System of Care Checklists

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Family Experience
of the
Mental Health System

System of Care Checklists From the FEMHS Study

The Family Experience of the Mental Health System was designed to meet a need for information from family perspectives about service access and delivery, as well as about specific aspects of services that are most and least helpful. Over a two year period, families shared their experiences as they sought services, entered treatment, and remained in or terminated treatment.

A **Findings Compendium** was developed, along with the following checklists, which summarizes findings and their policies and practice implications. Based on the experiences of the families in the study, as well as evidence-based and promising practices, these checklists can help guide the development of systems of care as they address child and family issues of: Medication; Decisions and Responsibilities of Care; Pathways and Access to Care ; and, Helpfulness of Formal Organizations and Informal Supports

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System of Care Checklist:
Family Experiences with Medication

Family Experience of the Mental Health System

- ☐ Clinicians individualize therapies, and medication regimens, according to the age, gender, culture, ethnicity, and other life circumstances of the child and family.
- ☐ Physicians and health practitioners are aware of and incorporate into treatment the cultural beliefs about mental health, the effectiveness of psychotropic medication, and the use of alternative medicines and folk beliefs for children and youth and their families to whom they provide services.
- ☐ Care coordinators are aware of and incorporate into service planning the cultural beliefs about mental health, the effectiveness of psychotropic medication, and the use of alternative medicines and folk beliefs for children and youth and their families to whom they provide services and supports.
- ☐ School officials and necessary staff are encouraged to be involved in medication management as they often play a supportive role in helping to detect signs of significant behavioral problems or side effects from medication.
- ☐ System of care partners, such as therapists, doctors, case managers and teachers, investigate the rationale behind non-compliance with medication regimens when it occurs.
- ☐ Prescribing physicians are aware of the availability of certain prescriptions, and plan temporary remedies when access may be delayed.
- ☐ Physicians and other child-serving professionals support parents in making decisions on the use of psychotropic medications through informed consent, based on risks and anticipated benefits.
- ☐ Parents are partners in the management of medication prescribed for their children and are kept well informed during the process of identifying the proper medication and dosage, and its effectiveness.
- ☐ Families are informed of and understand the right of parental choice, and the right of access to effective treatments.
- ☐ Legislators and policy-makers consider the scientific evidence and the needs of children with serious emotional disturbances above the transitory controversies when passing legislation or revising policies.
- ☐ A community-based education campaign is on-going to combat stigma and provide education about the utility, risks and safety of psychotropic medications and medication alternatives.
- ☐ Pediatricians and specialty mental health providers communicate and coordinate with one another, other necessary team members and the family about the medications they are prescribing to children.

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System of Care Checklist:
Decisions and Responsibilities of Care

Family Experience of the Mental Health System

Making decisions can be "easier" if…

- ☐ Parents have access to information about child development and behavior that can help them make decisions whether or not to seek an evaluation.
- ☐ Assessments are provided in a timely fashion so that families and providers can have information which, combined with what parents know, may help them recommend a course of treatment.
- ☐ Families understand how their child's health, social life, education, and development may be affected by the child's emotional or behavioral problems.
- ☐ Families feel comfortable asking questions of their physical or behavioral health care provider, school personnel, or other agency staff, and feel comfortable asking for second opinions.
- ☐ Families have access to a family organization that can provide information, services and support.
- ☐ Current and accurate information about services available and treatment options and alternatives is easily accessible to all families, providers, and the community, including pediatricians.
- ☐ Schools provide parents with on-going information about their child's behavior in school, such as peer and adult relationships and learning problems.
- ☐ While seeking services and during service planning and implementation, providers/care managers assist and support the family in examining all life domains that may impact service and treatment decisions.
- ☐ Parents know that the information they share about their child's development is respected and their lives will not be judged.
- ☐ Families know their privacy is protected, and when, how and why confidential information may be shared.
- ☐ The child is included in the decision-making process when appropriate.
- ☐ Families and service and support providers understand and address the barriers families face while seeking services and attempting to continue treatment and access services.
- ☐ Families are given information about specific ethnic or cultural groups that may impact the treatment decisions they make for their child, such as specific groups being over-represented in a program that has been recommended.
- ☐ Providers review their own processes with families for families to access service and treatment and make necessary changes or enhancements.
- ☐ Policies are in place which support a wide and varied selection of providers and services.
- ☐ Families have easy access to information about the credentials and expertise of the providers who may be or are working with their child.
- ☐ Agencies provide flexible hours and location of services.
- ☐ Agencies provide culturally competent treatment and services.
- ☐ Families have the opportunity to provide feedback about individual treatment providers and/or other agency staff, such as receptionists, who are in contact with families; and, individuals and agencies respond to it accordingly.
- ☐ Families have access to information about eligibility requirements for services and about their health care insurers.
- ☐ Families understand their right to advocate for their child, their right to refuse treatment for their child, and the process to make a formal complaint without penalty or retribution.
- ☐ Services are coordinated across agencies and providers who communicate effectively with family, youth and each other.

