failure involves the silencing of youth and families. When opportunities to participate are undermined and efforts to verbalize needs and priorities are disqualified, engagement becomes unlikely and motivation decreases. Unfortunately, such processes have occurred in mental health too often in the past, and may help account for the low retention rate in community-based care and less-than-optimal outcomes in the past. Youth, as with parents and legal guardians, are much more likely to participate in treatment if they experience their input as valued and carefully considered by others, and see that their input helps guide the treatment plan that is developed.

CAPs should be certain to advocate for voice and choice of the youth and the families with whom they work. With youth, this involves helping them to articulate and bring forward their ideas to those with whom they interact. Child psychiatrists have unique training to understand processes that empower and mobilize others, and need to draw on this understanding as a catalyst for youth and family participation, both in clinical treatment and at the systems level.

Advocacy efforts by child and adolescent psychiatrists at the systems level should also be linked to similar efforts by family-run organizations, whenever possible. This partnership in advocacy is much more effective than advocacy in the absence of sustained family/consumer involvement.

F. Challenges and Opportunities in Providing Wraparound Service Planning

Not all states identify intensive care coordination in their state Medicaid plan or otherwise make this team planning process available. As a result, this resource is not available in every state. It is uncommon for commercial insurance to reimburse for wraparound service planning. Even when it is available, the inertia of a provider-driven system can be difficult to overcome, and sufficient training and ongoing coaching and supervision to support high fidelity wraparound may not be supported. Nevertheless, even when reimbursement for high fidelity wraparound/intensive care coordination is

absent, the tenants of family-driven, youth-guided care can be supported by CAPs within other models of service planning, as noted below.

Within the framework of family-driven, youth-guided care, the CAP strives to understand the needs, strengths and vision of the youth, while paying close attention to the youth's verbal and non-verbal communications, within an ecological, culturally sensitive context. CAPs can have an important role in promoting collaborative teamwork between providers and the family even if formal "wraparound" service planning is not available, by modeling behaviors consistent with system of care values and principles such as "no shame, no blame" and "nothing about us without us." In addition, maintaining hopefulness through a strengths-based approach also promotes High Fidelity Wraparound values.

Opportunities for a family-driven, youth guided care planning process are increased within current health care reform, in which payment reform within Accountable Care Organizations (ACO) supports both care coordination and the integration of behavioral health into the Patient-Centered Medical Home. For more detail, see the module on Administration and Finance.

CONCLUSION

The field of mental health is changing in its growing support of "family-driven, youth-guided" care within the system of care approach to care. Other child-serving systems, including child welfare, juvenile justice, primary care, and education are also embracing a philosophy consistent with this approach. There are many significant benefits to such an approach for the family, the youth and the CAP. CAPs have an opportunity not only to embrace this approach, but also to provide leadership in support of its implementation. Such efforts will build stronger alliances with youth and families, and also improve the quality of services and the treatment planning process.

APPENDIX 1

Residents must demonstrate an awareness of and responsiveness to the larger context and system of health care, as well as the ability to call effectively on other resources in the system to provide optimal health care. Residents are expected to:

IV.B.1.f) Systems-based Practice. Fellows must demonstrate an awareness of and responsiveness to the larger context and system of health care, including the social determinants of health, as well as the ability to call effectively on other resources to provide optimal health care. (Core)

* Accreditation Council for Graduate Medical Education. Program Requirements for Residency Education in Child and Adolescent Psychiatry.

https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/405_ChildAdolescentPsychiatry_2019_TCC.pdf?ver=2019-03-28-161025-277. July 1, 2019.

