A State-Level Tool Kit for Building a Community-Based Service System for Children and Youth with Special Health Care Needs and their Families

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Preface

How this Tool Kit was Created

In 2008, state CSHCN directors from Maine, Utah, and Colorado were attending a meeting. Through informal discussion, Maine and Utah leaders had learned of Colorado's CSHCN Program's evolution of moving from a direct services model to one that provided community-based infrastructure to support the six outcomes for Children and Youth with Special Health Care Needs (CYSHCN). The Maine and Utah state directors saw an opportunity to learn from Colorado, with an interest in learning from Colorado's evolution and replicating elements within their own states. With the help of the Champions for Inclusive Communities (ChampionsInC) national center funded by the Maternal and Child Health Bureau's Division of Services for Children with Special Health Needs and the Association for Maternal and Child Health Programs, a plan was laid to facilitate the exchange of knowledge and experience among state leaders, which we call a "learning community."

Defining a Learning Community

The concept of a "learning community" is one that is based on several key principles that guide how information is exchanged, with an emphasis on the value of everyone's perspectives and input. A learning community is a diverse group of people working together to nurture and sustain a knowledge-creating system, based on valuing equally three interacting domains of activity:

research: a disciplined approach to discovery and understanding, with a commitment to share what's learned;

capacity building: enhancing people's awareness and capabilities, individually and collectively, to produce results they truly care about; and

practice: people working together to achieve practical outcomes.

Such a community continually produces new theory and method, new tools, and new practical know how.

In a learning community, all members are equal partners—there are no "experts" per se; everyone comes to the table to offer their input and learn from one another.

From Senge, P., & Scharmer, O. (2001). Community action research: Learning as a community of practitioners, consultants and researchers. In P. Reason & H. Bradbury (Eds.), Handbook of action research. *London, England: Sage.*

Learning Community Participants

The Colorado, Maine, Utah participants were Title V CSHCN directors, family leaders, and

program directors, the Co-Principal investigator for ChampionsInC, and the CSHCN specialist from the Association of Maternal and Child Health Programs. A 2-day, face-to-face meeting was held in Colorado, followed by monthly teleconference calls. A second learning community was formed in 2009, comprised of Colorado, Kansas, Oklahoma, and Wyoming, with similar participants.

The structure of the meeting and conference calls are provided in this tool kit. ChampionsInC served as the facilitator of this process, working in partnership to create agendas, facilitating discussion, and serving as a resource. AMCHP provided assistance in summarizing minutes from these meetings as promoting the dissemination of this toolkit.

This toolkit reflects the process and outcomes that resulted from this learning community, with the intent of serving as a guide for other states interested in working toward developing stronger community-based service system. Although this tool kit can be useful to state leaders who work independently, it is optimal to work with other states, reaping the benefits of the experiences and advice from others.

It is important for readers to understand that this toolkit serves to provide guidance in systems change—it is not a prescribed "recipe" that must be followed exactly for the same outcome. Rather, it reflects a process consisting of key principles that are important in creating any systems change, a process that must be adapted to fit the unique characteristics of states and communities. The tool kit is merely a tool, designed to be used by state leaders coming together with other states to foster sharing and learning from one another. As with all tools, its value is based on the skills of the persons using it. These skills include strong leadership, valuing a partnership, and being transparent in your communication and activities. Throughout the toolkit, examples of the how to apply these skills are provided.

We hope that this tool kit assists state leaders and their community partners in the journey to develop community-based service systems that support CYSHCN and their families.

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Harper Randall and Jim Taliaferro, UT CSHCN bureau
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Shared Experiences in Moving Down the Pyramid: Strengthening Family-Centered Community-Based Service Systems

Introduction

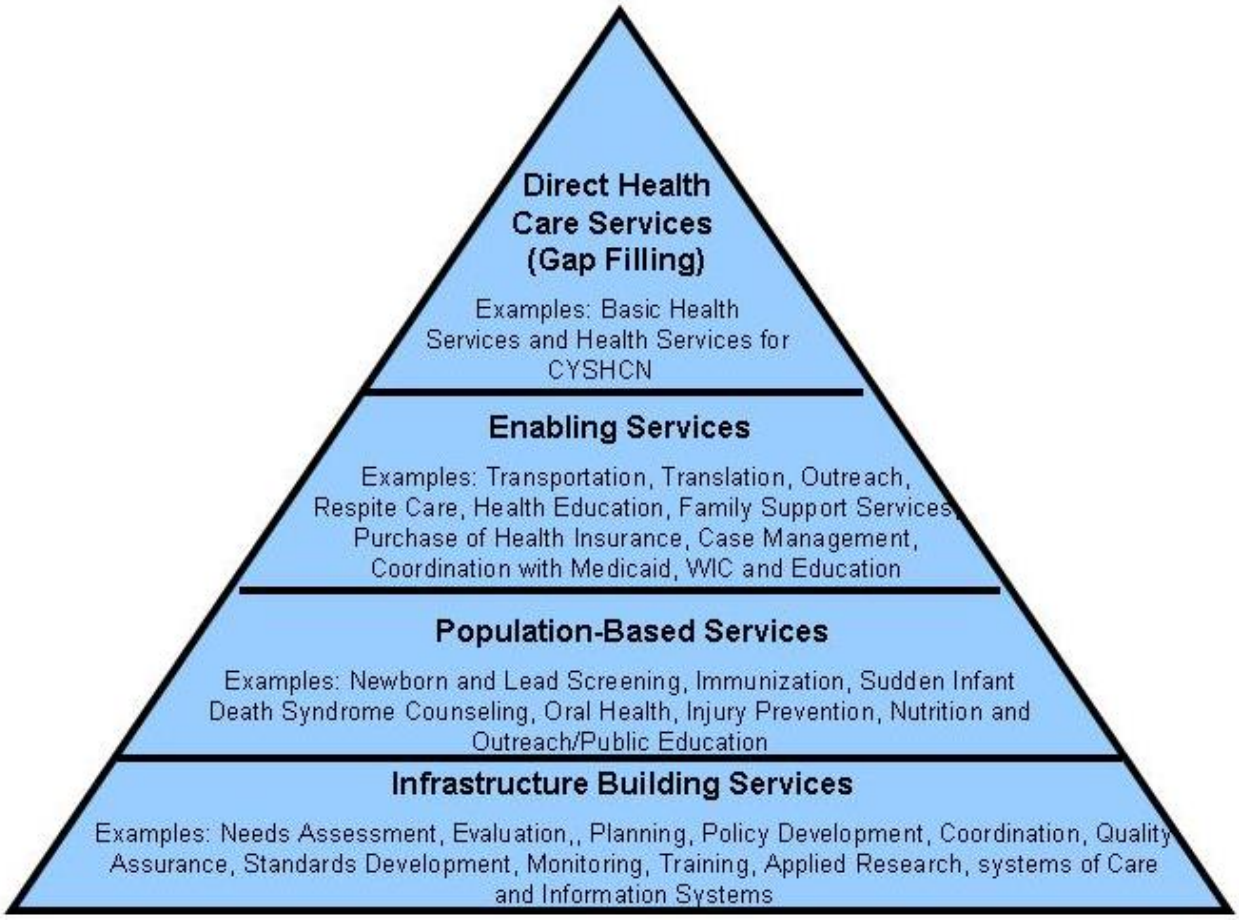
The state Title V Maternal and Child Health Programs have been an important entity in the provision of services for all children, particularly those with special health care needs. Within

each state's Title V program is a Children with Special Health Care Needs program. Over the past decades, the role of state CSHCN programs has evolved from originally serving "crippled children"—or children with specific, categorical conditions—to a population defined broadly as "those who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount required by children generally (McPherson et al, 1998)." Concurrently, federal legislation (OBRA '89) has emphasized the importance of CHSCN programs developing community-based service systems that are family-centered, comprehensive, coordinated and culturally competent.

