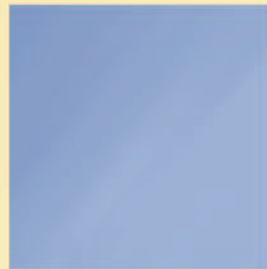


Building Systems of Care

*A
Primer*



BY

Sheila A. Pires

Human Service Collaborative
Washington, DC

FOR



National Technical Assistance Center for Children's Mental Health
Center for Child Health and Mental Health Policy
Georgetown University Child Development Center

SUPPORTED BY



Child, Adolescent and Family Branch
Center for Mental Health Services

SAMHSA

Substance Abuse and Mental Health Services Administration
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SHEILA A. PIRES
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Introduction



“The world that we have made as a result of the level of thinking we have done thus far creates problems that we cannot solve at the same level at which we created them.”

– ALBERT EINSTEIN –



A Bit of History About the System of Care Movement

Over the past decade and a half there have been concerted national efforts to help states and localities build **systems of care** for children and adolescents with emotional disorders and their families. *A system of care incorporates a broad array of services and supports that is organized into a coordinated network, integrates care planning and management across multiple levels, is culturally and linguistically competent, and builds meaningful partnerships with families and youth at service delivery and policy levels.* A review of the history of systems of care provides current system builders with an important context for their efforts. A brief retrospective of the system of care movement highlights the following national efforts:

CASSP

- In 1983, with a mandate and funding from Congress, the National Institute of Mental Health initiated the *Child and Adolescent Service System Program (CASSP)*, which provided funds and technical assistance to all fifty states, several U.S. territories, and a number of local jurisdictions to plan and begin to develop systems of care for children with serious emotional disturbance. CASSP recognized that children with serious disorders often are involved in multiple public systems such as education, child welfare, juvenile justice, and mental health and that planning more effective services for these children requires **interagency collaboration**.

National Family Voice

- In the mid-1980s a burgeoning family movement began to gather strength, and a national, **organized, family voice emerged**, with creation of the Federation of Families for Children’s Mental Health in 1989 and the growth of the National Alliance for the Mentally Ill Child and Adolescent Network (NAMI CAN).
- In 1986 Congress passed the *State Comprehensive Mental Health Services Plan Act*, which required all states to develop and implement plans to create community-based service systems for persons with serious mental illness, including adults and children, and mandated participation of family members and consumers in the development of state plans. This legislation reinforced the premise that most states would need to **redirect funds from hospital and institutional care to build community-based systems of care**.

MHSPY

- In 1989 the Robert Wood Johnson Foundation launched the *Mental Health Services Program for Youth (MHSPY)*, which funded 12 states and cities, and in 1992 provided replication monies to fund 15 more states and localities. This initiative introduced **managed care technologies** to the development of systems of care.

CMHS Grants

- In 1992 Congress passed legislation creating the *Comprehensive Community Mental Health Services for Children and Their Families Program*, which has funded 67 states and local communities to build systems of care. It is the

current major national source of funding for local system of care development. At the core of this program is the goal of developing a comprehensive array of community-based services and supports guided by a system of care philosophy with an emphasis on **individualized, strengths-based services planning, intensive care management, partnerships with families, and cultural and linguistic competence.**

- In 1993 the Anne E. Casey Foundation began the *Mental Health Initiative for Urban Children*, which focused system-building efforts at the **neighborhood level** in inner cities, advancing the use of **family resource centers as hubs for services and supports**, use of **natural helpers** as partners in service delivery, and inclusion of **parents and neighborhood residents as equal partners in the governance** of systems of care. Another contribution of the Casey program was to reframe the focus of system building from one of treating serious disorders only to that of **promoting emotional well-being in all children** and their families, including those children with serious disorders.
- In the mid-1990s **youth development principles** and approaches advocated at a national level from youth service arenas such as youth employment began to gather strength within systems of care, emphasizing the importance of youth leadership and involvement.

Complementing these national efforts are numerous initiatives sponsored by states, counties, cities, communities, and family organizations to build systems of care for children and adolescents with emotional disorders and their families.

