2nd EDITION

Building Systems of Care
A Primer

BY
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FOR
National Technical Assistance Center for Children’s Mental Health
Georgetown University Center for Child and Human Development

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Acknowledgments to the Second Edition

A
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“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 -
Introduction
A Word About the Second Edition

In the eight years since the first edition of *Building Systems of Care: A Primer*, there has been considerable growth in the system of care movement, with more states, tribes, territories, and communities understanding system of care concepts and embarking on or expanding system of care development. This is partly due to federal leadership and grant making. Communities in every state have had federal system of care grants through the federal Center for Mental Health Services or the Children’s Bureau. Growth also is due to a concomitant strengthening of the family movement and the burgeoning growth of the youth movement, with strong family-run and, increasingly, youth-run organizations supporting system of care development. System of care development also has benefited from expansion of evidence-based and effective practices that reinforce family-driven, youth-guided, and home and community-based system of care concepts. Growth also is the result of the natural progression of system change efforts. It has been said that it takes an average of 17 years for an effective practice in the health care field to “take hold.” It has been a little over 20 years since the system of care movement began. At this moment in time, we are seeing system of care values, principles, and concepts taking hold across child-serving systems at federal, state, and local levels in ways that were not seen in earlier years. Increasingly, the system of care framework is being applied to many different populations of children, youth, and families, from birth to 3-year-olds to transition-age youth and even to adult populations. New technologies have emerged for implementing system of care concepts, some of which draw on related fields such as managed care and public health. All this is by way of saying that an update to the original *Primer* is in order—to capture the sense of growth, new technologies, and expanded applications of the system of care concept.

Strategic Framework

Building systems of care is inherently a strategic process. *Webster’s Dictionary* defines strategic planning as “the science and art of mobilizing all forces—political, economic, financial, psychological—to obtain goals and objectives.” This terminology comes out of warfare! It assumes that there is clarity about goals and objectives. Creating that clarity and mobilizing “all forces” are key roles that system builders play. This document provides a strategic framework to support system builders in these roles by:

- Reviewing the history, values, principles, and operational characteristics of systems of care to create a context for system building;
- Exploring many of the functions that require structure in systems of care;
- Discussing examples and the pros and cons of various structural arrangements to promote improved outcomes for children, youth, and families involved, or at risk for involvement, in multiple systems; and
- Describing and providing examples of effective system-building processes.
**System Builders**

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

**Purpose and Organization of the Primer**

The Primer offers a roadmap for those involved in building systems of care for populations of children, youth, and families who are involved, or at risk for involvement, in multiple systems. In recognition of the 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 state, tribal, 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, tribal, and local system builders over more than 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, youth, local communities, cities, counties, tribes, states, and others who may wish to use it, in whole or in part, depending on their own needs and circumstances.

The Primer is organized into four main sections. It begins with the 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. This initial section is an important context-setting piece for those new to systems of care and for those wanting to understand the development of the system of care concept over time. Section I, Family Partnership, Youth Partnership, and Cultural and Linguistic Competence: Non-Negotiable Elements of Effective System-Building Processes and Structures, describes as essential the integration of family and youth partnerships and cultural and linguistic competence in all system of care structures and processes. These elements are integrated throughout the Primer as intrinsic to effective system of care structures and processes, rather than as stand-alone elements. However, Section I provides an important introductory discussion of why these elements—family and youth partnerships and cultural and linguistic competence—are non-negotiable characteristics of systems of care. Section II, 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 for key functions in systems of care. Section III, The System-Building Process, examines critical process considerations in system-building efforts.
The sections on *Structure* and *Process* provide a brief, explanatory overview of each structural element and process consideration. This narrative overview typically is followed by an example or examples borrowed from actual systems of care (although they may not be identified by name). Suggested resource materials or Websites are incorporated into each section. 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. The author hopes that this format also will encourage additions and modifications to the *Primer* over time as knowledge about systems of care continues to grow.

**A Bit of History About the System of Care Movement**

Over the past 20 years, there have been concerted national efforts to help states, tribes, and localities build *systems of care* for children and adolescents and families who require services and supports from multiple providers and systems. Those involved in building systems of care today are not operating in a vacuum. There is a considerable and rich history to systems of care. Twenty years ago, the concept of systems of care was applied initially to children and youth with serious emotional disorders and their families. It has evolved over time as a concept that can be applied to any designated population of children, youth, and families who require an array of services and supports from multiple entities.

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:

- 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 50 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*.

- 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). The family movement has been strengthened over time with the growth of state, tribal, and local family-run organizations and federal support through the Statewide Family Network Grant program.
• 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.

• In 1989, the Robert Wood Johnson Foundation launched the Mental Health Services Program for Youth, which funded 12 states and cities, and in 1992 provided replication monies to fund 15 more states and localities. Among other contributions, this initiative introduced the use of managed care technologies and one accountable Care Management Entity to the development of systems of care.

• In 1992, Congress passed legislation creating the Comprehensive Community Mental Health Services for Children and Their Families Program, which has funded over 140 communities in all states, as well as tribal communities and several territories, to build systems of care. It is the current major national source of funding for state and 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 with youth, 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. With federal support, YouthMove was launched, which today includes a growing number of state and local chapters and members from around the country who have mobilized to build and grow a youth movement and ensure that the voice of youth guides the development and implementation of systems of care.

• In 1999, the Supreme Court issued the Olmstead decision, which affirmed the right of individuals with disabilities, including children with serious behavioral health disorders, to live in the community rather than in institutions. The decision provided further impetus to system of care efforts to promote the most appropriate, least restrictive, home and community-based services.
In 2003, the *President’s New Freedom Commission on Mental Health* issued its report on transforming mental health care in America, which reinforced such system of care principles as family and youth partnerships, cultural and linguistic competence, individualized services, and early intervention. The report also introduced the application of a public health approach to children’s systems of care.

In 2003, the federal Children’s Bureau funded nine states and local communities to build systems of care for children, youth, and families involved in the child welfare system. In 2008, the Children’s Bureau funded regional technical assistance centers to work intensively with states to reform child welfare systems through application of system of care concepts.

In 2006, the federal Center for Mental Health Services launched the *Building Bridges Initiative* to engage residential treatment providers as partners in promoting system of care principles and concepts.

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

It is useful to review this history because the system of care movement is not static. Over time, system of care efforts have broadened to encompass not only children with serious emotional disorders, as originally envisioned by CASSP, but also other populations of children, youth, and families involved, or at risk for involvement, in multiple systems. The system of care concept has been increasingly embraced, not only by the children’s mental health field, which initiated the movement, but by other systems, such as child welfare and adolescent substance abuse treatment, with national support from federal agencies and foundations.