APPENDIX 2

RECIPROCAL PARENT-PROFESSIONAL EXPECTATIONS

Gordon R. Hodas, M.D.¹³

I. WHAT PARENTS SHOULD EXPECT FROM PROFESSIONALS:

- Constant affirmation that the family is the primary source of care for the youth (instead of ‘child’ – we used ‘youth’ everywhere else in the document, and that the professional is a consultant to the family).
- Respect – for the individual, cultural, and ethnic uniqueness of the youth and family, with the presumption of competence and positive intentions by the youth and family.
- Demonstration of authentic interest and caring.
- Support for parents or legal guardians in their role as primary caregivers of the youth.
- Opportunity for parents to share information and be listened to.
- Opportunity to identify priorities that are incorporated in the youth’s treatment plan.
- Opportunity to participate actively in planning, decision-making, implementation, and monitoring of care.
- A cohesive team process (including convening a child and family team, when indicated), with communication among service providers and with family.
- Access to quality mental health services that are welcoming and youth and family-friendly.
- Referrals to appropriate natural resources and family support.
- Referrals for advocacy and information, including books, web sites, and organizations.
- A thorough evaluation of the youth by evaluator.
- A clear and thorough explanation of diagnosis and related information, with collaborative discussion of implications for treatment, both verbally and in written report.
- Consideration of possible indications for psychotropic medication, with explanation of rationale and expected outcomes, when medication is recommended.
- Acknowledgement by providers of their professional limitations, when relevant.
- Following through on agreements reached collaboratively, and maintaining professional accountability.
- Respect for confidentiality concerns, as guided by regulations and identified by the family.
- The ongoing right to ask questions and be informed in a prompt and thorough manner.
- Support and technical assistance to others involved with the child (including schools, youth groups, and other community entities), as identified by family and child, regarding the child’s strengths and needs, and optimal ways to interact.

II. WHAT PROFESSIONALS SHOULD EXPECT FROM PARENTS:

- Interest by parents in working together respectfully.
- Interest in taking an active role in treatment.
- Efforts to identify strengths, concerns, priorities, and desired outcomes.
- Respect for professional's knowledge and experience.
- Healthy skepticism and respectful challenge, as part of meaningful dialogue.
- Willingness to express concerns to the professional, before drawing conclusions or withdrawing from care.
- Willingness to indicate when something is unclear, and to ask questions.
- Following through on agreements reached collaboratively.
- Openness to identify and seek out non-professional sources of support.

APPENDIX 3

FAMILY AND CONSUMER ORGANIZATIONS

Children and Adults with Attention Deficit Disorder

www.chadd.org

Family Voices

www.familyvoices.org

National Federation of Families for Children's Mental Health

www.ffcmh.org

Institute for Patient- and Family-Centered Care

www.ipfcc.org

Mental Health America

<http://www.mentalhealthamerica.net/>

National Alliance for the Mentally Ill

www.nami.org

PACER Center- Champions for Children with Disabilities

www.PACER.org

[The Family-Run Executive Director Leadership Association \(FREDLA\)](http://www.fredla.org)

www.fredla.org

Youth Move National

www.youthmovemational.org and chapters of Youth Move in individual states

Youth section of AACAP website

http://www.aacap.org/AACAP/Families_and_Youth/Youth_Resources/Home.aspx?hkey=58aaf61e-36ea-4a84-9a4c-58b2a434c869

REFERENCES

1. Accreditation Council for Graduate Medical Education. Program Requirements for Residency Education in Child and Adolescent Psychiatry. https://www.acgme.org/Portals/0/PFAssets/ProgramRequirements/405_ChildAdolescentPsychiatry_2019_TCC.pdf?ver=2019-03-28-161025-277. July 1, 2019.
2. Wotring JA and Stroul BA. The Intersect of Health Reform and Systems of Care for Children with Mental Health and Substance Use Disorders and Their Families. Washington, DC: Georgetown University Center of Child and Human Development, National Technical Center for Children's Mental Health. http://gucchdtcenter.georgetown.edu/publications/SOC_Brief_Series1_BL.pdf. Published 2011. Access January 19, 2014.
3. Stroul E, Blau G, eds. *The System of Care Handbook (Systems of Care for Children's Mental Health)*. Baltimore, MD: Brookes Publishing; 2008.
4. Institute of Medicine. Formulating new rules to redesign and improve care. In: *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001:61-89.
5. New Freedom Commission on Mental Health. *Achieving the Promise: Transforming Mental Health Care in America*. Final Report. Rockville, MD: US Dept of Health and Human Services; 2003. Publication SMA-03-3832.
6. Huang L, Stroul B, Friedman R, et al. Transforming mental health care for children and their families. *Am Psychol*. 2005;60:615-627.
7. Stroul B, Blau G, Friedman R. Updating the system of care concept and philosophy. Washington DC: Georgetown University Center for Child and Human Development, National Technical Assistance Center for Children's Mental Health, 2010.
8. Osher TA, Blau GM, Osher DM. *Shifting Gears: The Ambassador's Guide to Family Driven Care* [CD]. Rockville, MD: Federation of Families for Children's Mental Health; 2006.
9. Osher TA and Osher D. The paradigm shift to true collaboration with families. *Journal of Child and Family Studies*, 2002;11:47-60.
10. Pires SA. Customizing Health Homes for Children with Serious Behavioral Health Challenges, US Substance Abuse and Mental Health Services Administration. Center for Health Care Strategies website: http://www.chcs.org/usr_doc/Customizing_Health_Homes_for_Children_with_Serious_BH_Challenges_-_SPires.pdf. Published 2013. Accessed January 20, 2014.
11. Snyder A, Marton J, McLaren S, Fang B, Zhou M. Do high fidelity Wraparound services for youth with serious emotional disturbances save money in the long term? *The Journal of Mental Health Policy and Economics*, 2017; 20:167-175.
12. Friesen BJ, Huff B. Family perspectives on systems of care. In: Stroul B, ed. *Children's Mental Health: Creating Systems of Care in a Changing Society*. Baltimore, MD: Paul H. Brookes; 1996:41-69.
13. Hodas, G. Reciprocal parent-professional expectations. Pennsylvania Office of Mental Health and Substance Abuse Services, www.parecovery.org.

