SECTION II: UNDERSTANDING CHILDHOOD TRAUMA

CHAPTER I. TRAUMA IN EARLY CHILDHOOD

IN THIS CHAPTER

- ❖ **Childhood Trauma & Traumatic Stress Defined**
- ❖ **There are many types of traumatic experiences.**
- ❖ **Each child responds differently to traumatic events.**
- ❖ **Trauma can have lifelong effects.**
- ❖ **Early intervention and promoting resiliency can mitigate the effects of childhood traumatic stress.**

What Is Childhood Trauma?

Throughout childhood, many (if not most) children experience some type of *traumatic experience*, an event that threatens or harms their emotional or physical well-being. The NCTSN estimates that one in four children will experience a traumatic event before they are 16 years old. Traumatic experiences can be the result of a natural disaster such as an earthquake or tornado. Children can also experience trauma within their communities as a result of community violence and racial, cultural, or socio-economic discrimination. Sexual and physical abuse, loss of a family member, bullying, or medical procedures can also be traumatic.

> **Traumatic Experience**
>
> An event that threatens or harms emotional or physical well-being.
> - Poverty
> - Community violence
> - Refugee/ war zone
> - Racial and ethnic disparities
> - Physical/sexual abuse
> - School violence
> - Neglect
> - Medical trauma
> - Traumatic grief
> - Natural disasters

What Is Child Traumatic Stress?

While many children experience one or more traumatic event, every child has different physiological and psychological responses. Though most of us would agree that certain stresses are serious – experiencing a life-threatening attack or losing a loved one – we always have to remember that stress and trauma can only

be judged by those experiencing them. Variations in experiences, expectations, resources, and to some extent the way our brains and bodies are hard wired determine to a great extent what each individual perceives as stressful or traumatic.

Stress comes in many forms. It can be positive, alerting us to dangers. Some stresses can focus our attention on challenges that, if we can face them, will lead us to better places in our lives. Some stresses are tolerable but others can lead to long lasting physical and emotional affects. Stress and trauma can change the way we look at the world – making us more attentive to risk than to possibility. Furthermore, it does not take a major disaster to create levels of stress that impact health: the "hassles" and worries that come from feeling economically vulnerable or scrutinized because of one's race, religion, gender, or sexuality, are potentially as or more dangerous than exposures to even serious one-time trauma.

Child traumatic stress is caused when a child is exposed to trauma or chronic stress and develops persistent reactions that affect the way they function on a day-to-day basis. Traumatic stress can make it difficult for a child to succeed at school or interact with others. It can also plant the seeds of physical and mental health problems that children may have to face for decades. Child traumatic stress can have an impact on many areas of development:

> **Child traumatic stress**
> When a child is exposed to trauma or chronic stress and develops persistent reactions that affect their day-to-day functioning.

emotional and behavior regulation; relationship formation and trust; maintaining attention while trying to learn new skills and knowledge. Children who have experienced traumatic stress may come to providers' attention because of problems with their behavior, difficulties with sleeping or eating, or problems adapting to child care and school settings. In some cases, but certainly not all, childhood traumatic stress can lead to symptoms that are clinically diagnosed as post-traumatic stress disorder (PTSD). For example, the fifth edition of the Diagnostic and Statistical Manual (DSM-5) defined a developmental subtype of PTSD for children ages six years and younger. The preschool age-specific definition of PTSD is developmentally sensitive and focuses on recurrent psychological distress, avoidance behaviors, and increased arousal.
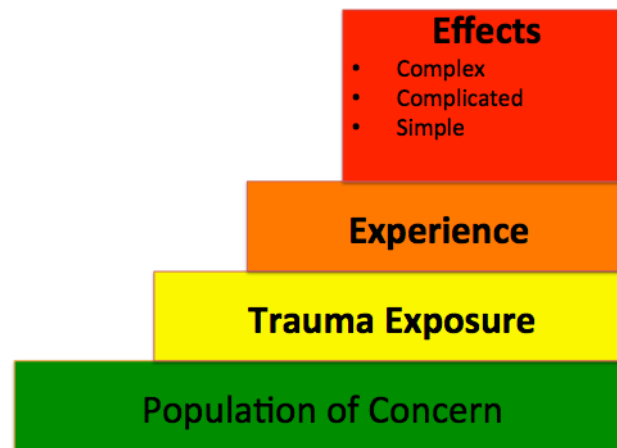
Exposure and Experience of Trauma

Exposures to chronic stress are fundamentally different than our experiences of chronic stress and should be assessed and addressed separately. *Exposure*

encompasses any population subjected to a traumatic event. *Experience* of trauma refers to how an individual responds to trauma exposure. Stress can be experienced as positive, tolerable, or chronically unsoothed ("toxic") depending on:

- The event
- Characteristics of the individual (e.g. resiliency and vulnerability)
- Factors in the family and community

Some of those who experience stress will continue to show *effects.* Effects can be targeted with simple interventions, specialty services for physical and/or psychological complications, or coordinated teamwork (see Figure 1)

Figure 1: Trauma Exposure, Experience, and Effects

Child Traumatic Stress and Gene Regulation

Though it has long been recognized that early childhood adversity can cause lifetime problems, it is only more recently that we have come to isolate and understand some of the mechanisms involved. For example, the field of epigenetics has produced evidence that our experiences can alter the function of our genes. Though the links are not well understood, we now known that experiences can change the ways that genes regulate key processes within our bodies.

Oxytocin

A hormone that plays a role in how we relate to other people (e.g., emotions we feel when we see our children and the desire we have to be close to and nurture others).

Two systems that have been explored in relationship to stress and trauma are the genes that regulate oxytocin and glucocorticoid receptors.