### Avoiding “Categorical Systems of Care”

The commonality of a system of care focus across major federal programs is encouraging, but there is a danger now in states and localities building “categorical systems of care,” depending on which federal or foundation initiative may be leading the way. One of the major opportunities that a system of care approach provides is to bring together related reform efforts and reduce a “siloed” approach to serving children, youth, and families. Those who have multiple system of care grants, for example, or related reform agendas underway, need to conceptualize these as part of the same cloth when they are focused on common populations of children, youth, and families.
System of Care Definitions

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, on those who also are at risk for serious disorders, or on a total eligible population (e.g., 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. There are growing examples of states’ embedding system of care values and principles into large-scale systems focusing on total populations, such as Arizona’s and New Jersey’s behavioral health managed care systems. These systems encompass all children in need of behavioral health services, not only those with serious disorders. North Carolina’s child welfare system also incorporates system of care values and applies them to all children and families involved, or at risk for involvement, in child welfare, not just to those with the most serious challenges.

The definition of a system of care for children with serious 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 Primer modifies this definition in recognition that the system of care concept has evolved to be applicable to any population of children, youth, and their families who are involved, or at high risk for involvement, with multiple services and systems. (One might also argue that the system of care approach is equally applicable to adult populations with multi-system involvement, such as frail elders or adults with co-occurring mental illness, substance abuse, and physical health problems.)

The Primer defines a system of care as:

“A broad flexible array of effective services and supports for a defined multi-system involved population, which is organized into a coordinated network, integrates care planning and care management across multiple levels, is culturally and linguistically competent, builds meaningful partnerships with families and with youth at service delivery, management and policy levels, has supportive management and policy infrastructure, and is data-driven.”
This definition incorporates the elements that are essential in a system of care. Specifically, the definition includes both formal services and informal supports. It maintains that services and supports must be effective (informed by evidence or experience) for the population or populations who are the focus of the system of care and that the system must identify a defined population or populations. Services and supports must be comprehensive and flexible and organized into a coordinated network. The definition also addresses the importance of service planning and care coordination that is integrated across programs and systems so that families and youth do not end up with multiple plans of care and care managers. It asserts that the system must be culturally and linguistically competent and that meaningful partnerships with families and with youth at all levels are essential. The definition specifies that management and policy infrastructure that supports the system of care is necessary, and that the system must use data to inform decision making, continuously improve quality, be accountable, and build support.

Organizing Framework Supported by Core Values

As Stroul has noted, the system of care concept provides an organizing framework, a philosophy, and a values base for systemic change, which can be applied to any population that requires services and supports across multiple providers or systems.

System of care core values originated over 20 years ago and include child/youth centered and family focused; community based; and culturally and linguistically competent. They developed, initially, out of a children’s mental health movement at a time when many mental health systems were adult focused and hospital based. Hence, values of “child and youth centered and family focused” were in direct response to concerns that children were being treated as “little adults” and not within the context of their families. The value of “community based” was in direct response to the lack of home and community services for children and families and the bias at the time to hospitalize children and youth with serious disorders. The value of “cultural and linguistic competence” was in response to concerns over the disparity in access to services experienced by racially and ethnically diverse children and families and their disproportional representation in restrictive services. These core values have evolved in meaning over time as multiple systems serving children, youth, and families have embraced a system of care approach.

Box A presents the values and principles for the system of care as initially articulated by Stroul and Friedman.
Original 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.


SAMHSA Description of System of Care

A system of care is a coordinated network of community-based services and supports that are organized to meet the challenges of children and youth with serious mental health needs and their families. Families and youth work in partnership with public and private organizations to design mental health services and supports that are effective, that build on the strengths of individuals, and that address each person’s cultural and linguistic needs. A system of care helps children, youth, and families function better at home, in school, in the community, and throughout life.

One can see these values reflected in how the federal Substance Abuse and Mental Health Services Administration (SAMHSA) describes systems of care (see Box B).
Family and youth leaders have expanded the concept of family and youth partnerships to assert as basic principles that systems of care must be family driven and youth guided (see Box C).

### C Family Driven and Youth Guided

**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 communities, states, tribes, territories, and nation. This includes:

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


**Youth-guided** means young people 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.

YouthMove, 2006, Technical Assistance Partnership, American Institutes for Research, Washington, DC.

The *Primer* summarizes system of care values and principles applied to any defined population of children, youth, and families as:

- Family driven and youth guided;
- Home and community based;
- Strengths based and individualized;
- Culturally and linguistically competent;
- Coordinated across systems and services;
- Connected to natural helping networks; and
- Data driven and outcome oriented.

One finds complementary values and principles in the family support movement that emanated from child welfare (see Box D) and in the field of youth development and youth services (see Box E).
**D** 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.


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**E** 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**: Serves all youth, or provides and tracks referrals for those youth whom the system 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.

System of care values also resonate closely with the principles that underpin the federal Child and Family Services Review (CFSR) process in child welfare, which mandates reforms in child welfare. CFSR principles include family-centered practice; community-based services; strengthening the capacity of families; and individualizing services. More information about the principles embedded in CFSR can be found at: www.acf.hhs.gov/programs/cb/cwmonitoring/results/index.htm.

**EXAMPLE A**

Alabama is an example of one of the first states to undertake reform of its child welfare system utilizing system of care principles and values, adding to them and adapting them for the child welfare system, and anticipating by several years CFSR principles in the process. For more information, read: Making Child Welfare Work: How the R.C. Lawsuit Forged New Partnerships To Protect Children and Sustain Families, Judge David L. Bazelon Center for Mental Health Law, Washington, DC, May 1998. (www.bazelon.org)

**EXAMPLE B**

Nevada, Kansas, North Carolina, Oregon, and North Dakota are examples of state child welfare systems that more recently adopted system of care values and principles to guide their child welfare reform activities.

Shared system of care values are what guide a system-building process. Achieving consensus on values across diverse stakeholder groups is a first step in system building. We all come to this work with values that we have integrated into our lives from our cultures, families, work environments, neighborhoods, and the like. These values are tested over time and shaped as system building proceeds. System builders need to create an environment in which it is safe for stakeholders to express their values, and system builders need to provide leadership in developing sufficient common ground for system building to advance. The most successful and sustaining system-building efforts have been those that establish their values early, use them to guide their decisions, and revisit them often to ensure they still hold.