OTHER RESOURCES

- American Academy of Pediatrics. The medical home medical initiatives for children with special needs. *Pediatrics*. 2002;110:184-186.
- Anderson CM, Robins CS, Greeno CG, Cahalane H, Copeland VC, Andrews RM. Why lower income mothers do not engage with the formal mental health care system: perceived barriers to care. *Qual Health Res*. 2006;16:926-943.
- Moore KA, Chalk R, Scarpa J, Vandivere, S. Family strengths: often overlooked, but real. *Child Trends: Research Briefs*. August 2002.
- Walker JS, Bruns EJ. Building on practice-based evidence: using expert perspectives to define the wraparound process. *Psychiatr Serv*. 2006;57:1579-1585.

Case I – Training Director Version – For Discussion

Kelly is a 14 year old girl who just started her freshman year of high school. She is an honor roll student, plays flute in the school band, and is on the soccer team. Her teacher has noticed that recently she looks physically uncomfortable in class and will frequently request to go use the bathroom for extended periods of time. The teacher was also concerned about Kelly's recent drop in grades and kept her after class to talk. Kelly was tearful and admitted to the teacher that she has been experiencing periods of shortness of breath, increased heart rate and abdominal pain. The teacher advised Kelly to go to the guidance office to sit down and take a break whenever she felt uncomfortable. Kelly began to go the guidance counselor several times a day and would text her mother to pick her up from school early. Kelly's mother would pick her up whenever she requested, which led to her missing many days of school.

1. If you were the teacher, how could you best approach Kelly, and what would you advise her to do?

Kelly eventually began to refuse school altogether, and most days of the week she would not attend school. On the days that she was present, she was unable to make it past second period before her mother had to pick her up from school. The teacher called a parent-teacher meeting to discuss her absences. Her mother then revealed that Kelly had been complaining of severe abdominal pain, poor appetite, and episodes of nausea with occasional constipation. Her mother took her to the pediatrician. She underwent a thorough work-up and was diagnosed with acid reflux. Kelly was started on omeprazole but continued to complain of abdominal pain and refused to go to school in the mornings.

Several more months passed and Kelly went from being on the Honor Roll to being a D student. She accumulated 20 absences from school and the truancy officer contacted her parents. She was at risk for being kicked off the soccer team and the school band due to her poor academic performance. Her mother's response to the school's concern was that Kelly's absences were the result of a medical illness, so they should not be counted against her. The school then requested that the family provide documentation of this medical illness from her pediatrician.

Kelly and her parents returned to the pediatrician's office requesting documentation. The pediatrician was concerned about the multiple missed days of school and asked to meet with Kelly alone to find out what might be going on. Kelly confessed that ever since middle school she worries about not doing well in school, gets nervous when she has to speak up in class, and feels sick before soccer games and band performances. Kelly said she has been feeling much more overwhelmed since the start of high school. Kelly tells her pediatrician that she is very stressed out about her grades, her stomach is still hurting, and she feels like a burden to her family. She then tells him that sometimes she just "wants to get away and forget about everything".

2. If you were the pediatrician, what steps would you take at this point?

The pediatrician calls one of his child psychiatrist colleagues in the community about Kelly but the psychiatrist's wait list to be seen is over 3 months. However, the child psychiatrist offers to consult with the pediatrician over the phone.