What is the MCH Pyramid?

An overall picture of Title V's role in achieving such service systems is best depicted in what is known as the "MCH Pyramid."

Such an evolution from serving children with categorical conditions via centralized, specialty services to building a system that provides the infrastructure to serve this broadly defined population of CYSHCN in their home communities is commonly referred to as "*moving down the pyramid."*



What is a "community-based service system"?

Although the MCH pyramid provides examples of the MCH-related activities to support such a system, it does not directly define a "community-based service system, particularly in regard to what such a system looks like for CYSHCN and their families.

A definition of a "community based service system" was created by the learning community states, with particular input from family leaders: is defined as:

- Services are family-centered, coordinated, culturally effective
- Provided in communities, fitting with family routines
- Strengthens community capacity, such as:
    - Medical homes in collaboration with other services and supports
    - Creative financing (e.g., blended funding, public-private partnerships)
    - Care coordination, interagency applications, care plans
    - Coordinated screening and monitoring across programs/providers
    - Community-based resources to support transition
- Based on MCH pyramid and supports core public health functions:
    - Resource development and outreach, such as family leaders
    - Public information (i.e., service directories, importance of screening)
    - Technical assistance, training to community providers
    - Mobilizing community partnerships

Ten Essential Public Health Services to Promote Maternal and Child Health in America

The Centers for Disease Control and Prevention's (CDC) National Public Health Performance Measures Program developed National Public Health Performance Standards for state and local public health systems and for public health governing bodies. The **Essential Public Health Services** provide the fundamental framework for the NPHPSP by describing the ten critical public health activities that should be undertaken in all communities:

1. Assess and monitor maternal and child health status to identify and address problems.
2. Diagnose and investigate health problems and health hazards affecting women, children, and youth.
3. Inform and educate the public and families about maternal and child health issues.
4. Mobilize community partnerships between policymakers, health care providers, families, the general public, and others to identify and solve maternal and child health problems.
5. Provide leadership for priority setting, planning, and policy development to support community efforts to assure the health of women, children, youth and their families.

6. Promote and enforce legal requirements that protect the health and safety of women, children, and youth, and ensure public accountability for their well-being.

7. Link women, children, and youth to health and other community and family services, and assure access to comprehensive, quality systems of care.

8. Assure the capacity and competency of the public health and personal health work force to effectively address maternal and child health needs.

9. Evaluate the effectiveness, accessibility, and quality of personal health and population-based maternal and child health needs.

10. Support research and demonstrations to gain new insights and innovative solutions to maternal and child health-related problems

Taken from:

http://www.amchp.org/AboutTitleV/GuideforSeniorManagers/Pages/GuideforSeniorsChapter1Framework.aspx

What is the Purpose of this tool kit?

Moving down the pyramid has been a challenge for many states, and there are no "how-to" guides on making such a transition. Additionally, state are each unique in the extent to which they are centralized or decentralized, receive strong or weak funding, have extensive or minimal community-based specialty services.

This tool kit serves to support State and community leaders in achieving the following outcomes:

1. Gain new knowledge about mechanisms to establish community-based service systems in your state

    a. Within the CSHCN program, considering fiscal reallocation
    b. With their CSHCN program partners, collaborating on funding and other supports

2. Understand the importance of a stakeholder team to guide your overall effort, particularly ensuring a strong family voice.

3. Apply community-level assessments to determine strengths, needs of families, and the service system at the community level. Integrate these needs assessments into your Block Grant 5-year needs assessment as appropriate.

4. Identify resources and colleagues at the national level that can offer support and technical assistance to guide your work plan.

5. Identify tools to measure desired outcomes of your community-based service system implementation.

This tool kit is designed to offer guidance to state- and community-level CYSHCN leaders in developing strong *community-based service systems* for Children and Youth with Special Health Care Needs (CYSHCN) and their families. We want to help states develop strong CSHCN community service systems, with special emphasis on:

- Achievement of the 6 outcomes for CYSHCN specified in the Title V block grant and the MCH pyramid
- Meeting the needs of all CYSHCN and their families
- Ensuring strong partnerships w/Families (parents, siblings, etc.) and youth
- Supporting a community-level infrastructure
- Implementation at the community level
- Building leadership among CSHCN administration and families/consumers

Tool Kit Table of Contents

The tool kit is organized by the key steps that are important in any systems change, particularly building a community-based system of care.

Step 1: Inspiring a Shared Mission and Vision

Establishing a Vision and Mission is a process of coming together to set direction and focus for the group's efforts. Participating in this process helps a group begin with the end in mind, and to stay focused on the results for which they are aiming. Establishing a vision—a statement of your dream or ideal conditions—and a mission—what you do and why—provides shared language and common purpose for targeted action and intervention. Establishing a Vision and Mission is a key process to help groups assess, prioritize, and plan for change.

What is a Vision Statement?

The first step in beginning the journey toward developing a community-based service system is to understand your vision of what such a system would look like—most importantly, what it would mean for CYSHCN and their families.

Your vision is your dream. It is what your organization believes are the ideal conditions for your community; that is, how things would look if the issue important to you were completely, perfectly addressed. It might be a world without war, or a community in which all people are treated as equals, regardless of gender or racial background.

Whatever your organization's dream is, it may be well articulated by one or more *vision statements*. Vision statements are short phrases or sentences that convey your community's hopes for the future. By developing a vision statement or statements, your organization clarifies the beliefs and governing principles of your organization, first for yourselves, and then for the greater community.

There are certain characteristics that most vision statements have in common. In general, vision statements should be:

- Understood and shared by members of the community
- Broad enough to include a diverse variety of local perspectives
- Inspiring and uplifting to everyone involved in your effort
- Easy to communicate (e.g., they are generally short enough to fit on a T-shirt)

Here are some examples of vision statements that meet the above criteria:

- The newly drafted vision of the Utah Bureau of CSHCN is to ***enhance the health and quality of life for children and youth with special health care needs and their families.***

- The Colorado Department of Public Health and Environment's Health Care Program for Children and Youth with Special Needs (HCP) believes that all families deserve the opportunities and support to promote the maximum potential of their children.

What is a Mission Statement?

The next step builds on your vision statement: developing a *mission statement.* An organization's

mission statement describes *what* the group is going to do and *why* it is going to do that.

