From Revolution to Evolution: Changes in Children’s Mental Health Practice Over 25 Years

Medicalization of Child Mental Health

- Evolution of child mental health as a medical specialty unlike its social beginnings
- Medicalization led to limited treatment options
  - Outpatient Psychotherapy – Individual, Family, Group
  - Acute Inpatient Hospitalization, Partial Hospitalization
  - Residential Treatment – Often in “boarding school” settings
  - Informal Respite, e.g., sent to live with aunt and uncle

Family-Blaming Treatment Paradigms

- Theory of neurosis
- Theory of cold mothers with schizophrenia and autism
- Improvement with family systems theory in late 1960s, but still based on dysfunctional family systems
- Relinquishment of custody to obtain needed services funded only by Child Welfare and Juvenile Justice systems

Insurance Coverage

- Private health insurance supported only outpatient, acute inpatient, and partial hospitalization
- Public health insurance only paid for part of residential

Gee... This is still pretty much how it is today!
Beginnings of Change
- Shift from “treatment” to “intervention”
- Adult rehab-based model
- Developmental disabilities community-based alternative interventions

Origins of SOC Concept
- Began with federal CASSP 25 years ago
- Participatory process with multiple stakeholders (policy makers, service providers, agency administrators, TA providers, family members, advocates, leaders in cultural competence, etc.)
- First articulated in 1986 monograph
- Intent to provide a framework to guide reforms in systems and services

Application of SOC Concept
- Shaped the work of states, communities, tribes, and territories – some elements in nearly all communities
- Foundation of the federal CMHI in 1992
- Surgeon General’s Conference on Children’s Mental Health National Action Agenda
- Basis of recommendations of children’s subgroup of the President’s NFC
- Framework for reform by other child-serving and adult systems

Original SOC Definition
A coordinated network of community-based services and supports characterized by a wide array of services, individualized care, services provided within the least restrictive environment, full participation and partnerships with families and youth, coordination among child-serving agencies and programs, and cultural and linguistic competence

System of Care Framework

Why Update?
- Construct is dynamic
- New insights through natural evolutionary process based on experience and increased knowledge
- New issues have arisen in the field
- 25th anniversary seen as an opportune time to re-examine and update
What Needs Updating?

- Have been previous updates and clarifications, e.g. Primer, Issue Brief
- Considerable consensus on what aspects should be updated based on latest thinking, experience, and data
- Many issues raised by authors in special journal issue devoted to updating the concept edited by Sharon Hodges and Kathleen Ferreira at USF (February 2010)

Population

- Originally crafted for children and youth with SED
- Applicability to children and youth at risk and to other populations and other child-serving systems is apparent
- Subsequent iterations should reflect broader application and relevance to populations besides children with SED

Core Values

- Add three core values to the basic definition:
  - Community-based
  - Family-driven and youth-guided
  - Cultural and linguistic competence
- So intrinsic that they should be included in the overall definition, in addition to their specification as core values

Capture Dynamic Nature of SOCs

- SOCs not static, change over time
- Policies, organizational arrangements, service delivery approaches, and treatments change based on changing needs, opportunities, environmental circumstances, and populations
- Even well-developed SOCs do not remain in a steady state, but continually strive to improve
- This characteristic should be made explicit

Specify Desired Outcomes

- Make explicit the ultimate outcome – to improve the lives of children and their families
- Use language in current federal definition calling for SOCs and services to enable children, youth, and families to “function better at home, in school, in the community, and throughout life”

Broaden to Incorporate Public Health Approach

- Need for a public health approach to mental health increasingly recognized
- Concept should recognize potential for SOCs to incorporate or link with promotion, prevention, and early intervention, in addition to services and supports for high-need youth and their families
**Accountability**
- Accountability is a critical element
- Should be a core component of the concept to monitor and manage the ability to address the elements of SOCs (“fidelity”), quality, the achievement of goals, and child and family outcomes
- Tracking mechanisms and feedback to administrators and clinicians should be a routine function in SOCs

**Individualized Care**
- Add greater emphasis on individualized, flexible approach to services
- Wraparound process has become one of the most significant practice-level approaches to planning and delivering services within SOCs
- Emphasis on individualized, wraparound approach should be increased

**Role of Natural Supports**
- Specification that SOCs should provide a “broad array of services and supports including both traditional and nontraditional services and supports and informal and natural supports”
- Acknowledge importance of natural supports (such as extended family, community and cultural organizations, cultural brokers, faith communities, peers, etc.)

