

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

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

### **Knowledge**

The resident will demonstrate an adequate knowledge of:

- 1) The “new rules” for a 21<sup>st</sup> century health care system endorsed by the Institute of Medicine that specifically support the practice of family-driven, youth-guided care. (1)
- 2) The definition of family-driven, youth-guided care. (1,2,4,5,9,10,11)
- 3) Guiding principles of family-driven care. (1-12)
- 4) Differences between provider-driven and family-driven care. (1,2,5,7,8,10,11)
- 5) Difference between “professional” and “experiential” knowledge. (2,9)
- 6) Examples of family support services. (3,7,8,9,11)
- 7) Major national and local family/consumer organizations advocating on behalf of youth with mental health needs. (1,4,8,9,11)
- 8) The component steps of the wraparound, or care planning team process. (1-12)
- 9) The role of the child and adolescent psychiatrist in family-driven care. (1-12)

### **Skills**

The resident will demonstrate the ability to:

- 1) Elicit information about youth and family strengths, traditions, and culture in the evaluation process. (4,6,8,11)
- 2) Incorporate youth, family and community strengths, and culture into formulations and treatment recommendations. (3,4,6,8,11)
- 3) Work within a wraparound, or team planning process. (1-12)
- 4) Work with families as partners and include family members in decision-making when creating treatment plans. (1,3,4)
- 5) Work with families and family organizations in advocacy and training activities. (4,9,11)
- 6) Create treatment plans that are individualized for the particular youth, family and community. (1,3,5,6,8)

### **Attitude**

The resident will demonstrate the commitment to:

- 1) Adopt respectful attitudes of “Family voice and choice,” “Nothing about us without us,” and “No blame, no shame” when working with families. (1,2,9,11)
- 2) Appreciate that youth and family members have strengths that should support treatment goals. (1,4,6,9)
- 3) Appreciate that youth and families have expertise in identifying and prioritizing their needs. (1,4,6)
- 4) Demonstrate a readiness to advocate for and with the youth and family. (4,9,11)

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\* Parentheses refer to systems-based practice competencies in the RRC Program Requirements.<sup>1</sup> See Appendix 1 for complete list of competencies.

## OVERVIEW

Family-driven, youth-guided care is consistent with all 12 elements of competency in systems-based practice as described in the ACGME Child Psychiatry Program Requirements (Appendix 1). It is important to note that family-driven, youth-guided care is also important in supporting competency in 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 organizations.

In the following text, the term “family-driven” care will be used to abbreviate the longer “family-driven, youth-guided” care that is the title of this module.

## I. INTRODUCTION

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 care in order to achieve competence in systems-based practice because several of the principles of family-driven, youth-guided care are explicitly endorsed by the Institute of Medicine (IOM) in the “new rules” for a 21<sup>st</sup> century health care system<sup>2</sup>:**

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

Family-driven, youth-guided care was explicitly named and further emphasized in the report of the President’s New Freedom Commission on Mental Health,<sup>3</sup> which was “designed to advance the community-based service delivery system built on efficiency and demonstrably effective practices.”<sup>4</sup> Family-driven, youth-guided care derives from the principle of child-centered and family-driven care that is a first core element of the system of care philosophy, as first described in 1986.<sup>5</sup> In 2009, AACAP approved a policy statement, “Family and Youth Participation in Clinical Decision-Making”, that underscores this important concept ([http://www.aacap.org/cs/root/policy\\_statements/family\\_and\\_youth\\_participation\\_in\\_clinical\\_decisionmaking](http://www.aacap.org/cs/root/policy_statements/family_and_youth_participation_in_clinical_decisionmaking)).

Youth-guided means that while youth are minors and have not reached the age to have the final word on the care they need, 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 at the systems level has only recently been explicitly identified as important at federal and state levels. Youth-guided as defined by the Substance Abuse and Mental Health Services Administration (SAMHSA) means that youth have the right to be empowered, educated, and given a decision-

making role in the care of their own lives as well as the policies and procedures governing the care of all youth in the community, state, and nation. Youth voice is being developed by a national organization, Youth M.O.V.E. (Motivating Others through Voices of Experience). Elaboration on youth-guided and youth voice can be found at SAMHSA's Systems of Care site.<sup>6</sup>

## **II. KNOWLEDGE OF THE LARGER CONTEXT AND SYSTEM OF HEALTH CARE**

Family voice determines family-driven care; families must be central in defining what family-driven, youth-guided care is. 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).<sup>7</sup> 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 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 sharing decision-making and responsibility for outcomes.
- Families and youth are organized to collectively 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 practice 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.
- Community attitude change efforts focus on removing barriers and discrimination created by stigma.
- Communities embrace, value, and celebrate the diverse cultures of their children, youth, and families.