**Operational Characteristics of Systems of Care**

From a philosophy and values standpoint, there is far more synergy today among all the systems that serve children, youth, and families than there was 20 years ago when the system of care movement began. There are greater understanding and more examples of how to apply a system of care approach to different populations of children, youth, and families (and not just to children with serious emotional challenges as was the case 20 years ago when the movement began). There also is more shared understanding today across systems about the operational characteristics of systems of care.
Box F describes operational characteristics of a system of care as a customized approach to service delivery for children and youth with multiple system needs and their families.

### Operational Characteristics of Systems of Care

- Collaboration across agencies;
- Partnerships with families and youth, including with family- and youth-run organizations;
- Cultural and linguistic competence;
- Blended, braided, or coordinated funding;
- Shared governance (and liability) across systems and with families and youth;
- Shared outcomes across systems;
- Organized pathway to services and supports;
- Staff, supervisors, providers, and families trained and mentored in a common practice model based on system of care values;
- Child and family service-planning and service-monitoring teams across agencies;
- Single plan of services and supports;
- One accountable care manager;
- Cross-agency service coordination and care management;
- Individualized services and supports “wrapped” around children, youth, and families;
- Home and community-based alternatives;
- Broad, flexible array of services and supports;
- Integration of formal services and natural supports and linkage to community resources;
- Integration of evidence-based and promising practices; and
- Data-driven systems supported by cross-system management information systems and focused on continuous quality improvement.

The concept of systems of care developed and has taken root over time as an approach to address long-standing problems with traditional systems, many of which persist today (see Box G).

### Entrenched System Problems

- Lack of home and community-based services and supports both for children and youth and for families;
- Patterns of utilization—that is, the ways in which children and families use services and supports—in which relatively small percentages of children and families with the most serious and complex issues use a very large percentage of the service dollars because, for example, children are placed for too long or repeatedly in restrictive levels of care and because financing streams may create incentives to place children;
- High costs associated with these patterns of utilization;
- Racial and ethnic disparities in access to community services and disproportional representation in restrictive services;
- Administrative inefficiencies when multiple systems serving children and families create parallel delivery systems serving many of the same children and families;
- Knowledge, attitudes, and skills of key stakeholders (e.g., staff, supervisors, providers, clinicians, families, and youth) that do not embrace or know how to implement family-driven, youth-guided, culturally and linguistically competent, strengths-based, and individualized services and supports;
- A history of poor outcomes;
- Rigid financing structures; and
- Deficit models with limited types of interventions that do not lend themselves to a strengths-based, individualized approach.
A fundamental challenge to multiple system involvement in the lives of children, youth, and families is that no one system controls everything, and every system controls something. Systems of care represent a way to address this basic challenge of multiple system involvement in the lives of families and fractured accountability. Better outcomes are more likely to be achieved through the effective collaboration called for in systems of care.

**Systems of Care as System Reform or Transformation Efforts**

Systems of care fundamentally are about reforming or transforming systems. Box H highlights the shifts that systems of care are trying to achieve as system reform or transformation efforts.

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


System reform involves both system-level and frontline practice change. Box I illustrates shifts required at a practice level.
System reform not only involves changes in the way that staff and providers interact with families and youth but changes as well in the roles and expectations of families and youth themselves, as Box J illustrates.

Just as staff and providers need training and supports to make the shifts called for in systems of care, so, too, do family and youth partners and community partners.

In summary, systems of care as system reform efforts entail changes at multiple levels: policy level, management level, frontline practice level, and community level, exemplified in Box K.
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 and youth 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 a non-categorical approach also entails reform of those systems. While interagency players and cross-system stakeholders may be involved in a mental health reform or a child welfare reform just as they would be in an effort to build a system of care, there is a fundamental difference between the two, as shown in Illustration A. 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 populations of children, youth, and families involved in more than one of these systems.

**ILLUSTRATION A**

Categorical vs. Non-Categorical System Reforms

<table>
<thead>
<tr>
<th>Categorical System Reforms</th>
<th>Non-Categorical Reforms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health</td>
<td></td>
</tr>
<tr>
<td>Child Welfare</td>
<td></td>
</tr>
<tr>
<td>Juvenile Justice</td>
<td></td>
</tr>
<tr>
<td>etc.</td>
<td></td>
</tr>
</tbody>
</table>

A Shared Population Focus

An essential early focus of system builders needs to be on understanding the populations of children, youth, and families that are involved, or are at risk for involvement, in multiple systems and determining the populations of focus for the developing system of care, which may be the total population or subsets of the total. Several ways of thinking about subsets is by:

- **Demographics**, for example, Infants and toddlers? Transition-age youth? Racially and ethnically diverse children and youth experiencing disparities in access to services or disproportional representation in restrictive services?
- **Intensity of system involvement**, for example, children and youth in out-of-home placements, such as residential treatment centers or group homes
- **At-risk characteristics**, for example, children with birth families at risk of child welfare involvement, children in permanent placements at risk for disruption, families in which methamphetamine abuse is occurring, teen mothers under severe stress; and
- **Level of clinical/functional impairment**, for example, children with serious emotional disorders, children with serious physical health conditions, children with developmental disabilities, children and youth with co-occurring disorders, such as mental health and developmental challenges, and mental health and substance abuse problems.

System builders need to ask themselves, “Who are the populations of children, youth, and families that we are especially concerned about because they are experiencing poor outcomes and/or high costs in our current service systems or are at very high risk of experiencing poor outcomes and/or high costs if we do nothing?”

Understanding the prevalence of problems and current utilization—that is, the way that children and families use services and supports—also is essential. Visually, think of a triangle representing prevalence and service utilization among all children and families in a given state, tribe, territory, or community for problems that may lead to involvement with public systems (see Illustration B).
At the top of the triangle is the relatively small percentage of children, youth, and families with serious and complex problems who may be using a large percentage of the dollars; these are typically children and youth in out-of-home placements. In the middle of the triangle are various at-risk populations of children and families who need services and supports but where there may be few resources available (because a large percentage of the dollars is going to the top of the triangle). This middle tier includes families at risk for child welfare involvement, for example, or youth at high risk for juvenile justice involvement. At the bottom of the triangle are most children and families, who do not need specialized services and supports but where health and mental health promotion and primary prevention are imperative. In most states, however, very few resources are available for promotion and prevention (because the dollars are being spent on the rest of the triangle).