The following excerpt is taken from *Community Toolbox, The. (n.d.). Proclaiming your dream: Developing vision and mission statements. Retrieved August 31, 2009, from* http://ctb.ku.edu/en/tablecontents/sub_section_main_1086.htm

> "Mission statements are similar to vision statements, in that they, too, look at the big picture. However, they're more concrete, and they are *definitely* more "action-oriented" than vision statements. Your vision statement should inspire people to dream; your mission statement should inspire them to action.
>
> The mission statement might refer to a problem, such as an inadequate housing, or a goal, such as providing access to health care for everyone. Moreover, while they do not go into a lot of detail, they start to hint—very broadly—at how your organization might fix these problems or reach these goals. Some general guiding principles about mission statements are that they are:
>
> - *Concise*. While not as short as vision statements, mission statements generally still get their point across in one sentence.
> - *Outcome-oriented.* Mission statements explain the fundamental outcomes your organization is working to achieve.
> - *Inclusive.* While mission statements do make statements about your group's key goals, it's very important that they do so very broadly. Good mission statements are not limiting in the strategies or sectors of the community that may become involved in the project.
>
> The following examples should help you understand what we mean by effective mission statements.
>
> - "Promoting child health and development through a comprehensive family and community initiative."
> - "To create a thriving African American community through development of jobs, education, housing, and cultural pride."
> - "To develop a safe and healthy neighborhood through collaborative planning, community action, and policy advocacy."
> - "Promoting community health and development by connecting people, ideas and resources." (This is the mission of the Community Tool Box [http://ctb.ku.edu/])"

The following are some examples of learning community vision and mission statements.

Colorado

Colorado conducted a series of focus groups with families and providers throughout their state to help them guide their new vision and mission. This was a time for "proclaiming values" of why they existed and who they were to serve. Eileen Forlenza, a family leader and professional staff person from the Colorado CSHCN unit, raised these important points:

- Reach and Impact—How many children do we currently serve via payment for services versus the total number of CYSHCN in our state?
- 80/20—80% of the CSHCN unit budget was going to serve 20% of the CYSHCN population.
- Families as equal Partners—Moving away from the model of FOR families, to WITH families
- Putting the Public in Public Health—this tied their role back to the MCH pyramid and the 10 essential public health services.

The final outcomes of these meetings were new vision and mission statements: The Colorado CSHCN Unit (Medical Home Screening Programs, Family Leadership and HCP) has adopted the New York mission and vision: Vision: Colorado will have a comprehensive system of services and supports for CSHCN. Mission: The Colorado CSHCN Unit will improve the 6 national outcome measures for CSHCN.

In Colorado, the CSHCN unit is the broader entity and HCP is the program within the CSHCN unit that provides the regional care coordinators. HCP's Mission statement states, *HCP is responsible for building family driven, sustainable systems of health services and supports. Through interagency collaboration, we connect culturally respectful, community-based resources and provide outcome data.*

Utah

To develop their new vision and mission statement, Utah began by holding conversations with their own staff, including family leaders. It began with brainstorming about the concept of a "community based service system—what does this mean? What would it look like? Who do we serve? The list that resulted looked much like the definition provided in the introduction of this tool kit.

This in-house group drafted a new vision statement: to *enhance the health and quality of life for children and youth with special health care needs and their families.* The newly drafted mission of the Utah Bureau of CSHCN created was *to facilitate access to comprehensive, community-based culturally sensitive, appropriate health care and related services for Utah CYSHCN.*

This draft vision and mission statement was then shared with a broader stakeholder group that included the head of the Division for Child and Family Health Services, Maternal and Child Health Director, and family advocates, and medical home providers. See "Utah Visioning Power Point" as an example. The PowerPoint presentation used in the discussion is provided here.

The vision and mission statements were approved by the stakeholder group. The rationale for developing the new vision and mission was then articulated in a draft concept paper that discussed the challenges and desired direction for the Utah CSHCN program. See "Utah Concept Paper" as a model.

Maine

The Maine CSHCN director offers the following key points in guiding a vision/mission, building on Colorado's experience.

- Orchestrate a process by which a plan is defined
- Make sure the vision captures the guiding principles
- Link the vision to each team and individual
- Clarify what path not to take
- Consistently and continually communicate the vision and direction
- Devise tactics that mesh with the vision and strategy
- Implement the bold changes needed to make the vision real
- Keep an external focus—what we are doing for all CYSHCN, not how this impacts our program only.
- Plan for potential setbacks

Maine's new vision: Where Children and Families Come First

Maine's new Mission: To improve the health and well-being of our population by developing and sustaining community-based systems of care.

Going one step further, Maine articulated the following values.

- Our commitment, compassion, creativity, integrity, knowledge, and professionalism in providing the best services

- A trusting, collaborative partnership with families that respects their diversity and recognizes that they are the constant in a child's life

- A family-centered, coordinated approach designed to promote the health development and well being of children and their families.

- Medical homes that support and promote optimal health and family satisfaction

Points to Remember

Colorado recommends keeping the following points in mind.

- Communicate with all partners
- Make sure to *over*-communicate, even when you think everyone has heard the message.
- Acknowledge the skill set and strengths of local/PH staff in applying the vision and mission.

- Frame the change as new opportunities for families, for staff, for partners

Applying Step 1: Developing Your Own Vision and Mission Statement

Here are some questions to consider in your preparation for creating new vision and mission statements for your state:

- Who would you bring together from your "internal" CSHCN program staff to begin the discussion on building a community-based service system? Who on your staff do you anticipate will be your supporters, and who may be skeptical?

- How well does your current vision (your desired, long-range outcome) reflect the outcomes for the broad population of CYSHCN? How would you change it?

- How well does your current and mission statement reflect the role and work-scope for supporting a community-based service system? What changes would you want to make?

Step 2: Engaging Partners

Systems change cannot be done in isolation. Stakeholders must be part of your systems change efforts to ensure that their unique perspectives are understood and to understand how any changes in the system will impact these stakeholders. When stakeholders are part of the process, they are likely to feel a good deal of ownership for the process. It is important to involve the following three main groups of stakeholders.

1. Those involved in program operations: your key MCH and CSHCN administrators and staff;

2. Those served or affected by the program (i.e., families of CYSHCN and youth with SHCN, cultural groups)

3. Other entities that are part of the service system; for example, providers (such as Public Health nurses, Medical home primary care doctors), funding sources (such as Medicaid, Rehabilitative Services), interagency partners (such as Part C EI, schools, etc.)

Tips for Engaging Stakeholders

1. **Identify your "champions."** Champions are leaders who can clearly articulate the vision of developing a community-based service system. One essential champion is the state CSHCN director. Another critical champion is a state Family Leader, such as your Family Voices representative.

2. **Create a strategic planning stakeholder team**. Create a stakeholder team comprised of your "champions" as well other persons who either represent key policy and practice voices or represent the voices of those to be impacted by systems change. Ensure the team is a

functional size - approximately 8 to 10 persons worked well in the learning community states. Additional stakeholders can be involved, depending on the additional diverse voices needed.

3. **Engage community stakeholders.** It is important to create a stakeholder team that has community-level representation. Identify partners that can serve as the "door" into the community and that can provide a potential community/regional infrastructure, such as:

    - regional public health offices
    - key primary care providers (i.e., pediatric clinics)
    - existing community-based programs which already provide care coordination, such as Early Intervention programs that already provide service coordination for CSHCN birth to three years

4. **Frame the issue:** Colorado members reminded leaders to be careful about framing of the issue—make it clear that you're talking about a different way of serving communities. For example, in Colorado, they emphasized that 80% of their budget was going to 20% of the CYSHCN population—is that right? She also suggested conveying your own emotions/fears about what will happen to children and families (e.g., "We're all scared right now, but we have to think more collaboratively").