- Everyone who connects with children, youth, and families continually advances their own cultural and linguistic responsiveness as the population served changes.

Like cultural competence, the principles of family-driven care should inform all aspects of systems-based practice. Attitudes of “Nothing about us without us” (referencing decision-making regarding the youth’s care), “Youth and family voice and choice,” and “No blame, no shame” in work with families are important for competent systems-based practice from a family-driven, youth-guided perspective.

The need for family-driven care is well summarized by the following statement from the FFCMH<sup>7</sup>:

“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.”

There are significant differences between a provider-driven and family-driven system<sup>8</sup>:

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

	<b>Provider-Driven</b>	<b>Family-Driven</b>
<b>Source of Solutions</b>	Professionals and agencies	Child, family, and their support team
<b>Relationship</b>	Child and family viewed as a dependent client expected to carry out instructions	Partner/collaborator in decision-making, service provision, and accountability
<b>Orientation</b>	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
<b>Assessment</b>	Deficit-oriented	Strengths-based
<b>Expectations</b>	Low to modest	High
<b>Planning</b>	Agency resource based	Individualized for each child and family
<b>Access to Services</b>	Limited by agency’s menus, funding streams, and staffing schedules	Comprehensive and provided when and where the child and family

		require
<b>Outcomes</b>	Based on agency function and symptom relief	Based on quality of life and desires of child and family

### **III. USE OF RESOURCES WITHIN THE SYSTEM TO PROVIDE EXCELLENT PATIENT CARE**

#### **A. “PROFESSIONAL” AND “EXPERIENTIAL” EXPERTISE COMPLEMENT EACH OTHER: CHILD AND ADOLESCENT PSYCHIATRISTS AND FAMILY MEMBERS AS PARTNERS**

Family members, both parents and youth, have strengths that can support desired treatment goals. It is important to recognize the value of “experiential expertise” as a complement to “professional expertise” when working with families as partners in service planning and delivery. Professional expertise comes from formal education and training including scientific or “objective” sources such as research, books and articles, as well as experience gained through professional activity. **Experiential expertise comes from the lived experience of the youth and family. It informs the treatment process with what it is like to live in this specific family and with this specific youth in this specific community.**

**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 care plan and to promote optimal youth and family partnership in treatment.

**Family and youth voice is important to include at the system level as well as the individual youth and family service level.** That is, it is important in a system of care that is family-driven and youth-guided that family members, including youth, sit on oversight and policy making bodies. 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”** is the term from families and the FFCMH that describes the specific contributions of youth and family members to the system of care in which systems-based practice occurs. It is defined as follows<sup>9</sup>:

“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.”

<b>FAMILY SUPPORT SERVICES INCLUDE BUT ARE NOT LIMITED TO THE FOLLOWING COMPONENTS</b>
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 on 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
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 the following principles:

<b>PRINCIPLES FOR FAMILY SUPPORT</b>
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 themselves as a family.
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 (but only 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. Major family/consumer organizations, with national presence and local chapters, are listed below, along with their Web sites. They are sources of considerable information for both professionals and family members. There are also many other local and specialty oriented consumer organizations in addition to those listed below.

Autism Speaks – [www.autismspeaks.org](http://www.autismspeaks.org)  
Child and Adolescent Bipolar Foundation – [www.bpkids.org](http://www.bpkids.org)  
Children and Adults with Attention Deficit Disorder - [www.chadd.org](http://www.chadd.org)  
Family Voices - [www.familyvoices.org](http://www.familyvoices.org)  
Federation of Families for Children's Mental Health - [www.ffcmh.org](http://www.ffcmh.org)  
Institute for Family-Centered Care - [www.familycenteredcare.org](http://www.familycenteredcare.org)

Mental Health America - [www.nmha.org](http://www.nmha.org)

National Alliance on Mental Illness - [www.nami.org](http://www.nami.org)

Parent Training and Information (PACER Center) - [www.pacer.org](http://www.pacer.org)

## C. WRAPAROUND OR THE CARE PLANNING TEAM PROCESS

The principles of family-driven, youth-guided care are operationalized by the **care planning team, or wraparound process**. This is an approach to treatment, or care planning, for youth with complex needs and their families, which prioritizes family voice in the process. While many versions of this planning process exist, they all rest on the priority given to family “voice and choice”<sup>7</sup>:

“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.”

Briefly, 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 wraparound process is a core intervention implementing family-driven care and the system of care philosophy.<sup>10</sup>

The team is facilitated by a care coordinator, who may also have had experience with raising a child with complex needs. This complementary approach to the usual medical model for addressing mental health is a four stage process: pre-meeting preparation, the team meeting, implementation, and transition.