System of Care Concept and Philosophy

The system of care values and principles initially articulated by Stroul and Friedman for the federal CASSP program were developed with the population of children with serious disorders in mind. Increasingly, these values are being applied in all system of care building, that is, regardless of whether the focus is on only children with *serious* disorders, those who also are at risk for serious disorders, or on a total eligible population (for example, all Medicaid-eligible children, within which there will be children with serious disorders and those at risk). Indeed, one of the challenges in large scale reforms focused on total eligible populations of children—for example, large scale Medicaid managed care reforms—is incorporating and operationalizing system of care values and principles that were developed initially for populations of children with serious disorders but which are equally applicable to systems of care for all children.

The definition of a system of care for children with emotional disorders was first published in 1986:

A comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families.

The core values of the system of care philosophy specify that services should be community based, child centered and family focused and culturally and linguistically competent. The guiding principles specify that services should be:

- Comprehensive, incorporating a broad array of services and supports,
- Individualized,
- Provided in the least restrictive, appropriate setting,
- Coordinated both at the system and service delivery levels,
- Involve families and youth as full partners, and
- Emphasize early identification and intervention.

Following are the values and principles for the system of care as articulated by Stroul and Friedman.

Values and Principles for the System of Care

Core Values

1. The system of care should be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided.
2. The system of care should be community based, with the locus of services as well as management and decision-making responsibility resting at the community level.
3. The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

Guiding Principles

1. Children with emotional disturbances should have access to a comprehensive array of services that address their physical, emotional, social, and educational needs.
2. Children with emotional disturbances should receive individualized services in accordance with the unique needs and potentials of each child and guided by an individualized service plan.
3. Children with emotional disturbances should receive services within the least restrictive, most normative environment that is clinically appropriate.
4. The families and surrogate families of children with emotional disturbances should be full participants in all aspects of the planning and delivery of services.
5. Children with emotional disturbances should receive services that are integrated, with linkages between child-serving agencies and programs and mechanisms for planning, developing, and coordinating services.
6. Children with emotional disturbances should be provided with case management or similar mechanisms to ensure that multiple services are delivered in a coordinated and therapeutic manner and that they can move through the system of services in accordance with their changing needs.
7. Early identification and intervention for children with emotional disturbances should be promoted by the system of care in order to enhance the likelihood of positive outcomes.
8. Children with emotional disturbances should be ensured smooth transitions to the adult services system as they reach maturity.
9. The rights of children with emotional disturbances should be protected, and effective advocacy efforts for children and adolescents with emotional disturbances should be promoted.
10. Children with emotional disturbances should receive services without regard to race, religion, national origin, sex, physical disability, or other characteristics and services should be sensitive and responsive to cultural differences and special needs.

Stroul, B., & Friedman, R. (1986). *A system of care for children and youth with severe emotional disturbances* (Rev. ed.) Washington, DC: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health. Reprinted by permission.

The federal Comprehensive Community Mental Health Services for Children and Their Families Program, which is based on the system of care concept and philosophy, articulates the following values and principles:

Hallmarks of the System of Care Approach

- The mental health service system is driven by the needs and preferences of the child and family, using a strengths-based perspective.
- Family involvement is integrated into all aspects of service planning and delivery.
- The locus and management of services are built on multi-agency collaboration and grounded in a strong community base.
- A broad array of services and supports is provided in an individualized, flexible, coordinated manner and emphasizes treatment in the least restrictive, most appropriate setting.
- The services offered, the agencies participating, and the programs generated are responsive to the cultural context and characteristics of the populations that are served.

Center for Mental Health Services. (1998). *Hallmarks of the system of care approach*. In *Annual report to congress on the evaluation of the comprehensive community mental health services for children and their families program*. Atlanta, GA: Macro International, Inc.

One finds complementary values and principles in the family support movement and in the field of youth development/youth services:

Principles of Family Support Practice

1. Staff and families work together in relationships based on equality and respect.
2. Staff enhances families' capacity to support the growth and development of all family members—adults, youth, and children.
3. Families are resources to their own members, to other families, to programs, and to communities.
4. Programs affirm and strengthen families' cultural, racial, and linguistic identities and enhance their ability to function in a multicultural society.
5. Programs are embedded in their communities and contribute to the community building.
6. Programs advocate with families for services and systems that are fair, responsive, and accountable to the families served.
7. Practitioners work with families to mobilize formal and informal resources to support family development.
8. Programs are flexible and continually responsive to emerging family and community issues.
9. Principles of family support are modeled in all program activities, including planning, governance, and administration.