5. **Emphasize the "why."** There is often a tendency to jump into how the system should be changed. However, you must first ensure that stakeholders understand the "why" of your effort (e.g., "The kids in our state are not being adequately served"). It is usually easy to get agreement among stakeholders with the right "why" message and this is a critical step to inspiring the shared vision. Colorado held meetings with their regional public health staff to explain the dilemmas faced at the state level. The PowerPoint presentation, "Colorado Team Leader Meeting" shows how they conveyed the "why" in Colorado.

6. **Develop a shared vision**—what would we like to see for families in 5 years? What would we like to see working, what policies would we like to have in place, etc.?

7. **Outreach "Doors" into the Communities:** A stronger representation of community voices will be important at different times during this process. In addition, it is critical to share information consistently and frequently with stakeholders in communities throughout your state. Even though they may not be present for the meetings, keep lines of communication through venues such as emails, center website, etc. Colorado communicated with community stakeholders by "piggy-backing" on to other meetings going on in the community, such as existing interagency councils or other task forces. In the same spirit, identify venues for reaching families, such as family advocacy organizations, family support meetings, medical home offices, etc.

8. **Engage family leaders from communities:** This can be a time when family leaders can step up and support the vision, emphasizing the power of the community in working through the

transition. Getting community leaders involved from the beginning is critical. As an example, decades ago when mental institutions were closed, communities were not initially engaged in developing new supports, and as a result, they were unprepared and upset. Anna from Maine: As a family leader at the state level, she has been doing a lot of listening to other families, asking them questions, getting their perspectives. She sees that documenting their comments is important to address in their vision.

9. **Create a concept paper**: Utah leaders described the value of a "concept paper" that they have used to initiate communication with stakeholders (see "Utah Concept Paper" as a model). The concept paper serves to articulate the mission of Utah's CSHCN bureau in relation to the federal Title V purpose. It provides a concrete definition of a "community-based system of services" and what it means for families, followed by challenges that the state CSHCN program hopes to address via strategic planning.

   This concept paper was helpful, though it was still subject to misinterpretation. Family leaders were asked to review it, and some family leaders were quite upset that it appeared that CSHCN was another part of a movement to eliminate services. For example, "assessing community capacity" was viewed as meaning "dropping services." Through this important conversation, the strategic planning team recognized the importance of stressing their intention to enhance services via collaboration and not automatically do away with gap-filling direct services. This meeting with families also provided the opportunity to emphasize the budget cuts that are facing the program and the reality of needing to consider how funding can be used most effectively. We need to think more collaboratively because funds are being cut.

10. **Use P.R. Ambassadors:** A Colorado leader emphasized the importance of having multiple persons who can "spread the word" and spare the vision, inspiring the involvement of others. Identify "PR ambassadors" who can serve as spokespersons for spreading the vision. The CSHCN director alone cannot do it all.

11. **Create a Billboard message:** Although a concept paper may be appropriate for use with some stakeholders who are more integrally involved in strategic planning, it's important to also create a "billboard message" (i.e., a one-sided handout with no more than 10 bullets) that attracts the attention of a broad group of stakeholders (especially families across the state) and leaves them wanting to learn more. This can serve to get people engaged in dialogue. A sample billboard message could be, "*Funding Changes Demand We Think Differently.*" Eileen offered to help with a design for UT and ME if interested. This "billboard message" can even be used as a weekly reminder with your own staff and strategic planning team. It also can be used with public health offices, other community partners, family-to-family health information centers, etc.

Preparing for Resistance: Know the Perspective of Your Stakeholders

When stakeholders are not appropriately involved, any proposed systems change efforts may be ignored, criticized, or resisted. Additionally, even though appropriate attempts have been made,

there may still be resistance for any change. Here is some advice taken from The Community Toolbox: http://ctb.ku.edu

Dealing with Resistance Among CSHCN Staff

Moving toward a community-based service system may translate into changes in the roles of your staff members. When changes in the workplace are proposed, employees may have many reactions—some may be positive and supportive, while others may strongly resist. In addition to any operational changes that may occur (such as moving to new locations, new job assignments), staff may also experience emotional "transitions", which are psychological in nature. Because transition is a process of moving from an old world to the new, there are some key principles for CHSCN leaders to keep in mind when engaging their staff in this process. The book, *Managing Transitions: Making the Most of Change* by William Bridges is a resource that was used by Colorado, Utah, and Maine to guide their support and interaction with staff.

The following strategies were identified to address issues commonly faced:

Good leadership is critical during this time of transition

Leaders must stay positive and truly inspire this shared vision. Again, understand where your staff/stakeholders' fears are coming from—is it concern over loss of services? Families won't get what they need? That they won't know if they'll keep their job? One excellent resource for enhancing leadership is the Leadership Challenge, a leadership development program used by Colorado leaders that was developed by authors Jim Kouzes and Barry Posner. Go to http://www.leadershipchallenge.com for more information.

Family leaders are sounding boards

A state-level family leader in Maine reported that it was important that she do a lot of listening to other families, asking them questions, getting their perspectives. Documenting their comments is important to address in their vision.

Supporting staff through the Transition

In Maine, they have announced that the old system of paying for care has ended, and a new system is being developed. In the interim, state staff are not sure what to tell families who contact them. It was suggested that the aforementioned "billboard message" could be used to invite these families to participate in the effort to build a family-centered, community based system. Developing a call log—a simple form that could be used to track emerging issues, document what families are asking for—would be very useful for guiding the development of the new system model.

Encouraging Involvement of Potential Opponents as well as Allies

Below is an excerpt from the Community Toolbox found at: http://ctb.ku.edu/en/tablecontents/sub_section_main_1338.htm**),** which provides excellent information about obtaining support from those who are resistant yet critical to your systems-

building effort.

What do you mean by "involving opponents"?

It seems obvious that you would want to involve your allies in your group's plans. However, you probably have not considered involving your *potential opponents* as well. The idea may sound far-fetched, to say the least; it may even seem harmful to your group's goals.

However, think again. Maybe your opponents can indeed help you, in unexpected ways. As you will find out, collaborating with people with different goals and values—at least partially different—can be beneficial to you, and also to them. Both of you can win.

Why should you want to involve an opponent?

Collaboration with people you might otherwise think of as opponents can give you and your group several advantages. Among them are:

- You might be removing, or neutralizing, a potentially harmful critic.
- You might gain insight into the workings of your opponent.
- You might gain access to a group that has been previously closed to you.
- You could acquire new resources to solve a common problem. (To solve tough problems, the energy of many groups may be required.)
- You can find common values and beliefs you did not know were there.
- You can get to know your opponents as people.
- You can build a base of trust that might be helpful to you in the future.

Finally, and perhaps most important:

- Involving your opponents can change the status quo and help you make progress.

"Are they really my opponents?" Some useful facts about opposition...

1. *Opponents come in varying degrees*. Not everyone who might oppose you will defend his position until his dying breath. Those who are slightly or mildly opposed are potential targets for change. Moreover, some people may oppose you because they do not understand your issue, or simply out of habit—they are just not used to agreeing with you! When you talk with them further, you might find they are not your opponents at all.

2. *Opposition depends upon the issue*. Someone may be opposed to you on issue A; but that does not mean they will be opposed on issue B. On issue B, they could be your strongest ally. So be careful about making generalizations.

3. *Opposition is not forever*. Your opponents' position may change over time. Your position may change. This means that keeping polite (if not necessarily friendly) relations with your opponents is a good idea more often than not. You never know when it might pay off.

Here is a basic point to keep in mind: *Someone who disagrees with you is not necessarily an opponent!*

When should you involve opponents?