Stress and trauma can alter both of these systems, leading an individual to being chronically "on-guard" around others. For example, children raised in stressful environments may be more likely to have elevated blood pressure or allergies as

> **Glucocorticoid System**
> Part of the body's mechanism for responding to stress at a chemical level.

adolescents compared to children raised in less stressful environments. Epigenetics has also started to explain how parental exposure to stress and trauma, even before children are conceived, may be passed down to future generations.

Promoting Resiliency Through Early Intervention

The fact that people react differently to stress and trauma suggests that there might be ways to help those who experience traumatic events to feel less impact or recover more quickly. *Resilience* refers to the ability to buffer the impact of stress as it happens and recover from the impact more quickly and completely. Resiliency has two main components that are closely related: a person's own abilities – both innate and learned – to regulate their emotions and behaviors at a time of challenge, and the resources – social and material – that a person can mobilize for protection and response.

> **Resiliency**
>
> The ability to:
> - Blunt the impact of trauma as it happens and,
> - Recover from the impact more quickly and more completely.

There are many ways to define and measure recovery from a traumatic experience. For example, recovery can be measured by how quickly the body's stress responses return to a normal state. Alternately, we might consider what it takes for someone to return to a state of optimism and security or adapt to new realities peacefully (for strategies on promoting resilience see Section III, Element VI: Addressing Trauma-Related Health and Mental Health).

Research in a number of fields support promising interventions for trauma and stress-related concerns in early childhood, some of which might be able to alter physiologic responses with long-term somatic and cognitive effects. Table 1 lists some of those with the strongest evidence:

Table 1: Promising Interventions for Mental and Physical Health Professionals to Use for Young Children Experiencing the Symptoms of Childhood Traumatic Stress

Program (Target age)	Impact	Summary
Family Foundations (0-2)	Antisocial-aggressive Behavior, Anxiety, Conduct Problems, Depression, Externalizing, Internalizing, Prosocial with Peers	A universal prevention program to improve mother, child, and birth outcomes through promoting co-parenting quality among couples who are expecting their first child.
Nurse-Family Partnership (0-2)	Child Maltreatment, Delinquency and Criminal Behavior, Early Cognitive Development, Internalizing, Mental Health - Other, Physical Health and Well-Being, Preschool Communication/Language Development, Reciprocal Caregiver-Child Warmth	A nurse home visiting program for first-time pregnant mothers that sends nurses to work one-on-one with the pregnant women to improve prenatal and child rearing practices through the child's second birthday.
Family Check-up (Toddler Version; 0-2)	Conduct Problems, Externalizing, Internalizing, Reciprocal Caregiver-Child Warmth	The toddler version of the Family Check-Up (FCU) aims to prevent conduct problems among at-risk toddlers by improving the quality of parenting and has demonstrated success in increasing and maintaining caregivers' use of Positive Behavior Support.
Triple P System (0-11)	Child Maltreatment, Mental Health - Other	A public health approach to reach all caregivers s in a community to enhance parental competence and prevent or alter dysfunctional parenting practices, thereby reducing family risk factors both for child maltreatment and for children's behavioral and emotional problems.
Incredible Years –Caregiver (3-11)	Antisocial-aggressive Behavior, Close Relationships with Caregivers, Conduct Problems, Depression, Externalizing, Internalizing, Positive Social/Prosocial Behavior	A group-based parenting program that strengthens parenting competencies to promote young children's social, emotional, and academic competence and prevent the development of conduct problems, delivered in weekly group sessions for 3-5 months.
Parent Management Training – Oregon Model (3-18)	Antisocial-aggressive Behavior, Conduct Problems, Delinquency and Criminal Behavior, Externalizing, Internalizing	A group- or individual-based parenting training program that teaches effective family management strategies and parenting skills, including skill encouragement, setting limits/positive discipline, monitoring, problem solving, and positive involvement, in order to reduce antisocial and behavior problems in children.
Parent-Child Interaction Therapy (3-11)	Antisocial-aggressive Behavior, Child Maltreatment, Conduct Problems	A 12-week treatment for young children with emotional and behavioral problems, with one-half hour caregiver-child sessions, that places emphasis on improving the caregiver-child relationship, teaching effective parenting skills, and encouraging effective discipline.

Adapted from Blueprints for Healthy Youth Development

Core Readings and Resources

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- Materials on brain development and toxic stress at the Harvard University Center on the Developing Child: http://developingchild.harvard.edu

- Blueprints for Healthy Youth Development provides a registry of evidence-based positive youth development programs designed to promote the health and well-being of children and teens. Online at: http://www.blueprintsprograms.com

II. TRAUMA-INFORMED INTEGRATED CARE

IN THIS CHAPTER:

❖ **Trauma Informed Care Defined**
❖ **Models for integrating services with families/communities**
❖ **Models for integrating services between mental and physical health providers**

What Do We Mean by "Trauma-Informed Integrated Care"?