Family Support America. (2001). *Principles of Family Support Practice*. In *Guidelines for Family Support Practice* (2nd ed.). Chicago.

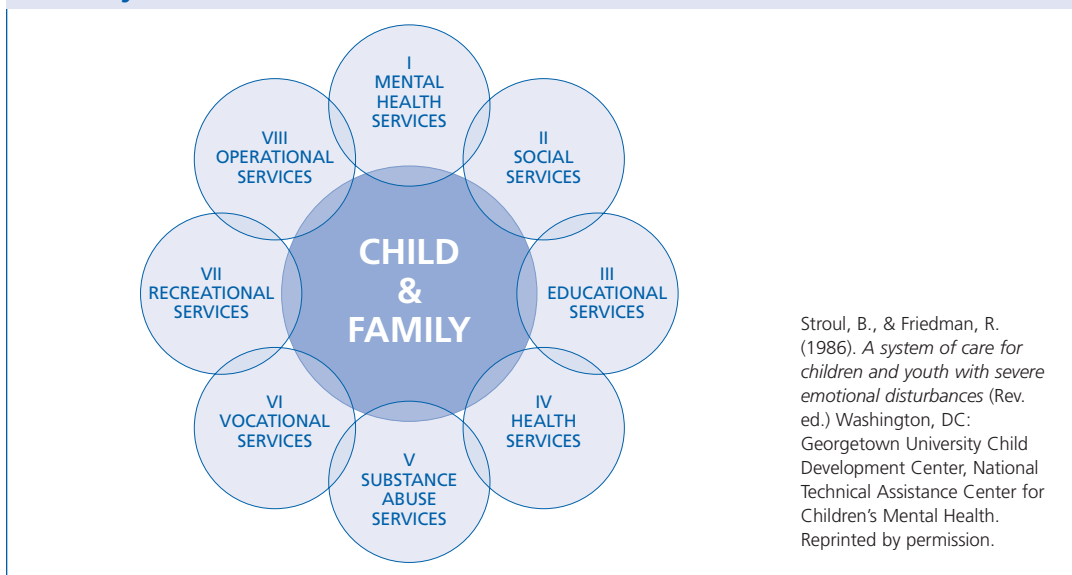
Youth Development Principles

1. **Adolescent Centered:** Adapts services to the adolescent rather than expecting the adolescent to adapt to the services.
2. **Community Based:** Provides local, integrated, and coordinated services.
3. **Comprehensive:** Recognizes the multiple needs of youth, and ensures comprehensive services and holistic care.
4. **Collaborative:** Draws on the resources of a community, or works in coordination with other programs to provide a range of services, in-house or through interagency agreements.
5. **Egalitarian:** Provides services in an environment and a manner that enhances the self-worth and dignity of adolescents; respects their wishes and individual goals.
6. **Empowering:** Maximizes opportunities for youth involvement and self-determination in the planning and delivery of services, and fosters a sense of personal efficacy that encourages youth to want to effect changes in their lives.
7. **Inclusive:** Services all youth, or provides and tracks referrals for those youth whom the program is unable to serve.
8. **Visible, Accessible, and Engaging:** Provides services that attract youth.
9. **Flexible:** Incorporates flexibility in service provision and funding to support individualized services.
10. **Culturally Sensitive:** Works to provide culturally competent services.
11. **Family Focused:** Recognizes the pivotal role that families play in the lives of high-risk adolescents.
12. **Affirming:** Targets strengths, not deficits, of youth and their families.

Pires, S., & Silber, J. (1991). *On their own: Runaway and homeless youth and programs that serve them*. Washington, DC: Georgetown University Child Development Center.