A Population-Driven Systems Approach

The strengths and needs of the populations of focus must drive the types of services, supports, and strategies that will be required in the system of care, the financing streams that need to be accessed, the stakeholders that need to be involved, and so on. For example, if the system is focusing initially on infants and young children and their families, it must partner with early intervention programs like Head Start and child care, and primary care practices are especially critical. If it is focusing on transition-age youth, as displayed in Box L, another set of players, funding streams, services, supports, and community resources comes into play.
Resonance With a Public Health Approach

Over the past decade, systems of care have moved closer to a public health framework, focusing not only on treatment for individual children with serious conditions but also encompassing promotion, prevention, early intervention, and education to improve outcomes and health, and developmental and behavioral health status for identified populations of children and youth. For example, early childhood systems of care, such as those in Colorado and Vermont, have created effective partnerships with early childhood settings, such as child care and Head Start programs, and with primary care to promote developmental and emotional well-being in young children. Other systems of care, such as those in Rhode Island, are partnering with the schools to implement universal, school-wide behavioral health promotion approaches, such as Positive Behavioral Interventions and Supports, to change school climate, reduce stigma, and promote emotional well-being, at the same time, linking youth with serious challenges to appropriate services. The President’s New Freedom Mental Health Commission Report stressed a number of important public health-related goals for a transformed behavioral health system, including education to reduce stigma, early screening, assessment and treatment, and reduction of disparities experienced by racially and ethnically diverse populations and those in rural communities.

Example: Transition-Age Youth

What outcomes (e.g., connection to caring adults, employment, education, and independence) do we want to see for this population?
What will our system look like for this population?

Policy Level
• What systems (e.g., housing, vocational rehabilitation, employment services, mental health and substance abuse, Medicaid, schools, community colleges/universities, physical health, juvenile justice, and child welfare) need to be involved?
• What dollars/resources do they control?

Management Level
• How do we create a locus of system management accountability for this population (e.g., in-house, lead community agency)?

Frontline Practice Level
• Are there evidence-based/promising approaches (e.g., Family Finding) targeted to this population?
• What training do we need to provide, and for whom, to create desired attitudes, knowledge, and skills about this population?
• What providers (e.g., culturally diverse providers) know this population best in our community?

Community Level
• What are the partnerships we need to build with youth and families?
• How can natural helpers in the community play a role?
• How do we create larger community buy-in?
• What can we put in place to provide opportunities for youth to contribute and feel part of the larger community?
The Importance of State, Tribal, 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. In addition, for states and communities with tribal populations, partnerships with tribes are essential. Tribes operate as sovereign nations, with their own rights and laws. Tribes have the right to intervene in situations that involve children and families who are tribal members, and tribal children and families often are involved in services and supports provided both through the tribes and by state and local systems.

Effective system building requires a partnership between state, tribal, and local stakeholders to clarify and address the ways in which state policies and practices (e.g., regulations, funding, and reporting requirements) can be strengthened or altered to support local and tribal systems of care. When the partnership is effective, system builders at all levels view themselves as part of the same system-building team. This partnership does not mean that there will not be tensions between state, tribal, 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-tribal and local-level system builders and treats them as part of the same system-building team.*

A Multifaceted Approach

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. Systems of care are concerned about “treatment efficacy,” ensuring effective therapeutic interactions between practitioners and children in care and their families.

Systems of care have been influenced over the past decade by the movement toward evidence-based and promising practices in child and family services—and vice versa. *Evidence-based practices* “show evidence of effectiveness through carefully controlled scientific studies, including random clinical trials”; these are practices that have had the benefit of research dollars. *Promising approaches* (also referred to as “practice-based evidence”) “show evidence of effectiveness through the experience of key stakeholders—
Building Systems of Care: A Primer

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 well-being of children and families.

Successful system builders recognize that all the above are needed to improve outcomes for children and families, in addition to strengthening the capacity of youth and families themselves to guard and enhance their own, and their children’s, 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 “effective services” 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, tribal, 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 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 (see Box N).

<table>
<thead>
<tr>
<th>Evidence-Based Practices</th>
<th>Show evidence of effectiveness through carefully controlled scientific studies, including randomized clinical trials</th>
</tr>
</thead>
<tbody>
<tr>
<td>Promising Approaches/Practice-Based Evidence</td>
<td>Show evidence of effectiveness through experience of key stakeholders (e.g., families, youth, providers, and administrators) and outcome data</td>
</tr>
</tbody>
</table>

Systems of care need both evidence-based practices and promising approaches (see Box M).
Introduction

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 to 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, tribe, territory, and locality.

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 quality is monitored, how services are financed, and the like.

Because much has been written already about the processes involved in building systems of care, the 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.

**WEB RESOURCES**

Substance Abuse and Mental Health Services Administration Systems of Care Section at: [www.systemsofcare.samhsa.gov](http://www.systemsofcare.samhsa.gov)

Children’s Mental Health Initiative Digital Library at: [www.cmhi-library.org](http://www.cmhi-library.org)

National Technical Assistance Center for Children’s Mental Health at: [http://gucchdtacenter.georgetown.edu](http://gucchdtacenter.georgetown.edu)

Technical Assistance Partnership for Child and Family Mental Health at: [www.tapartnership.org](http://www.tapartnership.org)


System of Care Alumni Network: [www.systemofcarealumni.org](http://www.systemofcarealumni.org)

Family Partnership, Youth Partnership, and Cultural and Linguistic Competence

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Youth Partnership, Support, and Development at All Levels 31
The Important Role of Family- and Youth-Directed Organizations 36
Cultural and Linguistic Competence 38
Overview

To be effective, system-building processes and structures need to support the ability to operate in cross-cultural situations and to partner effectively with families and with youth. Family and youth partnerships and cultural and linguistic competence are not stand-alone characteristics, but are woven throughout the fabric of system of care processes and structures (as are the characteristics of cross-agency collaboration and state, local, and tribal partnership noted earlier). Family and youth partnership and attention to diversity, along with a cross-agency perspective and state, local, and tribal partnership, are non-negotiable characteristics of effective system-building processes and structures. Building Systems of Care: A Primer integrates concepts and examples of family and youth partnership and cultural competence throughout its discussion of system of care processes and functions requiring structure, rather than having just a stand-alone section on these intrinsic characteristics of effective systems of care.