3. As a child psychiatrist, what advice would you provide to the pediatrician? What services could be offered on the individual and systems level?

4. In what way could the pediatrician explain to the patient's family that he is concerned that a mental health condition is contributing to Kelly's school refusal and recent decline in functioning?

5. In the context of youth-guided care, what would be the best approach to explain the anxiety and depression to an adolescent patient to get them on board with possible treatment options?

Case II – Training Director Version – For Discussion

Brian O. is a 7 year old boy who lives with his mother and step-father, referred by his pediatrician for evaluation of hyperactivity, distractibility and inattention, tantrums, and anxiety (school's concerns) and difficulties with peer relations and low self-esteem at school (Mrs. O's concerns).

Mrs. O. reports that Brian does not have behavioral problems at home and believes that his difficulties at school are due to lack of sufficient supports. There is a highly conflicted (instead of 'conflictual') relationship between the family and the school. The school has supported a previous neuropsychological evaluation that gave a diagnosis of ADHD and wants a medication trial for Brian, while Mrs. O is opposed to medication and wants a 1:1 aide for Brian at school.

Brian has several avid interests, including fish and sharks, certain movies, and Spiderman. He demands a lot of attention and needs to have things go his way, but his mother is able to be flexible in her approach with him. Brian complains that his teachers and classmates do not like him. He has no friends at school and has low self-esteem. He has been tested with an IQ of 131 and, based on this, is underachieving academically. He is also clumsy.

Brian loves animals because they are "gentle" and because "they can lie in bed with you" (although he has no pets because of allergies to dander). His three wishes are that he "could listen better, remember to do what people ask me to do, and have more control over what I do."

Brian's school counselor has known Brian since kindergarten and sees him as a likeable, bright boy who has special needs. She notes that there is a social skills lunch group at school but fears Brian's difficulty with controlling his behavior would interfere with him doing well in the group. She wants to work collaboratively with his mother. Brian also has a psychotherapist (social worker) who has diagnosed Brian with generalized anxiety disorder, and who works well with Brian, his parents, and also has a connection with his school counselor.

The evaluating child psychiatrist made diagnoses of high functioning autism spectrum disorder (ASD) and dysthymic disorder, with prominent symptoms of hyperactivity, impulsivity and distractibility. However, Mr. O., Brian's step-father, did not participate in the initial evaluation session. Mrs. O. stated that he is very concerned for Brian but that he is also very opposed to the idea of stimulant medication for Brian because he believes Brian will become addicted. A follow-up session was scheduled at an evening time when both Mr. and Mrs. O. could attend. Parents reviewed a draft of the evaluation note prior to the meeting. Impressions were reviewed and Mr. O. was invited to describe his concerns about stimulant medication, including his own history of previous substance abuse and his misinformation about stimulants based on what he had heard at an Alcoholics Anonymous meeting and from Scientology. Psychoeducation regarding Brian's diagnoses and about stimulant medication was given, including the medication's demonstrated efficacy in treating symptoms of ADHD often noted in children with high functioning autism. Mr. O's concern for his step-son was strongly supported. With parental permission, the reasons for previous parental unwillingness to consider a trial of stimulants were shared with the school and both "sides" were helped to avoid blaming each other for Brian's difficulties.

A team re-evaluation was held, based on the new diagnosis of autism. Mr. and Mrs. O. were agreeable to a trial of stimulant medication with the understanding that the school will provide an aide if the medication alone is not sufficiently helpful. This plan was written into Brian's new individualized education plan (IEP). School agreed to place Brian in the social skills lunch group and add a second leader for the group as a support for Brian's behavioral control. Both the parents and school staff were provided with resource information: a book, web sites, and a local conference on autism that was attended both by Brian's mother and his guidance counselor. Brian's parents were given contact information for the local Autism Resource Center, run by parents of youth with ASD. Brian was given a pet poodle and continued in his outpatient psychotherapy. Brian's pediatrician was agreeable to prescribe and monitor a trial of stimulant medication.

Brian had a good response to stimulants, and his mother and guidance counselor shared a positive experience at the conference on autism. Brian in turn had a positive experience in the social skills lunch group at school, and was thrilled to get a pet poodle. He continued to meet with his psychotherapist, who was better able to assist Brian in understanding why he had difficulty making friends, with the knowledge of Brian's underlying autism.