The system of care concept holds that *all* life domains and needs should be considered rather than addressing mental health treatment needs in isolation, and so systems of care are organized around eight overlapping dimensions:

FIGURE A System of Care Framework



The mental health dimension is emphasized due to its obvious importance for children with emotional disorders and includes a range of both nonresidential and residential services and supports (detailed in the section of the Primer on Benefit Design and Service Array).

The following box describes operational characteristics of a system of care as a customized approach to service delivery for children with emotional disorders and their families.

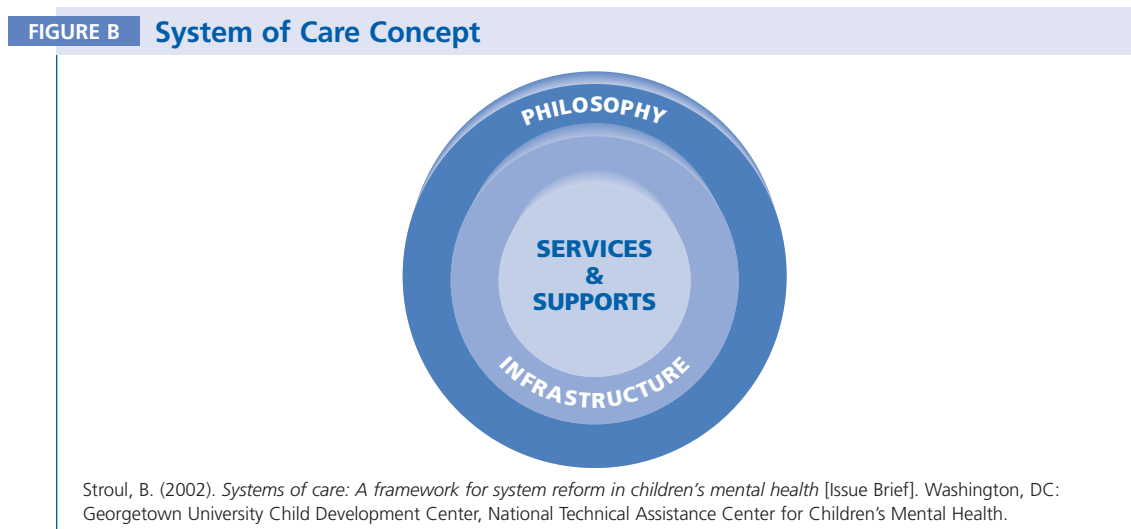
System of Care: Specific, Defined Approach to Customizing Care for Children with Emotional/Behavioral Disorders and Their Families—Operational Characteristics

Characteristics

- Collaboration across agencies
- Partnership with families
- Cultural and linguistic competence
- Blended, braided, or coordinated financing
- Shared governance across systems and with families
- Shared outcomes across systems, reflecting community values
- Organized pathway to services and supports
- Interagency/family services planning teams
- Interagency/family services monitoring teams
- Single plan of care
- One accountable care manager
- Cross-agency care coordination
- Individualized service/supports “wrapped around” child and family
- Home- and community-based alternatives
- Broad, flexible array of services, supports
- Integration of clinical treatment services and natural supports, linkage to community resources
- Integration of evidence-based treatment approaches
- Cross-agency management information systems

Pires, S. (2000). *System of care: Specific, defined approach to customizing care for children with emotional/behavioral disorders and their families—Operational characteristics*. Washington, DC: Human Service Collaborative.

Fundamentally, a system of care is a range of treatment services and supports supported by an infrastructure and guided by a philosophy.



System of care initiatives essentially are addressing entrenched systems’ problems having to do with patterns of utilization, costs, administrative inefficiencies, and poor outcomes. The following box highlights the shifts that systems of care are trying to achieve as *systems reform* efforts.