Family Partnership, Support, and Development at All Levels

(i.e., Policy Level, Management Level, and Service Level)

In effective systems of care, families are partners at policy making, management, and service levels of the system with other key stakeholders. Effective systems do not simply invite families to be part of the process—although asking families whether and how they want to be involved is a critical first step. They also actively support and engage families in a number of ways, for example, by providing tangible supports such as transportation, translation, and child care assistance; by recognizing and drawing on the knowledge and skills that parents bring to the table (e.g., utilizing parents as trainers of other stakeholders); by providing capacity-building support, such as training and peer and non-peer mentoring, that gives families the information, skills, and confidence to partner; and by asking families how they would like to be involved. Effective system builders recognize that families are diverse—racially, ethnically, linguistically, socioeconomically, and in family composition; thus, they utilize multiple strategies and structures for family involvement and support.

There are increasing examples of how systems of care are structuring family involvement at the various levels of the system (see Illustration 1.1). At the policy level, for example, families may comprise the majority vote on governance bodies; they may be part of the team that drafts legislation; they may participate on system design workgroups and on system advisory bodies. At the management level, families may be actively involved in developing and implementing quality improvement processes, in evaluating system performance, in helping to recruit and select personnel, in framing
Requests for Proposals, and in training activities, and they may be managers in systems. At the service level, in addition to the role that families play with respect to their own children, they may be service providers, care managers, family support workers, peer mentors, system navigators for other families, and advocates on behalf of other families.

Family partnership is a fundamental practice shift, which requires capacity building to change attitudes, build knowledge about how to partner, and teach and coach partnering skills. Concerns may arise about partnering with families—such as families lacking expertise about policy issues or families having too many personal crises to be reliable. System builders need to strategize ways to address these issues, such as training, orientation, and coaching (for families and other system partners) and connecting families to family organizations for supports. It is important for system partners to acknowledge that families may have experienced a system “culture” that fostered feelings of fear, anxiety, hopelessness, and powerlessness. As a result, families may feel anger, shame, and distrust, making them reluctant to partner. Again, system builders need to work in partnership to develop strategies to address these issues, such as supporting family organizations to work with families about practice change goals and with system partners to change the practice culture in agencies so that families do feel respected and sought after as partners.

Some systems of care fund family organizations to play various roles in the system of care; some hire family liaisons who work within the system. Some systems form alliances (unpaid) with family organizations and utilize paid family advocates within the system. There are pros and cons to whatever structure is developed for the involvement of families, depending on the particular locale and perspectives of different stakeholders. For example, families involved in some systems of care believe strongly that to be hired or paid by the system leads to co-optation, whereas families in other systems of care feel just as strongly that the system’s hiring of families allows for greater equalization of parent-professional status in the system and ensures that families get “inside” information directly from a family member (i.e., not filtered through non-family staff).
The points being made here are threefold:

- Family involvement, support, and development at all levels of the system must be structured, that is, deliberately organized and not left to happenstance, and multiple strategies are necessary to engage the diversity of families affected by systems of care.
- Whatever structures are put in place will have advantages and disadvantages to them, depending on local circumstances and stakeholder perspectives.
- It is incumbent upon system builders including families to be thoughtful about the pros and cons of different structures in order to understand how they will affect different stakeholders’ experiences, level of involvement, and attainment of system goals.

In the following example, family involvement is the building block on which all other structures of the system of care are based.

**EXAMPLE 1.1**

The Parent Support Network of Rhode Island (PSN) worked with the Rhode Island Coalition for Family Support and Involvement to develop a self-assessment tool for system builders, called *Family-Centered Practice: How are we doing?* The tool incorporates a family-centered rating scale that supports families, policy makers, administrators, service providers, and the like, to examine how programs, supports, or services are family centered. Examining the key areas supports system builders in identifying strengths and areas that need improvement. These key areas include: focus on the strengths of the child and family; support relationship building and community membership; foster mutual trust and respect between families and program staff and/or administration; promote family choice and control; offer families good information and access to information; and include families in policy decisions and program planning. ([www.psnri.org](http://www.psnri.org))

**EXAMPLE 1.2**

In a rural county in a northeastern state, family members took the lead in designing the system of care. They first prioritized services and supports needed, which included: respite; an advocate to help families navigate; information and referral; parent and sibling support; a family center; community supports such as after school activities, crisis services, and concrete assistance. They developed specific recommendations, which became the basis for system of care policies. For example:

- All committees, including the board and steering committee, should have at least 50 percent parent representation.
- Preference for all staff positions should be given to parents of children with special needs.
- Parents should participate as trainers in the training of all staff and volunteers.
- Parents should establish criteria for family-friendly agencies and award those that meet the criteria a “Family Friendly Seal of Approval.”
- Families should interview and “hire” those professionals and service providers working with them. Participants and service providers should have an agreement for a trial period after which either can decide to discontinue the contract. There should be scheduled periodic evaluations as part of every agreement to see if the match is successful and if the service suits the provider and the family.
- Families First should stress the importance of sensitivity to language that is respectful and inclusive of parents. Specifically, families should be referred to as “multi-stressed,” never “dysfunctional.” People using Families First services are “participants,” not “clients.” The term “advocate” should be used rather than “case manager.”

WEB RESOURCES

National Federation of Families for Children’s Mental Health at: www.ffcmh.org


YouthMove National at: www.youthmove.us


National Alliance on Mental Illness Child and Adolescent Action Center at: www.nami.org/caac


National Directory of Family-Run and Youth-Guided Organizations for Children’s Mental Health at: http://familyorgdirectory.fmhi.usf.edu


Key Questions: Family Partnership, Support and Development

- What are our structures for partnering with families at policy, management, and service delivery levels?
- What are the pros and cons to the structures we have for family involvement?
- Have we provided families with the necessary resources to partner effectively?
- Do we have strategies for building and growing a family-run organization to support family voice over time?
- How do our structures for family involvement and support promote or limit the participation of diverse families?

NOTES
Youth Partnership, Support, and Development at All Levels
(i.e., Policy Level, Management Level, and Service Level)

Many of the same points made about family involvement pertain to youth involvement as well. That is, partnerships with youth need to be structured at all levels of the system and not left to happenstance. This is particularly the case with youth partnerships because systems historically have been even slower to build meaningful partnerships with youth than with families.

Systems of care have begun to recognize the value of and embrace a “youth development” approach, that is, engaging youth as partners in program design and implementation, affirming and drawing on the strengths of youth, and involving youth in service delivery. Box 1.1 presents the principles articulated for a youth-guided system.