### 1a. 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 family partner.
- Culture, strengths and needs discovery, and development of a vision for the youth and family whereby 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.

### 1b. 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 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. Planning

- 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 domains 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. 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 was flawed, not that the youth or family or provider is to blame.
- The youth and family team continues to meet (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

- Preparation for sustainability after graduation.
- Goal to sustain gains made during the enrollment in wraparound, ideally with expanded use of natural supports.

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

- Training and supervision.
- 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.

For more information and materials on high fidelity wraparound go to the National Wraparound Initiative Web site at [www.rtc.pdx.edu/nwi](http://www.rtc.pdx.edu/nwi).

## **D. THE ROLE OF THE CHILD AND ADOLESCENT PSYCHIATRIST IN FAMILY-DRIVEN CARE**

Within the framework of family-driven care, the child and adolescent psychiatrist strives to understand the needs and strengths of the youth, paying close attention to the youth's



communications about these qualities. **The effort of the CAP to understand the youth's culture, strengths, and needs is made in partnership with parents, always with an attitude of respect** and with hopefulness about the benefits of collaboration with the youth and parents, as well as with others concerned about the well-being of the youth.

It is the responsibility of the child psychiatrist to support the youth to have voice and choice within the treatment process. Not infrequently, the focus on the youth's dangerous or unsafe behaviors by the larger system is not accompanied by sufficient attention to the underlying thoughts and feelings of the youth that may have motivated the behaviors of concern. **The child and adolescent psychiatrist is uniquely qualified to help youth enhance their capacities to identify and communicate their feelings and needs and to determine what will be helpful to address those feelings and needs.**

With sufficient administrative support and time, **child and adolescent psychiatrists can provide leadership for the promotion of a wraparound approach at such meetings as discharge planning meetings from hospital or residential care, or an additional meeting as part of an outpatient child psychiatric evaluation**, with particular attention to inclusion of input and coordination of effort from other "team" members. Often these same system partners, or "collaterals," have been contacted for input earlier in the evaluation, and their helpful involvement with the family can be enhanced by participation in a decision-making process about the plan of care (treatment plan) that is family-driven and youth-guided.

Roles and responsibilities of family members and child psychiatrists in their work with each other are further delineated in Appendix 2.

### **III. KNOWLEDGE OF PATIENT SAFETY AND ADVOCACY**

"Rule" 6 in the IOM *Crossing the Quality Chasm* states "Safety is a system property," meaning that the oath of Hippocrates, "above all else, do no harm," belongs not just to the individual physician, but to the system of care as a whole.<sup>2</sup> Families of youth with severe emotional disturbances (SED) are very often interacting with multiple involved individuals concurrently. Coordinated, respectful and collaborative communication between system partners can promote youth and family hopefulness. Conversely, systems that do not communicate adequately and/or communicate in a conflicted manner or in a way that give youth and families contradictory requirements can augment distress in the family, causing harm. **Child and adolescent psychiatrists have a leadership responsibility to model collaborative, respectful interactions with other involved system partners**, to help reduce the harm that "system stress" not infrequently causes to families both by loss of hope and by creating aversion in youth and parents to people who could be helpful.

When emotional disorders become apparent in their children, parents are often beset by confusion, anxiety, and fear; they do not have the information they need to recognize and understand mental health problems or to locate appropriate, effective services.<sup>11</sup> **Child and adolescent psychiatrists have an advocacy responsibility toward the education of youth and families regarding both the psychiatric care of the child as well as education about the**

**broader system**, both directly and indirectly, by providing access to other sources of information such as the internet, handouts and other printed material and family organizations. Care may be enhanced and harm may be reduced by enhancing methods of outreach to families that can promote their engagement with needed aspects of the system of care.

The first rule of *Crossing the Quality Chasm* is: “Care is based on continuous healing relationships,” as opposed to being based on office visits.<sup>2</sup> **Supporting the capacity of families to promote healing of their youth maximizes the impact of continuous healing relationships embedded within the family.** Conversely, disrupted attachments, when occasioned by multiple placements in out-of-home settings, can be harmful to the health of youth. Short term emergency response, e.g. repeated hospitalizations or acute residential treatment, while necessary for safety, must be balanced against long term harm caused by disrupted attachments between the youth and his or her parents, as well as the discontinuity of providers that families very often experience when their child requires an out-of-home placement.