The Substance Abuse and Mental Health Services Administration (SAMHSA) outlines three criteria for *trauma informed* services, programs and organizations:

- **Awareness***:* Realizes the widespread impact of trauma and understands potential paths for recovery

- **Detection:** Recognizes the signs and symptoms of trauma in clients, families, staff, and others involved with the system

- **Integration:** Responds by fully integrating knowledge about trauma into policies, procedures, and practices, and seeks to actively resist re-traumatization

The Agency for Healthcare Research and Quality (AHRQ) defines integration as a process unifying care across different providers and sites. In our case, it specifically means breaking down barriers between primary care, mental health services, families, and communities (Figure 2). If viewed from a family perspective, integration also includes unifying services for children and other members of their families, especially caregivers

Figure 2: Integrated Care

For us, *trauma-informed integrated care* refers to services that unite primary care, mental health, families, and communities while also integrating knowledge of the impact of trauma on all aspects of care. Trauma-informed integrated care seeks to understand the origins of trauma faced by members of communities, to aid efforts to prevent trauma, and to help those who experience trauma flourish despite it. The first step to trauma-informed integrated care is bringing together all members of the team representing primary care, mental health, families, and community services. Only once these key players are "at the same table" can care be transformed using a trauma-informed

> **Trauma-Informed Integrated Care**
>
> Services that unite primary care, mental health, families, and communities to effectively understand, prevent detect, and address trauma in the community

lens. In the next sections we will explore models of pediatric integrated care. In the following chapters we will outline *how* services for children and families can be integrated and trauma-informed.

Models of Integrating Services, Families, and Communities

Medical Home Model

In the 1960s, the American Academy of Pediatrics proposed the idea of the "medical home" for children as "a cultivated partnership between the patient, family, and primary care provider in cooperation with specialists and support from the community." Though the idea has proven more difficult to implement than initially thought, medical homes are now more widely established. Many states and agencies have sponsored medical home learning collaboratives, from which we have drawn valuable lessons. More information is available at www.medicalhomeinfo.org.

Chronic Care Model

The chronic care model (CCM) (Wagner 1996) has provided a way of thinking about how to integrate primary and specialty care for conditions that need treatment and monitoring over time. The CCM outlines roles for patients, primary care providers, staff, and specialists as well as principles of collaboration between generalists-specialists and providers-patient-community.

The CCM provides the following guidance for specialist-generalist collaboration:

- **Systematic monitoring:** Generalists should routinely look for common problems faced by their patients so that they can intervene early or try to prevent the problems altogether.

- **First-Line Intervention***:* Generalists should have the tools and assistance to provide first-line care for the problems right away.

- **Follow-up Systems:** Systems should be in place to follow-up the first-line treatment and decide if it has been successful.

- **Collaboration***:* When more treatment is needed, generalists should be able to work closely with specialists to assure that patients get the added care they need, and that the added care fits with the patient's other medical needs (this is often referred to as "stepped care").

In addition, the CCM emphasizes provider-patient-community collaboration. The CCM is a model of behavior change, and one of its goals is to help providers partner with patients to develop and nurture over time the skills required for "self-management." In our case, that means helping families feel more in control of their lives and develop the skills and knowledge to navigate the stressful circumstances that they face.

Table 2 looks at specific activities associated with the CCM to integrate services, families, and communities:

Table 2. Activities Associated with the Chronic Care Model (CCM)

Element of the CCM	Activities
Patient self-management support	Develops patient skills through coaching, education, and problem solving. *(e.g. Psychotherapy and psycho-education to promote self-management and engagement in care)*
Clinical information systems use	Facilitates information flow from relevant clinical sources to treating clinicians – most often this means assuring that information from specialists, community programs, and primary care providers can be shared and used to provide the best care with the least burden to the patient/family; *(e.g. "patient portal" with ability for families to access and track their own information; update system with progress reports or follow-up surveys)*
Delivery system redesign	Re-definition of physician and staff work roles to facilitate anticipatory or preventive rather than reactive care *(e.g. screening, discussing concerns, prevention counseling)*
Provider decision support	Facilitated provision of expert-level input to generalists to reduce need for consultation separated in time and space from clinical needs *(e.g. telephone consultation services for primary care doctors or easy ways to contact specialists)*
Community resource linkage	Support for family needs from resources outside the health care organization *(e.g. resource box in clinic for community support organizations)*
Health care organization support	Organization leadership and tangible resources to support goals and practices of the CCM

Adapted from Woltmann (2012)

Models of Integrated Clinical Services

Each primary care office has a unique structure in place to work with their mental health affiliate – and vice versa. At the level of health care organizations, different services might be provided by the same organization (possibly even the same location) or require coordination across sites. Scheduling and medical record systems might be unified or separate. Clinicians caring for a family might meet regularly as teams, have protocols for talking with each other one-to-one, or have little or no communication with each other. The following table sets out some of the possible combinations and assigns each a "degree of integration," with close and full integration theoretically being better.

Table 3. Levels and Degrees of Integration

Degree of Integration	Organization	Facility	Records and Scheduling	Communication
Minimal	Separate	Separate	Separate	Sporadic
Basic distance	Separate	Separate	Separate	Periodic
Basic on-site	Separate	Co-located	Separate	?
Close partly	Same	Co-located	Some shared	Regular
Close fully	Same	?	Shared	Team meetings

Adapted from Doherty (1995)

We will now take a moment to explore three specific models of integrated clinical services that can effectively facilitate collaboration between primary care providers and mental health providers: (1) co-location (2) screening, brief intervention, and referral to treatment and (3) task shifting. In practice, elements of all three of these models are often combined.

Co-location

Co-location refers to the placement of a specialist physically in a primary care office (or the opposite – placing a general medical provider at a site that mostly provides mental health services). There is some evidence that co-location increases the proportion of patients who are able to complete a mental health referral. However, there are a number of potential pitfalls, and not all co-location efforts have been successful. Benefits and pitfalls of co-location are summarized in Table 4.