### 1.1 Principles of a Youth-Guided System

- Youth have rights
- Youth are utilized as resources
- Youth have an equal voice and are engaged in developing and sustaining the policies and systems that serve and support them
- Youth are active partners in creating their individual support plans
- Youth have access to information that is pertinent
- Youth are valued as experts in system transformation
- Youths’ strengths and interests are focused on and utilized
- Adults and youth respect and value youth culture and all forms of diversity
- Youth are supported in a way that is developmentally targeted to their individual needs

YouthMove, 2006, Technical Assistance Partnership, American Institutes for Research, Washington, DC

As youth voice has grown in systems of care, youth themselves have conceptualized systems as needing to support youth, at individual, community, and policy levels, to move along a continuum from youth guided, to youth directed, to youth driven, as the following schematic, Illustration 1.2, developed by YouthMove shows.
Youth also have conceptualized the shifts to a youth-guided system as a “ladder” symbolized by Illustration 1.3.

**YOUTH GUIDED**

Young people 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 care for all youth in the community, state, and nation. This includes giving young people a sustainable voice, and the focus should be toward creating a safe environment enabling a young person to gain self-sustainability in accordance with their culture and beliefs. Through the eyes of a youth-guided approach, we are aware that there is a continuum of power and choice that young people should have based on their understanding and maturity in this strength-based change process. Youth guided also means that this process should be fun and worthwhile.

**YOUTH DRIVEN**

Youth initiated, planned, and executed in partnership with others
Youth advocate for other young people
Expert level of understanding

**YOUTH DIRECTED**

Continuing with youth-guided process
Increased knowledge of services and resources
In a safe place (not in continual crisis)
Taking a more active decision making role in treatment and in the system of care (policy, etc.)
Deeper understanding of system

**YOUTH GUIDED**

Knowledge of services
Voice in identifying needs and supports
Beginning to research and ask questions about resources
Learning how to self advocate
Beginning to understand the process of system and services
Articulate experience and what helps and what harms

**Education foundation** **Awareness foundation**
**Resources foundation** **Support foundation** **Philosophies**

Youth also have conceptualized the shifts to a youth-guided system as a “ladder” symbolized by Illustration 1.3.

**ILLUSTRATION 1.3**

**LADDER OF YOUNG PEOPLE’S PARTICIPATION**

Youth initiated and directed
Youth initiated, shared decisions with adults
Youth and adult initiated and directed
Adult initiated, shared decisions with youth
Consulted and informed
Assigned and informed
Tokenism
Decoration
Manipulation
There is a valuable body of youth development research and practice, which can inform the efforts of system of care builders. The Center for Youth Development and Policy Research, for example, has articulated a Youth Development Perspective, displayed in Box 1.2.

**1.2 A Youth Development Perspective**

- Engages and involves youth as active participants in the planning, implementing, monitoring, and evaluating of programs and projects that are designed to serve them
- Creates and strengthens the infrastructures that support positive development of all young people working through local citizens and with local partners
- Ensures young people have the skills and opportunities for voice, value and visibility in communities, schools, government and larger society
- Provides pathways and skills for emerging leaders to advocate for social justice and lead work of the social sector
- Encourages and empowers young people to adopt healthy lifestyles
- Supports young people to gain workforce skills and link them to meaningful employment
- Helps youth to develop the skills to avoid or mitigate conflict

**YOUTH ARE CURRENT RESOURCES, NOT FUTURE ASSETS**


The Center for Youth Development and Policy Research also articulated barriers to youth development as perceived by adults and as perceived by youth. Although there is some overlap in perceptions, there also are unique perspectives that youth have that are different from those of adults. For example, while both groups identify racism as a barrier, youth also identify ageism, sexism, stereotyping by appearance, and homophobia as barriers. Box 1.3 shows the importance of the youth perspective in a strategic system-building process.

**1.3 Barriers to Youth Participation**

<table>
<thead>
<tr>
<th>AS IDENTIFIED BY ADULTS</th>
<th>AS IDENTIFIED BY YOUTH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time</td>
<td>Ageism/Adultism</td>
</tr>
<tr>
<td>Funding</td>
<td>Money</td>
</tr>
<tr>
<td>Staffing</td>
<td>Racism, sexism, homophobia</td>
</tr>
<tr>
<td>Access to youth</td>
<td>Stereotyping by appearance</td>
</tr>
<tr>
<td>Lack of training (in how to work with youth)</td>
<td>Time</td>
</tr>
<tr>
<td>Politics</td>
<td>Transportation</td>
</tr>
<tr>
<td>Parents</td>
<td>Language</td>
</tr>
<tr>
<td>Adult staff not empowered</td>
<td>Lack of access to information</td>
</tr>
<tr>
<td>Program evaluation requirements</td>
<td>Lack of access to opportunities</td>
</tr>
<tr>
<td>Weak leadership</td>
<td>Lack of support from adults</td>
</tr>
<tr>
<td>Racism</td>
<td>Few role models</td>
</tr>
<tr>
<td></td>
<td>Lack of motivation</td>
</tr>
</tbody>
</table>

Initiating and continuing a dialogue with youth is a first step in all parties thinking strategically about how to break down barriers. There are many different roles for youth in systems of care (see Box 1.4).

### 1.4 Roles for Youth: Infusing Youth Voice at all Levels

- Engage youth in planning and implementation
- Create youth advisory boards
- Develop youth-run organizations
- Train and utilize youth as peer mentors
- Involve youth as educators/trainers/evaluators


It has been fairly common for youth movements in systems of care to be launched by family organizations. This approach can provide a stable home for a developing youth movement, though a potential drawback is that youth may feel they lack sufficient autonomy. Open and respectful discussion between youth and family organization stakeholders can lead to effective strategies for utilizing the strengths of an existing family organization to nurture a youth movement while supporting independence as the movement matures.

**EXAMPLE 1.3**

**Parent Support Network of Rhode Island**, the statewide family organization, brought youth together to launch a youth-driven empowerment, support, and advocacy group. This group became **Youth Speaking Out**, which emphasizes leadership development, community/civic service, and peer-to-peer support activities for youth with a wide range of mental health challenges, youth living in high-risk situations, and youth who have parents with substance abuse challenges or who are incarcerated. Youth from **Youth Speaking Out** have presented at local, state, and national conferences. They meet weekly, determine their own activities; participate in a broad range of community service activities, such as restoring shelters; and provide peer supports to one another. Staff from Parent Support Network, including a Youth Coordinator, offer support, guidance, and resources to help the youth achieve individual and group goals. ([www.psnri.org](http://www.psnri.org))
WEB RESOURCES
National Federation of Families for Children’s Mental Health at: www.ffcmh.org
YouthMove National at: www.youthmove.us
National Alliance on Mental Illness Child and Adolescent Action Center at: www.nami.org/caac
National Directory of Family-Run and Youth-Guided Organizations for Children’s Mental Health at: http://familyorgdirectory.fmhi.usf.edu

Key Questions:
Youth Involvement, Support and Development

■ How does our system of care incorporate a youth development framework?
■ What are our structures that support youth involvement at policy, management, and service delivery levels?
■ Have we provided youth with the necessary resources (funding, training, information, etc.) to partner effectively?
■ What are our strategies for building and growing youth voice in our system of care?