Characteristics of Systems of Care as Systems Reform Initiatives	
FROM	TO
Fragmented service delivery	Coordinated service delivery
Categorical programs/funding	Multidisciplinary teams and blended resources
Limited service availability	Comprehensive service array
Reactive, crisis-oriented approach	Focus on prevention/early intervention
Focus on “deep end,” restrictive settings	Least restrictive settings
Children out-of-home	Children within families
Centralized authority	Community-based ownership
Creation of “dependency”	Creation of “self-help” and active participation
Child-only focus	Family as focus
Needs/deficits assessments	Strengths-based assessments
Families as “problems”	Families as “partners” and therapeutic allies
Cultural blindness	Cultural competence
Highly professionalized	Coordination with informal and natural supports
Child and family must “fit” services	Individualized/wraparound approach
Input-focused accountability	Outcome/results-oriented accountability
Funding tied to programs	Funding tied to populations

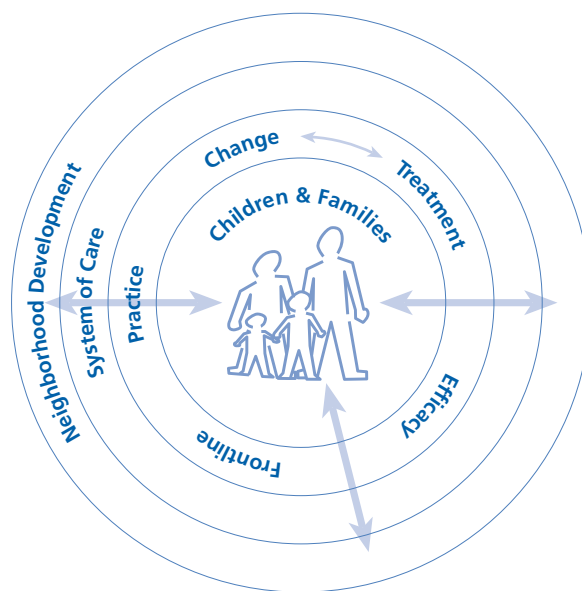
Pires, S. (1996). *Characteristics of systems of care as systems reform initiatives*. Washington, DC: Human Service Collaborative.

This section of the Primer began by reviewing the history of the system of care movement. It is useful to review the history because the system of care movement is not static. Over time, for example, system of care efforts have broadened to encompass not only children with serious disorders, as originally envisioned by CASSP, but also populations of children at risk for serious disorders. More recently, in response to the introduction of managed care into Medicaid, public mental health, and child welfare systems, there is a growing focus on building systems of care for total eligible populations of children and adolescents in given localities, for example, all children in a county or neighborhood who depend on public systems for behavioral health services, which, of course, encompasses children with and at risk for serious disorders.

Historically, systems of care have focused on the organization and financing of services to improve access to and availability of services and to reduce service and funding fragmentation. In addition, systems of care have focused on frontline practice, that is, on the skills, knowledge, and attitudes of service providers. Increasingly, systems of care are concerned about “treatment efficacy,” ensuring effective therapeutic interactions between practitioners and children in care and their families. Systems of care also increasingly recognize the importance of quality of life issues such as safety and

opportunities for recreation in neighborhoods and communities that affect the emotional well-being of children and families. In recent years there has occurred a certain polarization in some quarters with regard to “systems of care versus frontline practice versus community development,” a debate that, basically, makes little sense.

Successful system builders recognize that all of the above are needed to improve emotional outcomes for children and families, in addition to strengthening the capacity of families themselves to guard and enhance their own, and their children’s, emotional well-being. If frontline practice changes but families do not know how to access services, or services are not available, or the delivery system remains fragmented, then only a few families lucky enough to reach “efficacious treatment” will benefit. Conversely, if systems of care are built that improve access, availability, and coordination of care but frontline practice remains ineffectual, then systems of care will improve access but not outcomes. Similarly, if larger neighborhood conditions remain damaging, then, even though families get better services, they will continue to live within “risk conditions.”



Building systems of care is a multifaceted, multilevel process. It involves making changes at state, local, and even neighborhood levels. It entails changes at policy and service delivery levels. Effective system builders are multidimensional, strategic thinkers. They recognize the complexities of system building and tend to be stimulated rather than discouraged by the process. They also are realistic. They recognize that system building takes time, is developmental, and proceeds in both a linear and circular fashion. They weigh strategically which aspects of system building to tackle at which developmental stage and guard against exhausting themselves by trying to take on “everything at once.” They also constantly are looking for allies to engage in system building to spread the workload and maximize the resources.