Table 4: Benefits and Pitfalls of Co-located Services

Benefits	Pitfalls
"One stop shopping" Reduces the number of places clients have to visit, and sometimes allows more than one type of care to be delivered back-to-back in the same place **Reduce stigma:** May reduce some of the stigma or visibility associated with obtaining mental health or trauma services – the facility is not associated uniquely with mental health or trauma care **Personalized referrals:** Offers the opportunity for personalized referrals – specialist and generalist providers can meet together with a family to jointly plan how they will work together **Increase consultations:** May increase the chance that specialists and generalists can informally consult with each other or work as a team – they are in the same place and more readily find each other	**Does not ensure communication:** Being in the same building does not mean that generalists and specialists will meet each other or understand each other's jobs. This usually requires additional work **Diverts responsibility:** The presence of the specialist can lead the generalist to take even less responsibility for knowing about mental health or trauma care – the responsibility can just be shifted **Overload specialists' capacity:** The co-located specialist can be swamped with referrals, creating delays in treatment that discourage patients from returning (the same as when the specialist is located somewhere else) **Budget**: No one business model will work across all sites – in some places the specialist can bill separately for her services, in others there will have to be ways of factoring specialist costs into an overall budget

Below are a few suggested best practices for those interested in co-locating services:

■ **Develop a work plan**
Start off by developing a shared understanding between generalists and specialists about how they will work together. What will the specialist help the generalists learn? What criteria should be used to trigger informal consultations, team discussions, and referrals? The specialist may need to learn how the generalists work, too. Before starting, he or she may need to "shadow" the generalists and spend some time understanding how patients flow through the site.

■ **Make a communication plan**

Both generalists and specialists should set up rules for how they will communicate with each other and how their "native" work style will be modified to fit the shared environment. For example, mental health workers typically do not interrupt visits for telephone calls or knocks at their door, while primary care providers frequently break visits up into segments and, in some settings, may actually be seeing more than one patient simultaneously. How will these styles mesh, especially when there is a perceived need for a quick consultation or introduction of the patient and co-located therapist?

■ **Set up mechanisms for sharing information**

How will referrals be made, what information should they contain, and how will the specialist communicate their findings and suggestions back to the generalist? Can both specialist and generalist access the same medical record? How will families be able to control and consent for the exchange of information? Will mental health or substance treatment notes be kept separately from general medical records?

■ **Develop a business plan**

With different types of funding, reimbursements, and billing allowed, how do the generalists and specialists work in ways that are financially sustainable in the practice? How are their varying types of work and workload supported? How does the practice pay for some of the non-reimbursable activities, such as cross-education, consultation, and care management?

[Note that all of the above points are discussed in greater detail later in the toolkit, including strategies, since they apply to nearly all forms of integration, not just to co-location.]

SBIRT (Screening, Brief Intervention, Referral to Treatment)

SBIRT is a model originally developed to identify individuals who could benefit from alcohol and substance abuse treatment and link them to care. The SBIRT model might be seen as a special application of the Chronic Care Model as the two models have very similar elements. The core components of SBIRT are discussed in Table 5.

Table 5: Core Components of SBIRT

Universal screening in primary care
Identification of a specific problem
Provider and patient agree that there is an issue
They work to develop a shared understanding of why the issue requires help and why now is a good time to act
Brief counseling specific to the problem
What might the patient do about the problem now – including seeking more specialized treatment
4) Long-term tracking of the issue since
a) Many patients may not immediately want to seek care
b) Even those who seek additional care may give it up
c) Many problems are recurring, even if successfully addressed in the short term

Task Shifting

Task shifting (or sharing) is a term for strategies that try to move tasks usually delivered by specialists (who are in short supply) to less-specialized health workers who are more easily accessible. For example, in some systems, mental health professionals deliver all depression care. A task-shifting plan would move some first-line depression treatments to primary care. Ideally, task shifting always involves sharing – the specialist and generalist are really sharing responsibilities. Specialists support generalists by providing training, advice to specific patients, and by collaborating in the care of patients with greater levels of need. The main motivations for task shifting are listed in Table 6 below.

Table 6: Promising and Challenging Aspects of Task-Shifting

	Motivation/promising aspects	Drawbacks/challenges
Lack of specialists	If there are long wait times for specialist care, task shifting can help address the lack of specialists.	May be most suited to care of mild/moderate severity problems or interventions that can be relatively standardized; risk that generalists will be overloaded with new tasks
Reduces barriers to access	Moving the services to the place where they are needed or where clients are more comfortable receiving them reduces the barriers to accessing care.	Some clients may still prefer to see specialist or separate specialty and general care
Possible reducing costs	Costs may be reduced by shifting some tasks to workers who are more numerous, can be trained more rapidly, or whose services are less expensive.	Lack of business models for specialists who provide initial training and ongoing coaching/supervision for generalists (time, methods of communication)
Knowledge of families	Less specialized workers may have more local knowledge, or, in the case of primary care providers, more in-depth knowledge of families and their communities. Task shifting can thus build upon the existing, established, trusting relationships that families and children often have with their primary care providers.	For sensitive issues, residents of some communities may prefer seeking care outside the community; concerns about ability to maintain confidentiality especially in small or closely-knit communities

Task shifting happens all the time in primary care as new campaigns attempt to include more preventive services (for example, asking pediatricians to apply fluoride varnish to protect teeth, shifting that task from specialty dental providers). There seem to be some key points to successful task shifting:

- **Redesign task**
  Often the tasks cannot simply be moved – they have to be redesigned to fit the context of the more general care setting. For example, pediatricians cannot deliver lengthy protocols for treatment of children's anxiety, but they can effectively deliver suggestions to caregivers for modeling and rewarding positive behavior.

- **Modify diagnostic process**

The kind of meticulous diagnoses made in specialty care may not be necessary to offer patients a first-line treatment. Specialists need to use their expert knowledge to design effective and safe but simple interventions for generalists to use, based on the specific problems for which families ask for help, while the diagnostic process unfolds.