Three good indicators are:

- When the lines of communication are still relatively open—and especially when you believe your opponent is willing to talk with you
- When you see common values and opportunities—even if your opponent doesn't see them yet
- When, from your opponent's point of view, the cost of getting involved with you is not too great

When NOT to involve opponents: Some red flags

However, not every situation calls for collaboration. Sometimes involving your opponents would be very difficult, if not also damaging to your efforts. For example, when:

- There is a history of distrust, or actual deception, between you and your opponent.
- Your respective positions on this particular issue are strongly held, deeply entrenched, and completely opposed to each other.
- Your opponents are unwilling to talk with you.
- The time and energy costs in collaborating with your opponent on this issue would be just too great.

On some issues, it is certainly possible to "agree to disagree" in a respectful way. Remember, though—this does not mean you will be disagreeing the next time around.

How can you involve opponents?

Suppose you decide that it might not be such a bad idea to involve your opponents in your cause. It is good that you are open to the idea. However, since you may be on unfamiliar territory, just how should you go about doing this? What do you do first?

We suggest you consider using the following steps as a guide.

1. *Decide that you want to involve your opponents*. This is the first and possibly most important step; you need to make that basic decision before you can proceed further.

2. *Narrow your targets*. Whom would you like to involve? Probably not all opponents, rather only certain ones. But which ones? Try these criteria:

    - Those who have the power to help you get what you want
    - Those who have cooperated with you in the past
    - Those who agree with at least some of what you stand for
    - Those who could sway other opponents
    - Those who seem approachable, and whom you feel comfortable approaching

Some careful thinking ahead here is worth your while.

Clarify your goals. What do you want to accomplish through your involvement attempt? What would you like to see happen as a result? You probably do not want to shoot for the moon, but you can aim for some closer target on earth. This could mean:

- An agreement that your opponents will not oppose you publicly
- An agreement to try your ideas for a limited time, followed by impartial review
- An agreement to work together on a related issue

On the other hand, some other specific achievement you can count as a win—or, better, as a mutual win.

Make the commitment. Are you personally ready to work with your opponents? It may not be easy. It may be a bumpy ride. You may fail. So are you truly prepared to invest the real time and energy to make this outreach attempt? Take a pause here—because in a moment, you'll be plunging in.

Identify other stakeholders. That is, *other* people in the community will be affected by the issue or problem you care about—it's not just you and your opponent. We often call these people "stakeholders." For example, if the issue is the cleanup of a polluted river, there are many possible polluters, just as there are many river users. Both groups (and possibly others) are stakeholders in the condition of the river.

It is best to keep in touch with stakeholders and consult with them at the beginning. Why? Because (a) they may have sound insights into the problem, as well as good ideas for solutions; (b) if they are not consulted, they can disrupt the process or the outcome; and because (c) they will have to live with any solutions that are adopted—so they should legitimately have a voice. Therefore, ask, "Who else is involved? How can we learn about and utilize their ideas?"

Make the contact with your opponent. Get some discussion under way. However, this will not be ordinary talk or casual conversation; it will be planned-in-advance talk, with specific goals in mind.

As you start, are there some basic techniques you can use? There certainly are. Each situation is different—and take a close look at yours—but some of the techniques below might apply:

Establish ground rules. These are agreements on how you and your opponents will interact,

before any interaction actually takes place. Ground rules can remove some of the uncertainty of participants, and lower the chance of misunderstandings. Some common examples: the meeting site; the meeting time; the people attending. More possibilities: media relations; confidentiality; use of outside experts. And finally: setting an agenda—see below.

Set an agenda. This is one of the most important ground rules, which can and usually should be done in advance, together. The agenda specifically includes the items you plan to discuss; but more broadly, it also implies the goals of the meeting and suggests the general spirit in which the meetings will be conducted.

Organize subgroups. If your issue is very broad or complex, it may help to create subgroups or task forces. This will take more time and effort—but the advantage is that you can approach and deal with several distinct issues simultaneously. The subgroups can later report to the main group. One key to effective subgroups is keeping them diverse, so that a wide range of input can be collected on an issue.

Search for information. More times than you would think, groups oppose each other because they do not have access to the facts. Both groups *think* they know what the facts are—but both could be wrong. The "facts" could be incomplete, out-of-date, misinterpreted, or all of the above. So ask, "Do we have enough information to understand the issues and arrive at solutions?" You and your opponents might decide to review data together, or gather new data, perhaps using unbiased experts. This can give you a common basis for discussion.

Find a mediator. A mediator, facilitator, or other outside person can sometimes be helpful in your discussions. This is especially so if both sides really do want to talk, but when distrust has run high; when emotions might slip out of control; when you don't trust your own one-on-one communication skills; and when a good mediator is in fact available. (See Chapter 33, Section 15: Seeking a Negotiator, Mediator, or Fact-Finder.)

Involve other stakeholders. The most common discussion format is one-on-one, but that is not the only way to get the job done. Other concerned groups can get in on the discussions too. (A good mediator here can definitely make things easier.) A variation of this would be to have one-on-one discussions at the beginning, then to open things up to other groups as the discussions proceed or move to a conclusion.

Hold an exploratory meeting. If the issue is particularly difficult or complicated, you and your opponent can begin just by talking about the issue, and your feelings surrounding it—without making any requests, or any commitments whatsoever. Such an exploratory meeting can lay the groundwork for a more business-oriented meeting later on.

Meet more than once. Depending upon the people involved, your own goals, and the complexity of the issue, your discussions may take more than one meeting. Its fine to arrange another time to talk some more, especially if the matter is important to you and you sense signs of progress.

There is more to say about making the contact. Below are 12 additional "talking points" for dealing with opponents that will apply to most situations you run across.

1. Think in advance about your opponent's interests and values. You will not agree on everything; but look for areas where you have interests and values in common. You will probably find some.

2. Go in with the expectation that you are going to get something done, that you can in fact do some business together. *But:*

3. Start slowly. Do not expect too much at the beginning.

4. Be cordial and polite. Treat the other person as you would like to be treated.

5. Begin with some small talk, to build rapport, and to set the tone for the more serious work ahead.

6. Engage in some informal conversation about the issue. Do some sounding out. This will give you a clearer idea of what strategies are likely to work.

7. Make some specific propositions. Do not be hesitant about saying what your interests are and what you want.

8. Show how your proposals will meet the other person's interests (See #1 above.). Those others will think, or say, "What's in it for me?" You should have a good answer. So look for proposals where you both can win.

9. Listen very attentively to what the other person has to say—and how it gets said.

10. Be willing to compromise.

11. Have some back-up ideas in mind, in case your original proposals are rejected.

12. Make sure a variety of options have been explored before choosing any alternatives.

For more detail on these points, check out the classic book by Roger Fisher and William Ury, 1991, Getting to Yes, *Penguin Books, NY, especially their chapter, "Invent Options for Mutual Gain."*

Close the deal. The last step in your discussions is to reach agreement and close the deal, if you have one. What kind of deal are we talking about?

- The best kind is a commitment to a particular course of action. For example, your former opponent agrees to endorse your anti-violence program, or lend his/her name to an ad in the paper, or simply not to take sides on an issue. These victories may be small in and of themselves (or maybe not so small), but they might also be precedent setting.

- If you cannot get an action commitment, then you can agree on some general values and goals. Your former opponent says, "We will work toward reducing youth violence in our community." Or, "We support the expansion of affordable housing programs."