1. Describe how the above vignette illustrates aspects of family-driven, youth-guided care, by identifying at least seven different ways that the response to Brian demonstrates family-driven and/or youth-guided practices?

Case III – Training Director Version – For Discussion

Juan is an 11 year old Hispanic male with diagnoses of ADHD and ODD. He lives at home with his mother, 2 younger siblings, ages 4 and 7, and his mother’s live-in boyfriend of 4 years. Juan has virtually no contact with his birth father. English is a second language for his mother and “step-father” and they have difficulty speaking English. There is great concern that his ODD symptoms are increasing and he is heading towards a diagnosis of CD. He is a slight boy who tends to be bullied by peers. His mother’s boyfriend thinks Juan is smart, but sees him as a “sissy” because he is slight and does not like sports. Juan’s stepfather also tells him that he is “bad” due to his oppositional behavior. There is considerable conflict in the home between the children and their caregivers about following rules and maintaining respect. Juan has run away from home, and his mother and “step-father” are concerned that they may not be able to continue to have him live in the home. He has very few positive interactions with his parents or his siblings.

Juan has been very opposed to family therapy and to taking prescribed stimulant medication. Although Juan is opposed to participating in family therapy, he does have a therapist who meets with him on an individual basis. Juan actively participates and does not object to this. Juan has a child psychiatrist whom he sees on a monthly basis for medication management. He has few friends, underachieves academically, and is frequently in trouble at school because he frequently fails to follow directions from teachers. Juan has a good rapport with his art teacher and follows directions in this class.

Juan and his family participated in a child and family team planning process. A care coordinator and a Hispanic, Spanish-speaking parent partner worked with the family to identify their needs and strengths and to help them determine the composition of the team. When asked about his strengths and interests, Juan states that he has always enjoyed drawing. His mother agrees that he is good at drawing and notes that he got an “Excellent” in art last year in the 5th grade on his report card. Juan stated he did well in the class because he liked his art teacher.

The child and family team included Juan, his mother and mother’s boyfriend, the family’s care coordinator, and parent partner, Juan’s therapist, child psychiatrist, and his teacher. Juan agreed to attend the meeting only when he knew that some of the discussion would involve thinking about how to help him do more drawing and learn to draw better. The child psychiatrist, therapist, and teacher were not able to attend the meeting, but their input was obtained in preparation for the meeting.

At the team meeting, Juan’s interest in drawing was discussed. Juan showed some of his favorite drawings to the team. Juan and his mother were interested in the possibility of him taking art classes at the local art museum one or two afternoons a week. However, there was concern that if not given additional support, his behavior would likely get him in trouble in that setting and jeopardize the placement. His mother suggested that perhaps his art teacher from the previous year might be able to provide mentorship to him in the art class. Flexible funding was available to help support the cost of the art class and provide his former art teacher with support for her time with Juan in the class. The teacher of the art museum was receptive to Juan’s participation

in the class, with mentorship support. His former art teacher agreed to provide this assistance for the semester.

Juan was very pleased to know he could attend the art classes. Recognition and support for his interest in drawing generated willingness on Juan's part to take his medicine and attend family therapy. Juan was told that if he did well in one class, he could add a second. Juan was successful in his participation in the art class. One of his drawings won a prize in a competition and was displayed at the art museum. Juan was very proud of this recognition, as were his mother and his "step-father," who decreased his shaming of Juan as a "sissy" and his blaming of Juan as a "bad boy" who should be punished, a result of the respect he saw Juan receive from others on the team as well as his own pride at Juan's recognition for his drawing abilities. Juan participated in family therapy and took his medication consistently. He stopped running away from home and became less oppositional. His parents became more hopeful that they could parent him and a potential out of home placement was avoided.

This vignette illustrates the implementation of the concept of family-driven, youth-guided care within the context of a "wraparound" or youth and family team care planning process. Below are questions inquiring about knowledge, attitudes, and skills in the CAP that support family-driven, youth-guided care:

1. Describe at least six ways that this vignette illustrates service delivery that is family-driven and youth-guided, as opposed to provider-driven.
2. Describe how this vignette illustrates each of the following attitudes that are fundamental to family-driven, youth-guided care: a. "Nothing about us without us," b. "Voice and choice," and c. "No shame, no blame."
3. Describe at least three ways in which the professionals involved with Juan and his family effectively offer family-driven, youth-guided care.