Over time some basic tenets to guide system builders have become more clearly articulated.

Basic Tenets about Systems of Care

- The system of care concept is a framework and a guide, not a prescription. The concept of a system of care was never intended to be a “model” to be “replicated”; rather it was intended as an organizing framework and a value base. Flexibility to implement the system of care concept and philosophy in a way that fits the particular state and community was emphasized from the beginning. Different communities have implemented systems of care in different ways—no two are exactly alike. It is the philosophy, the value base, that is the constant.
- Systems of care change and evolve over time. The policies, organizational arrangements, service delivery approaches, and treatments change and adapt to changing needs, opportunities, and environmental circumstances in states and communities, in both positive and negative fashion.
- Since a system of care is not a discrete model, it is difficult to say definitively or precisely that one community has one and another does not. It is more appropriate to define the level of development. Building systems of care is a developmental process. Most communities throughout the country have some elements of the system of care philosophy and services in place, even if they are not all far along the developmental pathway.

Stroul, B. (2002). *Systems of care: A framework for system reform in children's mental health* [Issue Brief]. Washington, DC: Georgetown University Child Development Center, National Technical Assistance Center for Children's Mental Health.

As the structures and processes required to build systems of care are discussed throughout this Primer, it is important to acknowledge that there is no one correct way to structure the functions or organize the processes involved in system building. The system of care concept and philosophy offer an organizing framework and a value base that system builders may use as a starting point. Decisions about which structural approaches to implement and precisely how to organize the system-building process depend on the needs, strengths, characteristics, and context (political, economic, and social) of each state and locality.

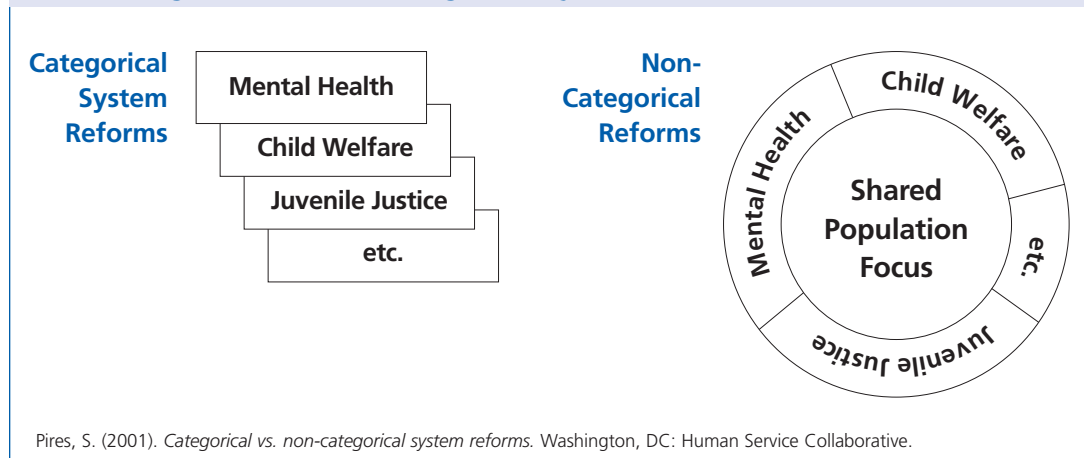
A Non-Categorical Approach

A system of care, by definition, is non-categorical, that is, it crosses agency and program boundaries and approaches the service and support requirements of families holistically. It adopts a population focus across systems.

A non-categorical approach is quite different from one that focuses on reform of a particular system such as a “mental health reform” or a “child welfare reform”—although reform of those systems is entailed in a non-categorical approach. While interagency players and cross-system stakeholders may be involved in a mental health reform or a child welfare reform as they are in a system of care building effort, there is a fundamental difference between the two. *One is a categorical system reform; the other is a non-categorical approach to improving outcomes for a population of children and families. Effective system builders recognize the difference between the two.*

There have been many categorical system reform efforts over the past two decades in children’s services—privatization in child welfare, for example, deinstitutionalization in juvenile justice and in mental health, inclusion in special education, and the like. A challenge for system builders is to identify the features of these categorical reform initiatives that can be incorporated into more holistic systems of care for targeted populations of children with emotional disorders and their families.