The role of therapeutic out-of-home placement in providing a safety net for youth at risk and their families (whether specialized foster care when available and the family will allow, or residential or hospital care) must nevertheless also be recognized and receive advocacy. **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” recently convened by SAMHSA to look at the role of residential and hospital care in the system of care noted that the issue is not so much the extent to which residential and hospital levels of care will continue to be necessary, but whether there is support for these levels of care to become more closely aligned with the recommendations of the President’s New Freedom Commission on Mental Health report.

As noted, **child psychiatrists should advocate for voice and choice of the youth in their care**, meaning they should help youth articulate and bring their point of view to the people with whom they interact. Youth are much more likely to be motivated to participate in treatment efforts if they feel their input has been listened to, and has helped to determine the treatment plan. Child psychiatrists have unique training in being able to understand the underlying thoughts and feelings that are crucial in motivating behaviors, both that are desired and that are of concern.

**Advocacy efforts by child and adolescent psychiatrists at the systems level should be linked to similar efforts by family organizations whenever possible.** This partnership of advocacy is much more effective than advocacy without family/consumer support.

## 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:**

- 1) work effectively in various health care delivery settings and systems relevant to their clinical specialty;
- 2) coordinate patient care within the health care system relevant to their clinical specialty;
- 3) incorporate considerations of cost awareness and risk-benefit analysis in patient and/or population-based care as appropriate;
- 4) advocate for quality patient care and optimal patient care systems;
- 5) work in interprofessional teams to enhance patient safety and improve patient care quality; and,
- 6) participate in identifying system errors and implementing potential systems solutions.
- 7) know how types of medical practice and delivery systems differ from one another, including methods of controlling health care cost, assuring quality, and allocating resources;
- 8) practice cost-effective health care and resource allocation that does not compromise quality of mental health care for children and adolescents;
- 9) advocate for quality patient care and assisting patients in dealing with system complexities, including disparities in mental health care for children and adolescents;
- 10) work with health care managers and health care providers to assess, coordinate, and improve health care;
- 11) know how to advocate for the promotion of health and the prevention of disease and injury in populations; and,
- 12) instruct in the practice of utilization review, quality assurance and performance improvement.

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\* Accreditation Council for Graduate Medical Education. Program Requirements for Residency Education in Child and Adolescent Psychiatry. [http://www.acgme.org/acWebsite/downloads/RRC\\_progReq/405pr07012007.pdf](http://www.acgme.org/acWebsite/downloads/RRC_progReq/405pr07012007.pdf). Accessed July 28, 2009.

## **APPENDIX 2**

### **RECIPROCAL PARENT-PROFESSIONAL EXPECTATIONS**

**Gordon R. Hodas, M.D.**

#### **I. EXPECTATIONS FOR PARENTS REGARDING MENTAL HEALTH SERVICES**

##### **A. WHAT PARENTS SHOULD EXPECT FROM PROFESSIONALS:**

- Constant affirmation that the family is the primary source of care for the child, and that the professional is a consultant to the family.
- Respect – for the individual, cultural, and ethnic uniqueness of the child and family, with the presumption of competence and positive intentions by child and family.
- Demonstration of authentic interest and caring.
- Support for parents or legal guardians in their role as primary caregivers of the child.
- Opportunity for parents to share information and be listened to.
- Opportunity to identify priorities that are incorporated in the child'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 child- 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 child 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.

## **B. WHAT PARENTS SHOULD EXPECT FROM THEMSELVES:**

- Readiness to take an active role and be an advocate.
- Willingness to work respectfully with professionals and consider their input.
- Willingness to express concerns to professionals, before drawing conclusions or withdrawing.
- Following through on agreements reached collaboratively.
- Readiness to identify and seek out non-clinical sources of support (i.e. advocacy groups, extended family/neighbors, and other community resources).
- A commitment to unconditional self-care and self-forgiveness.
- A commitment not to try to do it alone.
- A commitment to address the needs of the family as a whole and all family members.
- A sense of humor.
- A commitment to not give up.

## **II. EXPECTATIONS FOR PROFESSIONALS REGARDING MENTAL HEALTH SERVICES**

### **A. 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 professional, before drawing conclusions or withdrawing.
- 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.

### **B. WHAT PROFESSIONALS SHOULD EXPECT FROM THEMSELVES:**

- Presuming the positive about the child, parents, and family, including respectful assumptions about parents (The Four C's): competent, caring, caught, and changing.
- Respectful assumptions about children and adolescents: wanting to do well and doing the best they can, given current knowledge, stability, skills, and supports.
- Maintaining a welcoming, respectful, non-intimidating presence with child and family.