- If you cannot get that far just yet, another variation is to "agree in principle" on a general framework, from which details of agreement can be worked out later. For instance, "We agree that affordable housing is a real concern in our community, and we hope to be part of future discussions on how it can best come about." More talk will be necessary, but even getting this much agreement (in some cases) can mean you have come a long way.

The best way to express agreements, especially among people who have been opponents, is to put them in writing. The printed word lowers the chances of miscommunication. More than that: it gives both sides a sense of clarity and security. Your written agreement can be in the form of a one-paragraph note, or a longer "memorandum of understanding," or whatever name you both wish to give it. However, both sides should sign it, with copies all around. Handshakes, too—even a small bow.

*** Hint ***: If multiple issues are to be decided, you can use a "building block" approach where you make separate agreements (or commitments) on separate issues, tackling the easiest issues first.)

Now you have the involvement of your opponent on paper, but your work is not quite over. This is because you have to persuade others that the involvement you have obtained—and any agreements you have reached—are good deals all around. Then you need to see that everyone (yourself included) lives up to their end of the bargain.

All this means a few more steps.

1. ***"Sell the deal."*** The deal is made. Now you need to convince others to support you. This means three types of groups in particular.

    - First, your own supporters, particularly supporters not part of the earlier discussions. Of course, they should have been made aware that those discussions were going on. But now you need to show them that you got the best possible deal, and why. They need to know why trade-offs (if any) were made, and that any agreements made will be beneficial to everyone concerned. Otherwise, you run the risk of your supporters backing you grudgingly, or not at all—and then you will truly be out on a limb.

    - Second, other stakeholders. Convincing your supporters—or at least getting them to go along—is probably the easy part. But others will be concerned too, such as the stakeholders we mentioned in Step #5 just above. Are these stakeholders crucial to your success? Absolutely, because it is these people who will be implementing the agreements you have reached. They are on the front lines; they have to buy in.

Example:

Suppose you and corporation **X** agree on local minority hiring targets. Fine; but what about local businesses **Y** and **Z** down the road, who are next in line to be approached? In this case, they are stakeholders, whose support-in-principle (at the least) is very desirable before you knock at their door.

- Third, the general public. They may naturally wonder why you and your opponents are now working together. They may be suspicious, and think something is up. (They are correct.) They deserve an explanation, on practical grounds if for no other reason. That is, the general public too will need to understand and live with any agreements you reach.

In building support for any agreement, clear communication is the key to success.

2. ***Structure the agreement.*** Now that you have a final plan, do you have a structure to support it, both in the short and long term? That is, how do you know the agreements will not fall through? What is going to prevent your former opponents from wiggling out at the last moment, or backing out altogether, or even opposing you all over again? To avoid these consequences, and to prevent your deal from collapsing, you need some kind of structure to keep it standing up. In other words, you want to "institutionalize the deal."

   How to do it? You could have regular meetings every so often for a little while. Or possibly open meetings, with others involved. Or the involvement of a third party, if desired, upon request of either group. Or a formal review of the situation a few months later. These are examples of agreement-maintaining (or institutionalizing) structures, which can and should be built into the agreement during the time of the original discussions. Doing so can save you a lot of grief later on.

3. ***Monitor the agreement.*** That structure is good; but you've also got to check on events, and monitor the agreement to make sure things are going according to plan. Somebody has to use those structures to make sure things are heading in the right direction. Specifically: You need to watch your former opponent's actions, not just their words. Are their actions open for public inspection? Are they really doing what they said they would do? To verify this, you can keep notes and records—and this monitoring process can be built into the original agreement itself.

To sum it up

If you have followed the above steps, chances are good that you can arrive at some agreement with your former opponent, and some common actions as well. The chances are good, too, that your former opponent will comply. (Of course, you need to comply just as diligently, and perhaps go the extra mile in showing good-faith effort.) In that case, congratulations for doing good community work!—work that may not only lead to good outcomes now, but which can build a foundation for other collaborative action together in the future.

Resources

Chrislip, D. (1994). *Collaborative leadership: How citizens and civic leaders can make a difference.* San Francisco, CA: Jossey-Bass.

Fisher, R., Ury, W., & Patton, B. (1991). *Getting to yes: Negotiating agreement without giving in.* (2nd ed.). New York, NY: Penguin.

Gray, B. (1991). *Collaborating: Finding common ground for multiparty problems.* San Francisco, CA: Jossey-Bass.

Himmelman, A. T. (1992). *Communities working collaboratively for a change.* Minneapolis, MN: Himmelman Consulting Group.

Homan, M. (1994). *Promoting community change: Making it happen in the real world.* Pacific Grove, CA: Brooks/Cole.

Applying Step 2: Engage other Partners

- Is there an existing state –level team or group that you can use (also think beyond MCH) consisting of:
  - Your "customers":
    - ✓ Family leaders
    - ✓ Youth leaders
    - ✓ Those reflecting diverse cultures, esp. those under-represented
  - State-level agencies (directors)
    - ✓ Who are your partners in paying for services? (i.e., Medicaid, Shriners, etc.)
    - ✓ Who are your partners in providing and coordinating services? (i.e., Vocational Rehabilitation, Education, Part C, Public Health)
  - Those who can help with training or evaluation? (i.e., UCEDD's, LEND)
  - Community-level providers (physicians, public health nurses, etc.). What are the natural "communities" (counties? regions?) in your state to engage?
- Who will be your "champions"—those with the power and influence to support your efforts?
- Who will be your "ambassadors"—especially family ambassadors: those who can spread the vision and mission to a broader stakeholder group?
- Who will be your "reluctant" participants—those who you will want involved in your transparent activities?

Step 3: Assessing Community Capacity and Needs

Moving to a community-based infrastructure requires an understanding of the strengths and needs across the communities statewide. A first step in this process to look at the extent to which state-level policies and practices are in place to support communities. The ChampionsInC PDF document, **Community-based Assessment Tool for Title V CSHCN Leaders: *Examining State Capacity for Achieving a Community-Based Service System for Children and Youth with***

Special Health Care Needs provides an opportunity for the stakeholder team formed in Step 2 to assess the extent to which state policies and practices are supporting community-based service systems and how the state is supporting community-level policies.

It is essential to assess community capacity and needs from key stakeholders at the community level, with a particularly strong voice needed from families of CYSHCN and youth themselves. Colorado, Utah, and Maine used various approaches to gather information from communities to gain an understanding about:

- Which families of CYSHCN currently are not being served adequately
- Which services are families not accessing at the community level
- The resources in the community to support the 6 CYSHCN outcomes
- Existing partnerships within the community on which to build coordination/collaboration

The following strategies were used by Colorado, UT, and Maine to understand the capacity and readiness within their communities. The following tools were developed via a participatory action approach, whereby a team of state administrators, family leaders, and direct service representatives developed the content to fit the needs of communities in their state.

1. **Focus Groups:** Colorado, Utah, Kansas, and Maine brought stakeholders together to introduce the vision and mission of the State CSHCN program and to share the definition of a community-based service system. Focus group methodology was then applied to understand the perspectives of providers and families within targeted communities regarding the strengths of their community and their needs. Separate focus groups with providers and families are needed to ensure that families feel comfortable in sharing their opinions candidly. The Kansas "Town Hall Flyer" serves as an example of a community invitation.