■ Training on new ways to deliver care

Generalist providers need training to deliver new forms of care, but they also need ongoing support to become confident and competent in delivering that care.

■ Integrate new process

The new care has to complement and fit well into the work the generalists are already doing. It cannot simply add another task to a list of responsibilities that already is too long for the time allocated for primary care visits.

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III. PRINCIPLES OF PEDIATRIC INTEGRATED CARE

IN THIS CHAPTER:

❖ **Use a team based approach.**
❖ **Involve families and communities.**
❖ **Use data to monitor progress.**
❖ **Where possible build on existing capabilities rather than starting from scratch.**
❖ **Incorporate sustainability from the beginning (integrate the integration).**

While there are many models of integration, there are several overarching factors essential for developing pediatric integrated care programs across all models. Integrated care for young children and their families who have experienced chronic stress or trauma depends upon human relationships: how families and providers interact; how providers interact with each other; and how the staff and leadership of organizations come together around common goals. Accordingly, programs need to be customized to fit the unique resources, talents, and goals at each site (Butler, 2008).

In this chapter we briefly set out some foundational principles for creating integrated care for all patient populations. These insights stem from the challenge of making change in any system that involves human interactions around complicated and sometimes emotion-laden issues.

The following five ingredients can aid in the establishment (implementation), replication (spread), and maintenance (sustainability) of integrated care:

1. Team based approach
2. Family involvement
3. Data-driven
4. Adapted strategies
5. Sustainability built in from the beginning

The Essential Role of Teams

People often think that systems change is a leadership decision alone. Moreover, many times people expect leaders to mandate a change without consultation or involvement of the people who implement and experience the changes. A multi-level, multi-perspective, high-functioning team is essential to accomplishing effective and sustainable change in systems.

Who should be part of the team?
Leadership is essential, but leaders cannot do it alone. Similarly, one group of professionals cannot do it without the collaboration of others. Making change in complex organizations is an exercise in coalition building and requires the active participation of people with various perspectives and roles, from different (usually nearly all) levels of the organizational hierarchy. Ideally, any given site would have representatives of staff from each clinical (e.g. physician, nurse, medical assistant) and non-clinical (e.g. front desk, billing/coding, office manager) roles. We have found that teams involving the following members, at a minimum, can be effective at implementing and sustaining integrated care:

- **Senior Leader**: High-level administrator or leader from a primary care practice; responsible for providing leadership, support, and advocacy on behalf of the team. Ideally, someone who has a pre-existing working relationship with a counterpart at the corresponding trauma/MH center or practice.

- **Day-to-Day Manager**: High-level manager from the primary care practice who will oversee the activities of the team and actively guide the work of the Core Team. This person must have easy access to the Senior Leader and will have primary responsibility for overseeing and managing all work in this project.

- **Trauma Expert**: At least one member of the team should have expertise in providing trauma services for children 0-6.

- **Primary Care Expertise**: At least one member of the team should have expertise in primary care for children 0-6.

- **Family Advocate**: A family consumer who will represent family perspective on care needs and have expertise on family engagement strategies.

Team building

A group of people in the same room does not magically become a team. Facilitated activities, discussions, common language, group rules, and mutual respect help to build long-term teams that can lead, manage, and drive this work. Teams work best when there is a deliberate effort to make every member's voice equal – the team's power comes from its ability to legitimately represent and reflect the wisdom of everyone involved and the needs of those they represent.

Involving Families and Community is Essential

In the end, families and communities provide most of the care that children receive, especially young children. Involving families and communities in system change acknowledges their critical role in children's development and ensures that the new system effectively meets the families/patient's needs. Not engaging families as consultants and partners risks missing out on key insights that can make projects successful, especially regarding the range of experiences and preferences that families bring. Family involvement is critical to closing the gap between what providers think a family needs and what the family wants and will use.

> **Family and Community Engagement**
>
> Use families' perspectives to inform plans and system changes
> - Families should have input on tools, practice, and policies
> - Families can be champions and messengers
> - Communities can promote resilience and help address trauma exposure

Race and Culture

Incorporating families and community is particularly critical in clinics where providers are of a different race or culture than the patients. Every person has different expectations of and experiences with healthcare. We range in our level of trust in a health system and provider: in our attitudes towards medications; in our beliefs around other medical traditions; or concern about stigma associated with mental health care. Race or culture shape our healthcare system in general as well as individual's interactions with providers. Being open to these differences is critical to delivering effective care. With luck, it will be possible to avoid awkward errors and harmful misunderstandings; but even when these occur, comfort with differences offers a better chance that problems will be resolved with grace and respect.

Family as Advisors and Advocates

Adding a family advocate to an advisory committee or a team is a good first step but may not be sufficient to capture the range of family experiences. Rather, family or client/patient input need to inform tools, policies, and practices. In addition, family or client/patient feedback can be powerful tools for change within organizations. Families can also serve as champions for the program.

There are many ways to engage with families to elicit feedback and collaborate with community organizations. Specific strategies are outlined in Section III,

Element II: Providing Family Informed Services. Throughout this toolkit we will talk about the closely related need to be family and caregiver-inclusive in the care that is offered – what some call the "two generation" approach to child health.

Be Data-Driven

Data is useful and important, as it can inform choices in program design. It can help us (and our stakeholders) understand if what we are doing is making a difference, and thus help us advocate for the resources that we need to carry out effective programs.

Data to Inform Program Design
At the very beginning of your efforts to transform your system, take time to think through what data you already have available to you. What are your existing data sources – medical records, patient surveys, and provider surveys? These data can give information about:

- Quantity of care/services for patients (children and adults)
- Quality of clinical care for patients (children and adults)
- Quantity of work done by providers
- Quality of work done by providers
- Population-level generalizations / impact
- Financial implications

Use your data and the readiness assessment (Section 4) to determine your team's priorities.