**Cultural and Linguistic Competence and Focus on Disparities**
- Increasing diversity of the populations served by SOCs makes it essential to add greater emphasis to the core value of cultural and linguistic competence
- Specify that systems of care are responsible for strategies to ensure access to high-quality, acceptable services for culturally diverse groups
- Incorporate elimination of disparities as part of the core value

**Updated Definition**
“A spectrum of effective community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them function better at home, in school, in the community, and throughout life”

**Core Values**
- **Family driven and youth guided**, with the strengths and needs of the child and family determining the types and mix of services and supports provided
- **Community based**, with the locus of services as well as system management resting within a supportive, adaptive infrastructure of structures, processes, and relationships at the community level
- **Culturally and linguistically competent**, with agencies, programs, and services that reflect the cultural, racial, ethnic, and linguistic differences of the populations they serve to facilitate access to and utilization of appropriate services and supports and to eliminate disparities in care
Guiding Principles

1. Broad, flexible array of effective, evidence-informed services and supports, including traditional and nontraditional services, informal and natural supports
2. Individualized services guided by a strengths-based, wraparound service planning process and an individualized service plan
3. Least restrictive, most normative environments that are clinically appropriate
4. Ensure that families, caregivers, and youth are full partners in services and policies/procedures at all levels
5. Service integration, linkages across administrative and funding boundaries and mechanisms for system-level management, coordination, and integrated care management
6. Care management for coordination of services
7. Services and supports needed to meet the social-emotional needs of young children and their families
8. Services and supports needed to facilitate the transition of youth and young adults to adulthood
9. Incorporate or link with mental health promotion, prevention, and early identification and intervention
10. Rights protection and advocacy
11. Continuous accountability mechanisms at the system level, practice level, and child and family level
12. Nondiscrimination

What the SOC Concept is Not

- Not a “model” to be “replicated” like a manualized treatment
- Not a single “program” but a coordinated network of services across agencies
- Not a “treatment or clinical intervention” that directly improves child and family outcomes without accompanying changes at the practice level to provide appropriate, effective, evidence-informed, individualized, community-based, family-driven, youth-guided, culturally competent services and supports

What the SOC Concept Is

- Basis for a “paradigm shift,” “ideal” to describe how child-serving systems should function, vision for transformation
- Organizational framework for system reform based on a clear value base
- At the most basic level, a range of services and supports, guided by a philosophy, and supported by an infrastructure

System of Care Concept

Specification and related process monitoring has prompted evolution:

- Responded to concerns about fidelity/quality and extent to which wraparound was living up to its own principles
  - Created pressure for practice change at the service level—walk the talk of wraparound practice
- Greater adherence to family/youth voice drives service and system evolution more broadly
  - Open up the service level to fuller learning from families—helps drive practice change
  - Put pressure on systems to evolve and provide more of what families want—services/supports and providers
Over- or Underspecification?
Evolution has created new concerns and dynamics around the tradeoff between specification and flexibility
- Service Level
  - Wraparound robots, wrap free spirits, and teaching to the test
  - How best to assess
- Roles
  - Some consensus through NWI on roles—facilitation, family partner
  - Various states, purveyors certifying facilitators, family partners, youth partners
- Organizational Level
  - Standards still contentious, though some states have some standard expectations

Valuing Youth Voice
Wow!
- Currently a major theme in systems of care/wraparound thinking, but not a lot of explicit attention to what this means at the practice level
- Potential to have a tremendous impact, both directly on service level and through that to system level
- Current But...
- Lack of specification about how this should happen, what to look for—i.e., mostly still in the talk-the-talk phase
- Challenges around how to balance youth and family perspectives, how to increase youth voice as developmentally appropriate across the transition ages

Two revolutions, two orientations
Empirically Supported Treatments:
- Professionally-driven
- Disorder/diagnosis specific
- Structured
- Consistent
- Manualized
- Based on science
- Shown to work through RCTs

Systems of Care:
- Families as full partners
- Availability of youth and parent support
- Individualization
- Availability of a range of services and supports
- Cultural competence/adaptation to local community context

More rigid, procedure-based
More flexible, value-based

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Evolution = Resolving the tensions?
- Modularization of evidence-based practice
  - Modularized Approach to Treating Children with Anxiety, Depression, and Conduct problems (MATCH-ADC; Weiss, et al.)
  - Managing and Adapting Practice (MAP; Chorpita et al.)