2. **Stakeholder surveys**: Utah was particularly interested in assessing the specialty care capacity within the communities that were traveling clinic sites. A web-based survey was disseminated to stakeholders who were familiar with the specialty care services within their community in order to gain insights into the gaps in services for CYSHCN. See "Utah's Community Stakeholder Survey" to see this example.

3. **Community mapping.** A community map is a visual depiction of the services and supports—both public and private—available to families of CYSHCN in a target community. Ideally, the map is best completed by a small team (3-4 members) of community members to develop a draft version of the community service map. The center of each map identifies the target population (i.e., CSHCN). A separate map of services for youth/young adults with special needs should be created given the differences in services for this population.

   The team identifies the services and supports, placing the most frequently used services close to the center. When filling out the map, in addition to typical private and public agencies, other groups should be considered such as, churches, consumers, civic groups, and other sources of formal and informal supports. After the services and supports are identified, the map can also be used to visually depict the relationship among various entities, such as colored arrows depicting coordination among agencies.

As an example of how a community map has been used, Augusta, Maine chose to assess the extent to which their community was coordinating services, particularly with a medical home provider called The Vickery The map provided an outline of the relationship among public and private services available in the community. The child and family was depicted in the center. Other community agencies radiated around the center and a key was developed to represent the role of each agency/program. The draft map was shared with the larger community task force for additions and corrections.

A discussion of the findings from the mapping exercise should center on:

- What services and supports are strong in the community?
- What services/supports are lacking and may need to be addressed?
- To what extent are services and supports coordinated?

This information becomes a key piece in developing plans for improving the community-based service system.

4. **Community self-assessment to assess community resources/capacity**: Earlier work conducted by ChampionsInC staff involved the development of a community self-assessment designed to capture the resources and inter-agency collaborative efforts within a community that pertain to ensuring accessible, coordinated, comprehensive, and culturally competent services for families with children ages birth to 5 years. The assessment was completed by a small community-level stakeholder team, who then verified the report with the broader community stakeholder group. This survey can be adapted to cover a broader age range.

5. **Use of national survey questions with families at a community level**. The National Survey of CSHCN provides state-level data on the broadly defined population of CYSHCN. Data can be analyzed to determine the survey findings of rural versus urban areas, but data cannot be obtained at a county or city level. However, the survey questions can be replicated in the development of community-level surveys. For example, states may be interested in learning more about the challenges in communities across their state that relate to difficulties families face in accessing services, or the extent to which families report that they receive adequate support in coordinating services.

   The final step in the assessment process involves summarizing the findings and using the information to guide the development of a plan. Utah developed a matrix to summarize the data gleaned from their stakeholder surveys and focus groups.

Applying Step 3: Assess Your Community

- How will you define your "communities" (i.e., by counties? Public health offices? Metropolitan areas)?

- What existing information do you have now about your communities/regions within your state?
    - State-wide data (i.e., surveys)
    - Data from your state partners
- How can you engage communities?
- How can you identify "ambassadors" into the community?
- How will you bring together families, youth, and providers from the community?
- How can you find out about the strengths and needs of your communities?
    - resources: Services, specialty care, and care coordination
    - community interagency groups
    - support services (transportation, respite, etc.)
- Who can assist you in gathering community assessment information and help with analysis?

Step 4: Developing a Plan

This step involves developing an Action Plan for improving community-based service systems throughout the state. Key activities are:

1. Identify the strengths and challenges of the community-based system of care for CSHCN based on the existing data
2. Target priority areas for implementation
3. Identify strategies to address priorities.
4. Create a plan that articulates resources, persons responsible, and target dates for completion.
5. Disseminate the plan.

At this point, it is critical that the State Leadership Team include the top administrators of the division to ensure the plan has the needed support by top decision-makers. Equally important is ensuring representation from community-level providers who will play a key role in implementation, with strong family representation to ensure the plan truly is addressing the needs of families.

Identify the Strengths and challenges of the community-based service system of care based on the existing data

The leadership team interprets the data results for the purpose of action planning by answering the questions:

- What appears to be working well in communities for CSHCN and families in terms of the six core measures?
- What appear to be the challenges or greatest needs of communities in serving CSHCN and their families?

Utah created a matrix that was used to summarize the strengths and challenges within the targeted communities in their state. Again, see the "Utah Community Planning Matrix" for an example.

Target priority areas for implementation

Given the diverse strengths and challenges that may be present across communities, it is important to consider priority areas that are consistent with the vision and mission statements, the broader strategic plan for the MCH or Lead Department, and the agendas of your key partner organizations.

In developing priorities, the State Leadership Team can ask itself:

1. *What are the universal strengths in communities throughout the state?* For example, Colorado had public health offices that were known by the public and that already provided some resource and referral information to families in the community. This was identified as a strength in developing an action plan.

2. *What are the universal needs in communities throughout the state?* In Colorado, the need for improving the coordination of services that was universally expressed by the communities.

3. *What are the potential priorities of the state that may reinforce these priority areas?* Drawing a relationship between your priorities and the existing priorities of the broader MCH or Department of Health Plan is important. Additionally, consider the priorities of your state's governor or legislature that may be related to the strengths and needs you have identified. Identifying continuity in the priorities of communities you have identified to that of the broader system will facilitate obtaining buy-in from needed leaders and strengthen the acceptance of your plan.

Identify potential strategies to address priorities

To develop the Action Plan, the leadership team must apply a process for identifying potential implementation strategies and reach decisions regarding those strategies that are the most appropriate. A typical process includes these activities.

1. Brainstorm implementation alternatives—what are some ways that these needs can be addressed?

2. Discuss these alternatives to determine which are likely to be the most cost-effective, considering the state budget.

3. Review the selected strategies with other administrators, providers within the represented agencies, and family representatives. Are there other state implementation efforts underway that can support your efforts? For example, a state AAP chapter may be implementing some medical home training that can play a role in your implementation plan.

Again, the Utah Community Planning Matrix identified potential strategies that could be used to address the needs.

Create a plan that articulates resources, persons responsible, and target dates for completion

Once the key implementation strategies are identified, an Action Plan is created, serving as a blueprint for working toward achieving needed improvements. Essential components of an action plan include:

1. A reiteration of the desired long-term outcomes, using the group's vision statement to guide the development of the strategic plan.

2. Create specific objectives that articulate the key components, i.e., regional/county CSHCN offices/staff; care coordinator services; family leadership; interagency collaboration; outreach; support of medical homes.

3. Specify the activities to be performed under each objective

4. Identify agencies and persons responsible for taking the lead

5. Develop target dates for completion of the activities, with attention to when you want to begin implementation of new activities.

6. Identify methods for measuring and monitoring progress: obtaining formative information from the communities about how implementation is progressing; developing ways to monitor the activities occurring within the communities; measuring the outcomes for children and families served.

It is important that the communities throughout the state are involved in the identification of implementation strategies that make sense for their community. Although there will be statewide objectives and strategies, communities also must have flexibility in involving specific resources and addressing unique needs. This may come in the form of developing complementary community-level plans.

Disseminate the strategic/action plan

As in the dissemination of the vision and mission statement, it is critical to share the Action Plan with families, communities, and state level stakeholders. The "PR Ambassadors" play a critical role in this dissemination. It also is important that the Leadership Team regularly communicates progress toward completing the strategic plan to these same constituents.