Data to Monitor Progress
To the greatest extent possible, make sure that the work is driven by the best data possible. At the very beginning of your work, take the time to think through what data you need to monitor your progress. If possible, consult with data experts in your office to review your data collection plans. Having data that demonstrates your success will enable you to develop support for your efforts and sustain the work over time.

Data that tracks outcomes can also sometimes come from existing sources, but often it has to be collected in a new way. Maybe this new way – a survey of family needs or preferences, an attempt to track completion of referrals – can eventually

be built into day-to-day operations or maybe it only happens periodically or with a small sample of patients.

Data need not always be big, especially in the planning stages of your work. You can try a new screening tool or a way of talking about concerns with a handful of families and ask for their feedback; based on the results you can try something else, make adjustments, or move to a larger scale.

Meeting the Needs of the Clinic

Re-hauling a system to be integrated and trauma-informed can be overwhelming. It is a daunting task to change systems, implement new trainings, and develop tools. However, it is not necessary to "recreate the wheel." This toolkit provides examples of evidence-informed tools, practices, and processes implemented successfully by more than twenty teams in their efforts to deliver trauma-informed integrated care. For example, your team might be interested in instituting developmental screenings but another team may have already established mechanisms and provided training on how to use screening tools and how to provide counseling about the results. Many of these strategies and tools are incorporated into the supplementary materials and you will be directed to these tools throughout the toolkit.

Evidence-Informed Treatments
Over the last few decades there has been a growing emphasis on providing medical care that is based on solid research findings – often referred to as "evidence-based care." Closely related is the idea that the best medicine happens when we are able to make a firm diagnosis and then apply the evidence-based treatment that fits that diagnosis.

Using evidence-based care is a wonderful idea, and a worthy goal, but it turns out to have a number of limitations. First, the range of problems that individuals and families encounter is much greater and more diverse than the body of research on effective treatments. There are many conditions and combinations of conditions for which there is no definitive research on which to base care.

Second, the kinds of people involved in research are frequently not the same as those who come to clinics or doctors' offices needing treatment. "Real" patients may have different preferences for alternative treatments, and they are more likely to have multiple other problems than the ones presented by patients involved in research.

Finally, the care given in research projects is usually different from what happens in regular medical care. Supports for patients and the extent of clinician training are often much greater in research, and thus the impact of treatments in research projects is often greater than the impact of the same treatments when used in regular care.

Thus, in day-to-day care, we often hope more to be "evidence-informed." We look for information from research, and from the opinions of experts, and try to be clear about why we are offering a particular type of care in our system. Ideally, we pair evidence-informed care with consistent efforts to monitor how well our patients do and whether there is any new information that might lead us to new treatment.

Adapting Materials to Fit Specific Populations
Each clinic has a unique setting and therefore the most successful idea from one site may need some adapting to use at another location. Again, in the world of evidence-based care, scientists and policy makers often worry that if there is too much "adaptation" then the care could differ drastically from the original, losing its effectiveness. This is a real concern, but it is balanced by the concern that the original version might not be feasible or effective at the new site because of differences in patient needs or staff expertise. There are at least two ways of striking this balance:

- When adapting material, understand what your source thinks are the most important aspects of the process or treatment – then make sure to try your best to keep those aspects intact.
- Figure out how you will know if the adaptation is successful – be data driven!

The following table lists some of the possible aspects of a strategy or treatment that might need to be adapted to fit in different sites.

Table 7: Adapting Models for New Settings

Issues Related to:	Considerations
Adapting content to patients & populations served	Extent of cultural and linguistic diversity likely to be encountered
	Coverage of mental health topics as it relates to local needs and priorities based on clinical data (versus staff perceptions)
	Manifestations of clinical problems described match local language and idioms of distress
	Selection of mental health topics and treatments tailored to local treatment resources (including medications available)
	Locally-relevant variation in the prevalence of related somatic conditions (both as co-morbidities and as causes of mental health problems)
	Within each symptom/condition cluster: Suggested case-finding and outcome measurement questions and tools appropriate to local language, culture Menu of possible brief interventions chosen for appropriateness
Structure & culture of the health care system	Visit characteristics – length, expectations of patients and providers, usual communication style; who, in addition to the patient, usually comes to the visit
	Physical settings available for visits – relative privacy, possibilities for safety
	Possibilities for follow-up visits related to cost, distance
	Availability of complementary and competing community resources (including traditional care)
	Extent of specialist mental health consultation likely to be available
Training staff & clinicians	Making training materials accessible (technical level, language, pace, format) to varying staff levels
	Adapting training topics to coordinate with other training and capabilities that might be available
	Shifting the order or emphasis of coverage of topics to be responsive to local priorities as perceived by staff
	Developing training case examples that reflect local populations and providers
	Finding or writing clinical aids (screeners, patient education materials) in the proper language and that are culturally appropriate, and thinking about how to proceed when they don't seem to be available
	Understanding clinical culture with regard to training or working in teams with clinicians from other professional backgrounds or levels

Sustainability from the Beginning

Sustainability has many dimensions. We often think about it from a financial point of view, but it also has components at the emotional, quality, and workforce levels. Thinking about sustainability from the beginning can help avoid:

- **Emotional burnout** – Designing new systems can be stressful and overwhelming

- **One-shot interventions** – One-shot trainings/orientations to new processes/skills rarely have sustained impact, even though they are important to get things started. Follow-up is needed to help people solidify their understanding and work out inevitable problems

- **Loss of trained professionals –** Good integrated care probably helps with burnout and may reduce turnover, but people's lives are always changing. Changes you test and implement must be sustainable in the broader organization and include plans for training new staff

- **Lack of funding** - Be ready (eventually) to quantify the time and materials required for what you are proposing. Are there possibly direct financial benefits?

