

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	<p>Extent of cultural and linguistic diversity likely to be encountered</p> <p>Coverage of mental health topics as it relates to local needs and priorities based on clinical data (versus staff perceptions)</p> <p>Manifestations of clinical problems described match local language and idioms of distress</p> <p>Selection of mental health topics and treatments tailored to local treatment resources (including medications available)</p> <p>Locally-relevant variation in the prevalence of related somatic conditions (both as co-morbidities and as causes of mental health problems)</p> <p>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</p>
Structure & culture of the health care system	<p>Visit characteristics – length, expectations of patients and providers, usual communication style; who, in addition to the patient, usually comes to the visit</p> <p>Physical settings available for visits – relative privacy, possibilities for safety</p> <p>Possibilities for follow-up visits related to cost, distance</p> <p>Availability of complementary and competing community resources (including traditional care)</p> <p>Extent of specialist mental health consultation likely to be available</p>
Training staff & clinicians	<p>Making training materials accessible (technical level, language, pace, format) to varying staff levels</p> <p>Adapting training topics to coordinate with other training and capabilities that might be available</p> <p>Shifting the order or emphasis of coverage of topics to be responsive to local priorities as perceived by staff</p> <p>Developing training case examples that reflect local populations and providers</p> <p>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</p> <p>Understanding clinical culture with regard to training or working in teams with clinicians from other professional backgrounds or levels</p>

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	<p>Who are the leaders we need on board?</p> <p>What do we need them to do?</p> <p>How can we help them do it?</p> <p>What would happen if a key leader leaves? Is there a broad base of champions?</p>
2. Agency Fit and Capacity	<p>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?</p> <p>What resources are needed to do this, in terms of technology, documentation, or internal infrastructure, and how will these resources be obtained?</p>
3. Documentation	<p>How will this work be documented, managed, and monitored to ensure it occurs consistently and with the desired intent?</p> <p>Can this documentation be built into existing systems of reporting or patient care (for example, easily extracted from electronic medical records)?</p>
4. Data	<p>What data will be collected to monitor the fidelity of this work and how will they be used?</p> <p>Can data relating to these efforts be made part of routine monitoring or feedback to providers or clinical sites?</p>
5. Expectations	<p>What will happen as leadership changes, staff turns over, technology changes, or fidelity begins to drift?</p> <p>Are there realistic expectations about how long change will take, how soon results will be apparent or how big an impact will be seen?</p>
6. Replacement (Integrate the Integration)	<p>Most of all, how will the new program make existing burdens lighter and benefit seemingly unrelated programs?</p> <p>What existing tools, practices, or processes are these practices or processes replacing or improving?</p> <p>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?</p>
7. Staffing	<p>What staff is needed to do this work and how are they being prepared to do it?</p> <p>If existing staff are being given new roles, have they been involved in the process and do they see the new roles as positive?</p> <p>How will ongoing needs for training and supervision, be assessed and met?</p> <p>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?</p>

Adapted from Agosti (2014)

Core Readings and Resources

- Benzer JK, Beehler S, Miller C, Burgess JF, Sullivan JL, Mohr DC, Meterko M, Cramer IE. Grounded theory of barriers and facilitators to mandated implementation of mental health care in the primary care setting. *Depression Res Treatment* 2012; doi:10.1155/2012/597157.
- Crabtree BF, McDaniel RR, Nutting PA, Lanham HJ, Looney JA, Miller WL. Closing the physician-staff divide: a step toward creating the medical home. *Fam Pract Management* 2008(April):20-24. www.aafp.org/fpm.
- Curran, Bauer, Mittman, Pyne, and Stetler, 2012: Effectiveness-implementation Hybrid Designs: Combining Elements of Clinical Effectiveness and Implementation Research to Enhance Public Health Impact. *Medical Care*, 50(3).
- Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: new guidance. Medical Research Council (UK). www.mrc.ac.uk/complexinterventionsguidance
- Glasgow RE, Lichtenstein E, Marcus AC. Why don't we see more translation of health promotion research into practice? Rethinking the efficacy-to-effectiveness transition. *AJPH* 2003;93:1261-67.
- McAllister JW, Cooley WC, Van Cleave J, Boudreau AA, Kuhlthau K. Medical home transformation in pediatric primary care--what drives change? *Ann Fam Med*. 2013 May-Jun;11 Suppl 1:S90-8.
- Nutting PA, Miller WL, Crabtree BF, Jaen CR, Stewart EE, Stange KC. Initial lessons from the first national demonstration project on practice transformation to a patient-centered medical home. *Ann Fam Med* 2009;7:254-260.
- Nadeem E, Olin SS, Hill LC, Hoagwood KE, Horwitz SM. 2013. Understanding the components of quality improvement collaborative: a systematic literature review.
- Nadeem E, Olin SS, Hill LC, Hoagwood KE, Horwitz SM. A literature review of learning collaboratives in mental health care: used but untested. *Psychiatric Services* (in Advance) June 2, 2014.
- Nutting PA, Crabtree BF, Miller WL, Stange KC, Stewart EE, Jaen CR. Transforming physician practices to patient-centered medical homes: lessons from the national demonstration project. *Health Affairs* 2011;30:439-445.

- Ovretveit, J, Bate, P, Cleary, P, Cretin, S, Gustafson, D, McInnes, K, McLeod, H, Molfenter, T, Plsek, P., Robert, G., Shortell, S., Wilson, T. (2002). Quality collaborative: lessons from research. *Qual. Saf Health Care*, 11(4): 345-51.
- Parry, GJ, Carson-Stevens, A, Luff, DF, McPherson, ME, Goldman, DA. (2013): Recommendations for Evaluation of Health Care Improvement Initiatives. *Academic Pediatrics*, 13(6S), S23-S30.
- Stange et al, 2014: Metrics for Assessing Improvements in Primary Health Care. *Annu. Rev. Public Health*. 35:423-42.
- Wissow LS, Tegegn T, Asheber K, McNabb M, Weldegebreal T, Jerene D, Ruff A. Collaboratively reframing mental health for integration of HIV care in Ethiopia. *Health Policy Plan*. 2014 Jul 10. pii: czu058.
- Agosti, J. (2014). Sustainability Checklist. Los Angeles, CA and Durham, NC: National Center for Child Traumatic Stress.