FIGURE C Categorical vs. Non-Categorical System Reforms



The Importance of State and Local Partnership in System Building

The system of care concept emphasizes the importance of local control and ownership of the system. The more “local” a system is, the more likely it will reflect community strengths, needs, values, and day-to-day realities. However, system building at local levels cannot sustain itself without state-level commitment; indeed, systems of care at local levels may not even be able to get off the ground without state-level involvement, much less sustain themselves over time. For better or worse, state-level policies and practices have an impact on local systems of care.

Effective system building requires a partnership between state and local stakeholders to clarify and address the ways in which state policies and practices (e.g., regulations, funding, reporting requirements) can be strengthened or altered to support local systems of care. When the partnership is effective, system builders at both levels view themselves as part of the same system-building team. This does not mean that there will not be tensions between state and local levels; such tensions are inevitable if only because there are different, and sometimes competing, constraints, demands, and resources at each level. However, tensions are more likely to be resolved when there is an effective partnership in place rather than a “we-they” operating mentality. *This Primer is intended for both state- and local-level system builders and treats them as part of the same system-building team.*

System Builders

This Primer refers to those involved in developing and implementing systems of care as “system builders.” The term “system builders” is meant to encompass *all* key stakeholders at national, state, and local levels—families and youth, providers, line staff, administrators, policy makers, and evaluators—recognizing that effective system building entails collaboration, consensus building, and partnership across these stakeholder groups and across national, state, county, city, and neighborhood levels.

The Role of Process and Structure in System Building

Building anything involves *processes* and *structures*. As defined for this Primer, *process* fundamentally has to do with who is involved in a system-building effort; the roles, rights, and responsibilities each is accorded or assumes; and how these various players communicate, negotiate, and collaborate with one another. Process also has to do with being strategic (or failing to be). *Structure* refers to those functions that become organized in certain defined arrangements—for example, how children enter the system, how services and supports are individualized, how care is managed, how services are financed, and the like.

Because much has been written already about the processes involved in building systems of care, this Primer devotes more attention to the structural aspects of system building, specifically, the role that structure plays, the functions that require structure, and the challenges and opportunities posed by different structural arrangements for key system of care functions. In no way is this skewing meant to suggest that process is less important than structure. Indeed, breakdowns in process are arguably more harmful to building systems of care and more difficult to repair than are structural breakdowns. Having said that, however, structure—how functions are organized—can undermine even the most effective system-building processes.

Purpose and Organization of the Primer

This Primer offers a roadmap for those involved in building systems of care, whether those systems are for children with serious disorders only and/or for children at risk or for total eligible populations of children and their families. Recognizing that there are many possible routes to take in a journey, the Primer is not meant to be prescriptive but rather to offer a framework for system builders at both state and local levels. The Primer uses examples from actual systems of care to illuminate the framework, drawing on the author’s experience and the experience of many other national, state, and local system builders over nearly two decades with the system of care movement. The Primer is

intended to be useful—as a roadmap, a reference, and a workbook—to family members and youth, local communities, cities, counties, states, and other stakeholders who may wish to use it, in whole or in part, depending on their own needs and circumstances.

The Primer is organized in three main sections. It begins with an *Introduction*, which discusses the history of the system of care movement, the system of care concept and philosophy, and current trends in system reform. This section also describes the values and principles that guide system building. Section I, *Structuring Systems of Care*, describes the role that structure plays in systems of care and the functions that require structure. It explores the pros and cons of different structural arrangements. Section II is on *The System Building Process* and examines critical process considerations in system building.

The sections on *Structure* and *Process* provide a brief, explanatory overview of each structural element and process consideration. In the section on *Structure*, this narrative overview typically is followed by an example or examples borrowed from actual local systems of care (although they may not be identified by name). In the section on *Process*, suggested resource materials follow the narrative overview. The Primer is organized in a workbook-like format, with key questions posed to promote thinking about the reader's specific system-building effort and space to make notes. It is the author's hope that this format also will encourage additions and modifications to the Primer over time as knowledge about systems of care continues to grow.