How to Build Sustainability into the Work
Sustainability can be a broad and poorly defined term. Using the acronym 'LADDERS' is one way to think about sustainability through an action-oriented lens. LADDERS stands for Leadership, Agency fit and capacity, Documentation, Data, Expectations, Replacement, and Staffing. Table 8 outlines key ingredients and guiding questions to help you think about the sustainability of tools, practices, and processes:

Table 8: The Elements of Sustaining Work: LADDERS

LADDERS	Guiding Questions
1. Leadership	Who are the leaders we need on board? What do we need them to do? How can we help them do it? What would happen if a key leader leaves? Is there a broad base of champions?
2. Agency Fit and Capacity	How does this tool, practice, or process support the overall direction of the organization? How can it be seen as essential to the agency's core mission? What resources are needed to do this, in terms of technology, documentation, or internal infrastructure, and how will these resources be obtained?
3. Documentation	How will this work be documented, managed, and monitored to ensure it occurs consistently and with the desired intent? Can this documentation be built into existing systems of reporting or patient care (for example, easily extracted from electronic medical records)
4. Data	What data will be collected to monitor the fidelity of this work and how will they be used? Can data relating to these efforts be made part of routine monitoring or feedback to providers or clinical sites?
5. Expectations	What will happen as leadership changes, staff turns over, technology changes, or fidelity begins to drift? Are there realistic expectations about how long change will take, how soon results will be apparent or how big an impact will be seen?
6. Replacement (*Integrate the Integration*)	Most of all, how will the new program make existing burdens lighter and benefit seemingly unrelated programs? What existing tools, practices, or processes are these practices or processes replacing or improving? How is the new work building on and combining with existing practices to ensure it is not just 'layering' something new on top of what is already being done?
7. Staffing	What staff is needed to do this work and how are they being prepared to do it? If existing staff are being given new roles, have they been involved in the process and do they see the new roles as positive? How will ongoing needs for training and supervision, be assessed and met? For new or existing positions involved in the program, is there a career path that will promote retention of skilled team members but allow them to grow and continue to find the job satisfying?

Adapted from Agosti (2014)

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IV. DEFINING PRIORITIES

IN THIS CHAPTER:

- ❖ **Define goals around trauma-informed integrated care.**
- ❖ **Assess readiness.**
- ❖ **Implement change through PDSAs.**

Why Are You Working for Pediatric Integrated Care?

There are many possible rationales for integrating pediatric care – most of which can be applied more specifically to programs targeting trauma/stress and families with young children. Different rationales may appeal to different stakeholders. Being able to articulate your rationales to various audiences will help gain support, keep the team together, and help you decide what to prioritize in your work now and what to address later.

Clear rationales can be especially important when it seems unlikely that programs will pay for themselves or save money. Systems are often willing to make new investments if the product is clear and if the program aligns with the mission and core values of a system.

It is also important to distinguish between rationales and goals, as both are important to consider (though we recognize that terms such as rationale, vision, and goals are often used in confusing and overlapping ways – the exact terms are less important than the concepts):

- **Rationale or motivation**: These are usually more general or are statements of values, mission, or guiding principles – for example, every family has a right to access quality care.

- **Goals:** These are usually more specific and ideally associated with something you can measure – for example, in order to give every family access to quality care, we will develop a business model allowing us to provide preventive care for all families in our community regardless of insurance status.

Table 9. Rationales and Goals for Articulating Impact of Integrated Care

Rationales	Goals
Increase access to behavioral health services /number served	→ Better detection of mental health trauma → Less loss from referral to follow-up → Reduce disparities, equalize opportunities for access to quality care
Increase quality	→ More expert service at point of first access and ongoing → Reduced time to service once in system → Better match of need to referred service
Increased choice/better fit with patient preferences	→ Family satisfaction with point of entry, place of care, locus of coordination → Reduction in "no-show" or treatment drop-out rates
Improved clinical outcomes	→ At the individual level → At the population level
Reduction in costs attributable to:	→ Delays in receipt of any or optimal treatment → Inappropriate or avoidable use of emergency facilities or inpatient stays → Use of expensive medications when there are alternative psychosocial or medication therapies → Disruption to unrelated services → Low rates of provider productivity because of missed appointments or premature termination of treatment → Time lost from work (among patients and staff)
Reduction in future illness, disability, and suffering through prevention and early intervention	→ Better coordination with community services and linking patients to community resources → Greater proportion of children participating in Early Head Start or pre-K programs → Greater proportion of children considered ready for primary school at the appropriate age

Readiness and Where to Start

The families, providers, and systems you work with are likely being asked to consider many other causes or projects at the same time. In the world of health services research this is often referred to as "competing demands" – different causes and priorities compete for attention and resources, and sometimes contribute to what staff members call "initiative fatigue."

Integrating care requires a careful assessment of competing demands. You don't want to implement a program at the expense of another that could be equally important; you don't want your initiative to fail because everyone is too busy with

other things; you don't want to be forgotten when a new concern arises tomorrow; you don't want to add to everyone's burdens; and you don't want this work to become focused on compliance rather than values and system change.

To see if your team is ready to plan, implement, and practice trauma-informed integrated care, we recommend that you examine your existing data sources and complete the Readiness Assessment, based on the Collaborative Change Framework (Appendix B). Completing this Readiness Assessment with your team will allow you think about *if* you are ready to start this work and help you identify *where* to start – by identifying the elements prioritized by your team.