Applying Step 4: Develop a Plan

- Analyze/synthesize your community-level data
    - What do you predict will be the strengths in the communities on which to build?
    - What do you predict may be some of the challenges?
- Identify implementation strategies: What are some of your potential ideas in how to promote community-level service systems:
    - Care coordination, in partnership with medical homes
    - Referral and outreach
    - Inter-agency collaboration
    - Family leaders in all communities
    - Pursuing financing/funding options
- Are some communities "more ready" than others? Which communities have the enthusiasm and foundation to serve as initial sites?
- What is your time line that is driving your systems change effort?

Step 5: Implementation

Moving to implementation of the newly planned community-based infrastructure often occurs in phases, based on the due dates specified in your plan. For example, Colorado implemented some aspects, such as creating regional offices as an initial step. The outline below describes the key implementation activities for Colorado, one of the learning community states:

a. Infrastructure building
    i. Decentralize and promote local systems building
    ii. Decrease direct payment services

b. Care coordination
    i. Promote the medical home approach
    ii. Communicate with Primary Care Providers

c. Family Leadership

   i. Utilize culturally rich consumers to tackle cultural health disparities
   ii. Empower families to take control of their child's health

d. Build a coalition between state and local services

e. Consistent Messaging

   i. Consider hiring a planner or a facilitator for added credibility or to expedite the process.
   ii. Political climate to support or hinder
   iii. Potential of media to help or hinder
   iv. Make sure you remain "on message" throughout process

f. Prepare and engage communities. Communities should decide (through their own community needs assessment) what their team would look like.

g. Prepare for transitions, particularly the internal process of staff adjusting to the change

   i. Assessment of staff skills
   ii. Adequately prepare staff for new organization and new work habits
   iii. Allow staff to "mourn"

h. Find new funding services for current children

   i. Meet with families to determine the gaps in services (i.e. respite care)
   ii. Convene community agencies and family advocacy organizations to talk services each organization offers
   iii. Local organizations identify local systemic barriers, so the state can help counties address these barriers

Colorado Care Coordination Model. A description of Colorado's implementation of care coordination can found at:

http://www.cdphe.state.co.us/ps/hcp/form/carecoordination/HCP%20Care%20Coordination%20Forms%202010/6-1-10%20HCP%20CC%20Policy%20and%20Guideline.pdf

It is important to remember that moving toward full implementation most likely will not happen quickly. Colorado's implementation occurred incrementally over a five-year period.

Applying Step 5: Implementation

- How will implementing these new ideas change your state-level program structure?
  - How will this change the roles of your state level staff? Will they need to develop new skills?

- How will it impact your budget?
- What will need to happen in terms of training/TA for communities?

What do you think may work best for implementation "spread" in your state? Implement across all communities at once?

"Pilot" in some communities, and gradually expand to new communities?

Step 6: Measuring Outcomes

Measuring the outcomes of your newly implemented community-based service system components is important for multiple reasons:

- To identify what's working and what's not—guide quality improvement
- Guide budget decisions
- Inform policy makers, legislature

Measuring outcomes of new community-based service systems must be tied to your mission and vision, providing you with important information to answer the following questions:

- What do you know about the effectiveness of your new program components (i.e., care coordination component?
- What do you know about the effectiveness of systems building efforts (interagency collaborations, CCN)?
  - Statewide
  - By county/region
  - For six CYSHCN performance measures
  - For all CYSCHN and families, especially under-represented groups

Community-Level Measurement Tools

Tools for measuring outcomes can be built upon the tools discussed in Step 2: Assessing Communities. The measures highlighted in Step 2 can be repeated to determine changes at the family and community level. In addition, additional measures can be developed to assess the effectiveness of your new program components, as provided in the examples from Colorado and Oklahoma.

Analyzing existing survey data. States can also gauge their systems change efforts by critically analyzing data from state and national surveys administered in their state. Examples are provided below.

National Survey of CSHCN. Thanks to the Data Resource Center (www.cshcndata.org), states can gain an understanding of how the service system is working for families over time. "Drilling down to better understand Outcome 5" provides step-by-directions for using this survey data to understand the impacts of service systems on families, particularly related to Outcome 5: Community-based service systems are organized so families can use them easily.

National Survey of Children's Health. This survey also provides valuable information pertaining to CYSHCN and their families, particularly concerning the medical home. This information also is available from the Data Resource Center (www.cshcndata.org).

Using Data to Communicate

Data can be a powerful tool in promoting your systems change effort for multiple reasons. First, sharing data increases recognition of your CSHCN program. Sharing results can be used to highlight your accomplishments or demonstrate the needs of families. Therefore, it is important to plan how you will use the data you collect.

- With whom do you share your data?

Well, first of all you should keep your supporters updated. Staff, volunteers, supporters in the community, and funders are all supporting groups that should be up-to-date on your group's efforts and successes. Keeping the issue in front of them helps them stay in touch with your purpose. It also deepens their understanding and commitment, and lets them know about any specific organizational needs that they might be able to meet.

You should also share your evaluation findings with your target population—the people you are trying to help. If you work with a heart disease prevention program and your evaluation shows an increased risk factor for members of a particular ethnic group, for example, you will want to let members of that group know in order to spark their interest and make them more receptive to whatever work you will be doing in their community. Your target group needs to know what and how they will need to change to improve their health.

Finally, the general public should be kept informed, including those people who might not fall into a particular affected or interested group for your coalition's focus. The support of the general public is very important.

How do you present your data?

There are various types of reports that can be used, depending on the audience. Some groups - those who you're trying to generate interest from or who only have a passing interest —won't want t a dry, dull, technical report. However, funding agents, grant writers, advisory boards, and program staff will most likely want detailed, explicit information. You should always take into consideration the type of group you're presenting the information to and tailor your presentation to that audience.

As found in the Community Tool Box (http://ctb.ku.edu/en/tablecontents/chapter_1036.aspx),

there are multiple ways to share your measurement information:

- **Technical reports:** This is a detailed report, best for funding agencies, program administrators, advisory committees

- **Executive summaries:** This consists of a few pages, usually at the beginning of a report, outlining a study's major findings and recommendations, useful for multiple audiences.

- **News release to the press,** best for wide distribution of simplified information meaningful to the general public.

- **Public meeting:** A gathering that's open to the general public where more general evaluation findings are released in a clear, simple manner, ideal for community-level communication.

- **Staff workshop:** A more interactive, working presentation for your group or coalition's staff and volunteers, best for program administrators, program staff, and service providers.

- **Brochures/posters:** Brief, simply worded printed materials that can be distributed and mailed to various stakeholders, especially families who you wish to serve.

Over-Communicate!

Colorado leaders emphasized the importance of "over-communication" to all of your stakeholders. In particular, it is important to ensure that CYSCHN system staff understand why it is important to collect outcome data and their role in sharing the findings accurately and meaningfully. This requires that state level staff repeatedly share the findings with staff and what the results mean to the program, the community, and families.

Applying Step 6: Measuring Outcomes

- Who do you have to help you develop a measurement plan?
    - State Statistics/Epidemiological office?
    - University-based researchers/evaluators?
    - State Family-to-Family Health Information Centers?

- What have you used to measure process/service outcomes (i.e., services delivered, numbers served) that you can build upon?

- What have you used to measure short-term outcomes (i.e., family ratings of how well services are meeting their needs, more children have medical homes, etc.)?

- What have you used to measure long-term outcomes? (state survey data?)