NOTES
The Important Role of Family- and Youth-Directed Organizations

Organizing family and youth networks through the work of a family- or youth-directed organization is a key strategy in systems of care to support family and youth involvement. Strategies include both partnering with existing family and youth associations/organizations and supporting the development of new ones where none exists. These associations or organizations can start as informal networks of support and can grow over time.

Some of the considerations in establishing a new family- or youth-directed organization include:

- Identifying and supporting natural family and youth leaders in the community;
- Providing adequate funding;
- Delineating relationships;
- Letting families and youth decide the mission, goals, structure, and activities of the new organization; and
- Partnering with families and youth in strategic planning for sustainability.

Key elements in contracting with existing family or youth organizations include ensuring that the organization has the following:

- Representation from the culturally and linguistically diverse families and youth involved in the system;
- Strong ties to the community and linkages with other family and youth groups, both locally and nationally;
- Clear expectations of what is required;
- Performance criteria and evaluation procedures; and
- Fair compensation for the work to be performed.

A family or youth organization can help to ensure a higher level of accountability from the system of care than individuals working on their own might be able to create, to ensure that families and youth receive the necessary services and supports and that they are involved in meaningful ways as system partners (see Box 1.5).

### 1.5 Role of Family- and Youth-Directed Organizations

- Mobilize family and youth voice.
- Provide a structure for implementing family and youth partnerships with the system of care.
- Engage and support families and youth, including families and youth who may feel disenfranchised from or distrustful of the system.
- Create ties to the larger community and to other family and youth organizations.
Through its capacity to develop family or youth leadership and mobilize a family and youth “voice,” an organization can strengthen the strategic approach to family and youth partnership building within the system of care. Family and youth organizations also can play an effective role in creating a safe space for families and youth to air concerns and obtain support to become involved in system change. Family and youth organizations that have viable partnerships with system partners, such as state, tribal, and local agencies, including access to resources (dollars, training, etc.), are in a position to build capacity to embed family and youth voice into all levels of the system. The strength of the relationships between these system partners and family- and youth-run organizations is a key factor in the sustainability and growth of family and youth voice in systems of care. The Family Involvement Center in Maricopa County, Arizona (Phoenix), provides one example from many of a family organization that through effective partnerships with state and local agencies, including access to resources, has meaningful and substantive involvement in the system of care at all levels (see Example 1.4).

**EXAMPLE 1.4**

**FAMILY INVOLVEMENT CENTER FUNCTIONS**

**Under State Mental Health Contract:**
- Policy and system management involvement
- Payment of stipends, transportation, child care to support family and youth partnership at policy/system management levels
- Training of families, providers, staff on AZ system of care principles and family and youth partnership
- In partnership with MIKid, development of a Latino family organization
- Building of family and youth movement

**Under Administrative Contract with Maricopa County Regional Behavioral Health Authority:**
- Staff and participate on Children’s Advisory Council
- Recruit and train family partners for variety of roles
- Recruit, train, and support family peer mentors
- Organize open education opportunities
- Provide information and referral
- Co-facilitate administrative meetings
- Train and provide technical assistance to providers on family and youth partnership

**Under Contract as a Direct Service Provider to Provide:**
- Peer mentoring
- Respite
- Behavioral coaching
- Skills training
- Health promotion
- Family support and education
- Personal aide services
- Case management

**Under Contract with State Child Welfare System:**
- Provide peer support for families at risk of child welfare involvement through a Family-to-Family approach

See: www.familyinvolvementcenter.org
Effective systems of care respect and make every effort to understand and be responsive to cultural and linguistic differences. Typically, systems of care are serving children, youth, and families from diverse racial, ethnic, and socioeconomic backgrounds. The recognition of this diversity undergirds the system of care principle and practice of individualizing services and supports.

As noted in the Overview, cultural and linguistic competence are not stand-alone functions but, rather, need to be infused within every structure that is built in systems of care and within the system-building process. The Primer tries to model the integration of cultural and linguistic competence into all aspects of system building by addressing relevant issues and strategies within each section in II. Structuring Systems of Care and by addressing cultural and linguistic competence as a core element of III. The System-Building Process. For example, within Section II, Subsection 2.20 of the Primer, Quality Management, Continuous Quality Improvement (CQI), and Evaluation, attention is paid to the disparities in data collection, analysis, and reporting that historically have been the case with respect to diverse populations and the importance of structuring quality improvement and evaluation approaches that are culturally and linguistically competent. In Section II, Section 2.13 of the Primer, Purchasing and Contracting, there is discussion of how certain types of contracting arrangements may disadvantage small, non-traditional, or indigenous providers serving diverse communities and the importance of structuring purchasing and contracting mechanisms that intentionally reach out to and include those providers. These are examples of how the Primer integrates cultural and linguistic competence throughout structural and process considerations rather than having just a free-standing section on the topic.

Although the Primer treats cultural and linguistic competence as an intrinsic element of every system of care function, it also is essential that system builders create structures that pay attention to cultural and linguistic competence across functions and within the ongoing system-building process. For example, some states and localities create planning and implementation teams or workgroups whose role is to assess cultural and linguistic competence issues and needs within system of care structures and processes and to develop and oversee appropriate responses and strategies on an ongoing basis.

In recognition that different terminology may be used across stakeholders and communities, the following definitions are offered for cultural and linguistic competence (see Box 1.6).
I. Family Partnership, Youth Partnership, and Cultural and Linguistic Competence

Culture matters because culture affects:

• Attitudes and beliefs about services;
• Parenting and child rearing;
• Expression of symptoms;
• Coping strategies;
• Help-seeking behaviors as well as helping behaviors;
• Utilization of services and social supports; and
• Appropriateness of services and supports.

Valuing diversity is a key principle of systems of care. It should also be noted that federal law, Title VI of the Civil Rights Act of 1964, prohibits discrimination on the basis of race and national origin and also applies to cases in which individuals with limited English-speaking ability have trouble accessing services because of language barriers.