- Purveyors supporting adaptation for real world systems
  - Project KEEP (Adaptation of MTFC)

Evolution = Resolving the tensions?
- Availability of both wraparound care management and a range of ESTs in communities
- Community-level processes for identifying and implementing ESTs based on local needs
  - California Institute for Mental Health Development Team model
  - Ohio’s “Partnerships for Success” model
  - Communities that Care (http://www.commontaskforces.org)

- Greater specification and empirical testing of youth and parent support programs
  - E.g., Parent Empowerment Program (PEP)
  - Achieve My Plan (AMP)
Evolution of Family Involvement

- Lack of involvement
- Child and Adolescent Service System (CASSP) principles
- Families as Allies
- Family organizing
- Federation of Families for Children’s Mental Health
- Federal SAMHSA Grants
- National Wraparound Initiative

“Parent involvement is not some kind of fad that will pass: it is the core of systems change. It is the only thing that can make true reform in human services”


Definition of Family-Driven

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:

- setting goals;
- designing and implementing programs;
- monitoring outcomes;
- managing the funding for services, treatments and supports and;
- determining the effectiveness of all efforts to promote the mental health and well being of children and youth.

How Child Serving Systems Structure Family Involvement at Various Levels

<table>
<thead>
<tr>
<th>LEVEL</th>
<th>STRUCTURE</th>
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<tbody>
<tr>
<td>Policy</td>
<td>At least 51% vote on governing bodies; As members of teams to write and review RFPs and contracts; As members of system design workgroups and advisory boards</td>
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<tr>
<td>Management</td>
<td>As part of quality improvement processes; As evaluators of system performance; As trainers in training activities; As advisors to selecting personnel</td>
</tr>
<tr>
<td>Services</td>
<td>As members of team for own children; As family support workers, care managers, peer mentors, system navigators for other families</td>
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</tbody>
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“Fertilizing the Ground”

How have families and providers prepared to collaborate?


Second edition – 2000 FFCMH.org
How far have we come?

Since the 1970's professionals' views of parents seem to fall into four major categories:
1. As the cause of their child's problems which make them the focus or "target" for change;
2. As having deficits and in need of education;
3. As "clients" themselves in need of support and other services;
4. Or, as collaborators in the treatment/education of their child; focusing on their strengths and resiliencies.

Richard Donner, MSW, Ph.D. Introduction - Building Effective Partnerships with Families

Shifts in the Workforce
Peer to Peer Support

- Family Partner
- Family Support Specialist
- Family Navigator
- Parent Partner
- Parent Advisor

- Challenges to role:

Standard Training
Sequence

- Introductions
- Source of feelings
- Themes
- Characteristics of partnerships
- Strategies
- Power
- Evaluation

Where are Family Partners?

- Mental Health Community Clinics
- Wraparound Teams
- Schools
- Hospitals
- Day Treatment Programs
- Parent Run Organizations
- Government
- Universities

Family Partner Supports and Services

- Support groups
- Educational Forums
- Advocacy
- One on One Peer Support
- Support on Team
- Outreach
- Information and Referral
- Link to professional community

Child STEPs

The Child STEPs network, funded by the MacArthur Foundation, the Clinic Treatment Project (CTP) Based in the Judge Baker Center, Harvard University, the CTP studies the effects of combining evidence-based therapies for children's anxiety, depression, and conduct problems. Clinicians are taught to use cognitive behavioral therapy for anxiety and depression, and ongoing parent training for child conduct concerns.

- Integration of Family Partners within each clinic that is part of the two year study
Training for Family Partners
Parent Empowerment Program (PEP)

In 2000, a group of parent advisors from NYC’s Mental Health Association saw a need to provide better training and support to parent advisors across the country. Columbia University joined the parent advisors to develop PEP, which was pilot tested in an NIMH-funded study.

- Listening Engagement and Collaborative Skills
- Boundary Setting Skills
- Priority Setting Skills
- Group Management Skills
- Assisting Parents in Navigating the Mental Health System
- Meeting Children's Needs within the School System

The Family Partner in the Wraparound Process

- The Family Partner is a formal member of the wraparound team whose role is to:
  - serve the family;
  - help them engage actively and participate on the team; and
  - make informed decisions that drive the process.
- Family Partners have a strong connection to the community and are very knowledgeable about resources, services, and supports for families.
- The Family Partner’s personal experience is critical to their earning the respect of families and establishing a trusting relationship that the family values.

Lessons Learned

- Meaningful family involvement doesn’t just happen – there must be a strategy.
- It is always an evolution – this is a paradigm shift for providers and for parents.
- It is about relationships.
- Safe trusting environments need nurturing.
- Ground needs to be fertilized.

Additional Resources

- Building Systems of Care: A Primer, Press, Sheila. 2002. Georgetown University Child Development Center – gscdc.georgetown.edu

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