How to Implement Change through PDSA Cycles

Although this work is comprehensive, as described in the next chapter, it is not about making a massive one-time change that will take years to plan. Instead it is about developing effective practices and tools in your clinic that are realistic for you, your staff, and your families.

In order to ensure the practices and tools will be effective and have the results you want, we encourage teams to begin testing changes on a small scale using the Plan-Do-Study-Act / Adjust (PDSA) method. This method uses a series of very small, systematic, and rapid steps that allow you to gain valuable learning and knowledge as you continually improve the practice or process and let it grow and spread in natural ways that will be able to be sustained.

There are many benefits of implementing changes using PDSAs. First, PDSAs rely on an inclusive change process. Those who are closest to the work (including front desk staff, medical assistants, care coordinators, patient navigators, family advocates, providers, etc.) come up with their own ideas of what they'd like to do and then try them out. This is the opposite of organizational change that originates in a meeting room far from where providers interact with actual patients and changes are "rolled out" via email, policy change, or memorandum.

Second, because the tests are done first on a very small scale (with one family or one provider) results of the test are available quickly. There is no need to wait for a month – or even a week – before knowing if the idea is promising.

Third, many ideas can be tested simultaneously, as various team members can try the ideas that resonate with them most. This empowers team members and other staff to do what they know best, take initiative, and apply their own expertise to areas they want to improve.

Fourth, the successes and lessons learned even from these small tests are powerful motivators in bringing others on board. Rather than trying to convince a colleague that an idea has merit in concept, you have experience and some data to share about what it actually might look like in practice. This offers a compelling way of building consensus and accelerating the process of moving forward with new ideas. When several possible paths present themselves, a simple test helps to weigh the pros and cons of each option based on real data, rather than assumptions. For example, instead of spending months around a table debating the merits of various screening tools, or guessing which one might work best, you can simply try out the leading candidates with a few families who are willing to give you their opinions. This feedback can then help move your decision-making to the next stage, which is often to make some adjustments and, again, do a quick test of the revised version.

And fifth, the lessons learned when testing on a small scale first have minimal impact on the rest of the organization in terms of time and cost. The entire program or clinic isn't required to shift to a major new tool, method, or practice all at once before you have a very high level of confidence that it will actually work in your organization.

We have learned that PDSAs work best when you decide ahead of time what questions you are trying to answer. It helps to formulate a hypothesis about what you think might happen. And then you should always circle back to your higher-level data to ensure that these small tests are resulting in the types of improvements you intended. For example, if you are interested in improving the screening of mental and behavioral health problems, a series of PDSAs could help you to select the best screening tool for use in daily practice, based on family and provider feedback. The higher-level data you will want to review might include whether the tool is effective in promoting the assessment of children's behavior during primary care visits (how often it's getting used), how providers are using the information, and whether the tool improves caregiver interest in behavioral and emotional issues. While the "S" (Study) for the first small cycle may be primarily qualitative and anecdotal in nature (e.g., Did the caregiver understand the questions? How long did it take to administer? Was there anything missing from the questions asked?), the data that is collected as part of the study also grows as more cycles are tested. Thus, as a PDSA cycle moves from a small initial test to full implementation, your study phase will become more intensive and evaluative. Before you decide to make something standard practice, you will want to be certain that it is resulting in true improvements based on clear data and outcomes.

When using PDSA cycles, it is essential to realize that they are not intended to be once-and-done tests. Instead, teams use PDSA cycles in which each "A" (Act or Adjust) becomes the "P" (Plan) for the next cycle. In doing this, each subsequent cycle becomes slightly larger, involving more families or more providers. This expansion that occurs as the learning is continually applied helps ensure that the idea has merit across a variety of conditions, audiences, and providers. Moreover, it allows you to work out any "kinks" in the process along the way, further increasing the likelihood of being able to replicate and sustain the work.

Most teams will not start PDSAs on all elements at once. We suggest you consider starting with PDSAs that create "ah-ha" moments, focusing on elements that inspire motivation and support for future changes. For example, you may want to test strategies to develop a trauma-informed office early in the process to foster positive attitudes towards assessment and treatment of trauma-related problems.

Within each element of the Collaborative Change Framework, there are Change Strategies you can test using PDSAs. Below is a PDSA guide to help your team move from a broader Change Strategy to a PDSA that you could "test by next Tuesday."

Table 10. Steps for Planning and Implementing PDSAs

PLAN
What is the goal for this PDSA cycle?
What do you predict will happen?
What is the plan for the cycle? What are the steps to execute the cycle, including data collection (who, what, where, when)?

DO
Carry out the cycle. In brief terms, did it work as you expected?

STUDY
Summarize and analyze the observed results. What did you learn from this cycle? Include descriptions of successful interactions, unexpected challenges, and other special circumstances that may or may not have been part of the plan.

ACT / ADJUST
What actions are you going to take as a result of this cycle? (Check one)
Adapt the Test   Expand the Test   Abandon the Test
Plan for the next cycle. What changes are needed? If expanding or adapting, what will you do to continue your learning while beginning to spread the successes?

Change through Non-PDSAs

Not all improvement strategies will be in the form of Plan-Do-Study-Act cycles. Sometimes you don't have a question about how to address a challenge (no need to test a hypothesis); or there's only one way to do something; or you have a task or work plan to execute rather than something to *test*. In these cases, you probably have an improvement *task* rather than an improvement *test*. Although they are not PDSAs, these are important parts of your system improvement plan. You'll find several sample PDSAs and a few examples of other improvement strategies as we move step by step through the Collaborative Change Framework elements in chapter five.