In addition to recognizing that all children and families bring a unique cultural background with them, effective systems of care also acknowledge and address proactively the disparities in access and treatment that historically have been the experience of diverse families in traditional systems. One would be hard pressed to find a state or locality in the country in which ethically, racially, and linguistically diverse children and families are not overrepresented in the most restrictive, “deep end” services and underrepresented in quality community-based services. This finding tends to be the case even in states and communities with relatively few racial and ethnic minority families.

Numerous studies, as well as the U.S. Surgeon General in 2001, have documented that racial and ethnic minority children tend to have less access to services, receive poorer quality services, and are more likely to be placed into care. The first round of Child and Family Services Reviews in child welfare found that White children achieve permanency outcomes at a higher rate than children of color. Disparities include not only children, but families. For example, African American families are investigated for child abuse and neglect twice as often as White families.

### Cultural and Linguistic Competence: Definitions

**Culture**
A broad concept that reflects an integrated pattern of a wide range of beliefs, values, practices, customs, rituals, and attitudes that make up an individual.

**Cultural Competence**
Accepting and respecting diversity and difference in a continuous process of self-assessment and reflection on one’s personal (and organizational) perceptions of the dynamics of culture.

**Linguistic Competence**
The capacity of an organization and its personnel to communicate effectively and convey information in a way that is easily understood by diverse audiences, including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities.

A key aspect of a culturally competent approach is to understand the racial and ethnic disparities and disproportionality issues in one’s particular system. A system may also experience geographic disparities and disproportionality with, for example, rural areas being under- or overrepresented in the system, and certain populations beyond those that are racially and ethnically diverse may experience stigma and disparity in access to services, such as youth who are lesbian, bisexual, gay, transgender, or questioning (that is, youth who are sometimes referred to as “sexual minority youth”).

In a study conducted by the Congressional Research Service, child welfare administrators, supervisors, and workers offered their theories on why there is racial and ethnic disproportionality in child welfare, including: poverty and related issues, such as homelessness; lack of community resources to address a range of issues, such as substance abuse and domestic violence; greater visibility of minority families for reporting of child maltreatment; a lack of experience (among those working in systems) with other cultures and lack of familiarity regarding what constitutes abusive behavior across these cultures; and media pressure to remove children (Congressional Research Service, August 2005. *Race/Ethnicity and Child Welfare*).

Each of these potential reasons for the racial and ethnic disproportionality in child welfare lends itself to particular collaborative strategies for change. For example, combining resources across systems and partnering with natural helping networks might help to make more services and supports available. Training and coaching across systems and partnering with families and youth might help to increase cultural awareness and reduce biased decision making. Social marketing strategies might help to alleviate media pressure to remove children. The point is that cultural and linguistic competence, like all aspects of system building, must be approached strategically.

### EXAMPLE 1.5

**South Dakota’s Collaborative Circle for the Well-Being of South Dakota’s Native Children** was established because Native American children were so disproportionally represented in South Dakota’s child welfare system. Key stakeholders came together in 2005 and committed themselves to partnering to reduce the number of Native children in child welfare and to achieve better outcomes for Native children and families. The partners are (1) the nine Sioux Tribes; (2) the State Division of Child Protection Services; (3) birth parents, family caregivers, and youth; (4) and the provider community. Together, they created the Collaborative Circle, and since its creation, there reportedly has been a 10% reduction in Native disproportionality in child welfare. For more information, contact: [http://dss.sd.gov/cps/icwa/index.asp](http://dss.sd.gov/cps/icwa/index.asp).
Some years ago, Terry Cross of the National Indian Child Welfare Association and colleagues identified a “cultural competence continuum,” which still has relevance (see Illustration 1.4). The continuum moves from cultural destructiveness, to cultural incapacity, to cultural blindness, to cultural pre-competence, to cultural competence, to cultural proficiency. This construct provides one useful tool for assessing the cultural strengths and weaknesses of the system of care.

Systems of care fundamentally are concerned about organizational cultural competence. The following criteria are useful to identify culturally competent organizations; they are adapted from the monograph cited above, Toward a Culturally Competent System of Care.

“Cultural competence requires that organizations:

• Have a defined set of values and principles, and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally
• Have the capacity to value diversity, conduct self assessment, manage the dynamics of difference, acquire and institutionalize cultural knowledge, and adapt to diversity and the cultural contexts of the communities they serve
• Incorporate the above in all aspects of policy making, administration, practice, and service delivery, and involve systematically consumers, key stakeholders, and communities.”

Leaders in the area of cultural and linguistic competence also have identified core elements of a culturally competent system of care (see Box 1.7).

### 1.7 Core Elements of a Culturally and Linguistically Competent System of Care

- Commitment from top leadership
- Organizational self-assessment
- Needs assessment and data collection relevant to diverse constituencies
- Identification and involvement of key diverse persons
- Mission statements, definitions, policies and procedures reflecting the value of cultural and linguistic competence
- A strategic plan for cultural and linguistic competence
- Recruitment and retention of diverse staff
- Training and skill development in cultural competence
- Certification, licensing and contract standards that reflect cultural competence goals
- Targeted service delivery strategies
- Internal capacity to monitor the cultural competence implementation process
- Evaluation and research activities that provide ongoing feedback about progress, needs, modifications, and next steps
- Commitment of agency resources (human and financial) to cultural competence quality improvement


Using these and similar parameters, system builders can assess the cultural competence of their systems and develop strategies to address areas needing improvement.
I. Family Partnership, Youth Partnership, and Cultural and Linguistic Competence

WEB RESOURCES

The National Center for Cultural Competence (NCCC) at the Georgetown University Center for Child and Human Development maintains many online resources and tools addressing cultural and linguistic competence in systems of care, including:

- Conceptual frameworks/models, and guiding values and principles;
- Definitions of cultural and linguistic competence;
- Policies to advance and sustain cultural and linguistic competence; and
- Tools and processes for organizational or system self-assessment.

The NCCC also has a searchable database listing a wide range of resources on cultural and linguistic competence.

- National Center for Cultural Competence at: http://nccc.georgetown.edu

The Technical Assistance Partnership for Child and Family Mental Health at the American Institutes for Research supports a Cultural and Linguistic Competence Community of Practice and a Cultural Competence Action Team.

- Cultural and Linguistic Competence Community of Practice at: www.tapartnership.org/COP/CLC/default.php
- National Network to Eliminate Disparities in Behavioral Health at: www.nned.net

Key Questions: Cultural and Linguistic Competence

- How are we ensuring that cultural and linguistic competence is built into all system of care structures and processes?
- What are our examples of culturally and linguistically competent approaches at service delivery, management, and policy levels?

NOTES