- Respect for the knowledge and expertise of the family, and others involved with the child.
- Listening, remaining curious, and learning.
- Sharing power and collaborating.
- Clear explanations and a readiness to share information (books, Web sites, organizations, etc.).
- Following through on agreements reached collaboratively, and maintaining professional integrity.
- A readiness to advocate for, and with, the child and family.
- Acknowledging professional limitations, as relevant.
- Managing own emotions constructively.
- Not giving up.

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## **Family-Driven, Youth-Guided Care – Discussion Vignette I – Trainee Version**

Toni is an 8 year old girl who has been diagnosed as autistic since 2 years old. She has learned to use communicative language and has been followed by a child neurologist since 3 years of age due to the onset of major motor seizures. Over the past several months, she has experienced loss of motor functioning and language skills, tremor, and increased self-injurious behavior as well as difficulty with self feeding and loss of communicative speech, such that both her single mother and her school felt that the care she needed was beyond what they could sustain either at home or in her current educational placement. Her mother, Barbara, expressed concern that her deteriorating course could lead to death. Barbara is a single parent who is fairly isolated in her community and whose anxiety and very close attachment to Toni, while understandable at this time, nevertheless is viewed to impair significantly her best functioning on Toni's behalf.

Toni was admitted to a pediatric inpatient service for neurologic reassessment and psychiatric consultation. Her medical workup was negative (metabolic w/e, MRI, genetics/Retts) but her self-injurious behavior improved with addition of low-dose risperdal which was gradually titrated up to a dose of 1 mg bid because her mother had reported that a previous trial of seroquel for self-injury had resulted in excessive sedation. Applied behavioral analysis and OT consultation helped reduce symptoms by contingency management. Nevertheless, her tremor and loss of language function and low frequency, self-biting persisted.

After a two week hospitalization, uncertainty persisted within her doctors and other providers about optimal medication behavioral management and whether Toni could be maintained at home. However, her insurance company, which has been patient, is now saying that she no longer meets medical necessity for medical hospital level of care. Moreover, Barbara wants very much to bring her home, whatever the burden may be for her. You have been consulting during the course of the admission regarding diagnostic questions and psychotropic medication management and you are now asked for consultation by the child neurology attending about how best to support the neuropsychiatric needs of the youth at discharge, in particular regarding recommendations for discharge psychotropic medications and whether transfer for continued psychiatric inpatient care is indicated.

1. Compare how you would proceed in responding to the consultation request from a family-driven model versus a provider-driven model.
2. List examples of family support services that might be helpful to Toni and Barbara.

## **Family-Driven, Youth-Guide Care – Discussion Vignette II – Trainee Version**

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 conflicted relationship with the school. The school has supported a previous neuropsychological evaluation that gave a diagnosis of ADHD, and the school wants a medication trial, while Mrs. O. is opposed to medications 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 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 and do what people ask him to do, and have more control over what he does.”

Brian's school adjustment 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 cause him not to do 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 adjustment counselor.

The evaluating child psychiatrist made diagnoses of Asperger's Disorder 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 parents could attend. Mr. and Mrs. O. reviewed a draft of the evaluation note prior to the meeting. Impressions were reviewed and Mr. O. was invited to speak about his concerns regarding stimulant medication, including his own history of previous substance abuse and his incorrect knowledge about stimulants based on information he had received from AA and Scientology. Psychoeducation regarding assigned diagnoses and stimulant medication was given, including demonstrated efficacy in treating symptoms of ADHD often noted in Asperger's. Mr. O.'s concern for his step-son was endorsed. With parental permission, the reasons for previous parental refusal to consider a trial of stimulants were shared with the school and both “sides” were supported to avoid blaming each other for Brian's difficulties.

A team re-evaluation was held, based on the new diagnosis of Asperger's. Mr. and Mrs. O. were agreeable to a trial of stimulant medication with the proviso that the school would agree to implementation of an aide if medication was not sufficiently helpful. This plan was written into Brian's new IEP. The 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 parents and school staff were provided with education: a book, Web sites, and a local conference on Asperger's 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, his mother and guidance counselor shared a positive experience at the conference on Asperger's, Brian had a positive experience in the social skills lunch group at school, and he 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 Asperger's.

Describe how the above vignette illustrates aspects of family-driven, youth-guided care.

### **Family-Driven, Youth-Guided Care – Discussion Vignette III – Trainee Version**

The following is a definition of **formulation** created by the American Psychiatric Association Commission of Psychotherapy:

A biopsychosocial formulation is a tentative working hypothesis which attempts to explain the biological, psychological and sociocultural factors which have combined to create and maintain the presenting clinical problem. It is a guide to treatment planning and selection. It will be changed, modified or amplified as the clinician learns more and more about the patient.

Revise this definition, incorporating principles of family-driven, youth-guided care.