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System of Care Checklist:
Pathways to Care

Family Experience of the Mental Health System

☐ Families know whom and how to call to access service for their child with mental health needs.
☐ All aspects to accessing services are culturally and linguistically competent.
☐ Families are treated with respect and regarded as experts in knowing their children.
☐ Pediatricians and other initial points of contact and referral are aware of services and can make an accurate referral recommendation to the family for further mental health assessments.
☐ Eligibility requirements for specific programs are very clearly communicated to families and referral sources.
☐ Policies are in place that help systems of care, with multiple service providers, create clear service pathways.
☐ Policies are in place to ensure that every child in need of mental health service is able to access them.
☐ Policies are in place that can help families, agencies and providers address the racial and ethnic disparities in mental health service utilization.
☐ Current or proposed changes to mechanisms, such as managed care, designed to organize, deliver, and pay for health services need to increase access to care and promote evidence-based quality care, emphasizing prevention.
☐ All families have access to mental health services without having to navigate multiple systems.
☐ All families are able to make changes to service or treatment plans without having to re-navigate the system.
☐ Policies are in place to support establishing mental health as a mainline system of care, reinforcing the importance of incorporating education about mental health services, services to address stigma, and about the relationship of cognitive, physical and emotional development.
☐ Professionals who serve children in everyday settings have access to current information about mental health and mental health services and treatment.
☐ The pathway to care for mental health services recognizes and responds to socio-cultural and economic factors.
☐ Barriers to care are identified and appropriately responded to.
☐ Creating effective and efficient pathways to services is seen as a community responsibility, including the schools, courts, child welfare, and physical and behavioral health.

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System of Care Checklist:
Helpfulness of Formal Organizations and Informal Supports

Service can be more helpful to families if…

☐ The family is treated with respect and is seen as the lead in planning services for their child.
☐ The family is given all the information necessary to partner in treatment decisions and make decisions from a position of strength.
☐ Services are coordinated across providers.
☐ Communication among providers and between families and providers is effective and efficient.
☐ Families receive accurate information about what services offer and the eligibility criteria to receive those services.
☐ There is a positive relationship between the service provider and the child and between the parent and the service provider.
☐ Families feel confident in the skills of their child's service provider and have information available to them about the skills and experiences of specific providers.
☐ The service provider is accessible and responsive to the requests and needs of caregivers.
☐ Supports and services (i.e., mentors, sibling counseling, respite) are extended to the whole family.
☐ The care manager works in partnership with the family to examine all life domains and how to support each, as necessary (e.g., transportation, food, housing).
☐ Families receive regular contact from providers about their child's progress.
☐ Families do not have to wait an unreasonable amount of time for an appointment or sit in the waiting room an unreasonable amount of time for a scheduled appointment.
☐ Therapist, care mangers or other direct service personnel remain relatively constant while the child is in service.
☐ Families feel that the service addresses the need.
☐ All aspects of service provision are conducted in a culturally competent manner, including meetings with the family about the youth, or his or her services and treatment (e.g., conducted in the primary language of the caregiver).
☐ The approach to care is holistic and family-centered, and includes examining the role of extended family as a source of support as well as a source of stress.
☐ Families are aware of and have access to family advocacy and support organizations in their community.
☐ Families and treatment team members are clear about their roles and tasks.
☐ Agencies and service providers are flexible to meet the needs of the family, such as time of appointments and locations.
☐ Policies are in place whose main objectives are to raise the mental health literacy of the community.

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