



Engaging Families and Consumer in Program Planning, Implementation, and Evaluation

Toolkit

Title V Maternal and Child Health Services
Kansas Department of Health and Environment



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The Title V Maternal and Child Health (MCH) Services Block Grant was authorized in 1935 as part of the Social Security Act. Title V's mission is to improve the health and well-being of the nation's mothers, infants, children, and youth, including children with special health care needs and their families. The program is funded through the Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB) and administered by the Kansas Department of Health and Environment, Bureau of Family Health.

Find more information at www.kansasmch.org or <https://www.kdhe.ks.gov/626/Maternal-Child-Health-Block-Grant>.



Introduction

Families and consumers provide firsthand knowledge and insight to areas that program staff may not have considered, as well as suggestions on how to drive positive change for Kansans. There is a collective vision across state agencies serving children and families to support systems and services that meet the basic needs of Kansans, including access to quality health care, education, social service systems, and community-based resources. While the early childhood systems coined the “Every Child Thrives” vision this is evident across crosses all service delivery systems and is articulated in many ways.

All In For Kansas Kids

Through the collaborative work to improve the early childhood care and education (ECCE) system, Kansas agencies have also adopted a shared belief that supportive relationships, healthy environments, and aligned services can provide families a solid foundation to support this vision. This shared believe also commits to striving to meet six guiding principles: child- and family-centered; data-driven; strengths-based; equitable; transparent and accountable; and transformative and dynamic. To support these principles, family voice and partnership were established as critical elements of the All in for Kansas Kids Strategic Plan.

The Family Leadership Team was created as a critical working group within the Early Childhood Governance Structure, and in partnership with the Bureau of Family Health Family Advisory Council, are working to establish a shared vision for family and consumer partnership (FCP) across agencies. While that work is ongoing and Kansas has not yet adopted a formal ‘definition,’ it is clear that all systems serving children and families believe that family partnership is a vital component to service delivery.

More information about the varying definitions across agencies and partners can be found in the Appendices.

About This Toolkit

This toolkit is designed to share information about state and national frameworks that guide our collective approach to engagement and partnership with the families and consumers served. This resource is designed to assist local or state programs are supported to, and feel confident, engaging families or consumers in a variety of ways. The information in this toolkit outlines the views and desires of families in Kansas and organized by “levels of engagement” such as: engaging families for input, feedback, or buy-in; as advisors; or in leadership and support roles. The goal of the toolkit is to assure:

- families or consumers are engaged in meaningful and mutually beneficial ways;
- family or consumer engagement practices are supported at both community and state program levels;
- evaluation activities consider family voice, choice, and experience related to services provided; and
- opportunities exist to partner with those with lived experiences and served by programs to inform and advance policy at the local, state, and national levels.

This toolkit is comprised of input and feedback directly from Kansas families and includes web-based content, resources and examples of engagement activities, and a planning tool to assist programs in developing a “Family and Consumer Engagement Plan,” if desired.

Toolkit Resources

This toolkit has been developed with cross-system and cross-sector implementation in mind. The toolkit is available for all Kansas organizations and communities to utilize. As such, we also welcome the inclusion of examples from local and state Kansas implementation efforts. Agencies and organizations are invited to share their engagement strategies, activities, and lessons learned. This tool is not designed to be a ‘guide’ on how to do this, as that will vary from community to community and must be tailored to each target population. The goal is to highlight best practices and innovative ideas taking place across Kansas and invite you to consider adding your organizations’ resources and activities.

Frameworks

There are many frameworks at the state and national level that focus on engagement and partnership of families and consumers. Each offer various components that may be valuable to the work you do and support your efforts to engage and partner in different ways. These components include foundational **principles**, quality **standards**, engagement **strategies**, and evaluation and **assessment** approaches.

Framework	Key Content	Components
Levels of Family Engagement in Title V	Levels of Engagement Input, Advisory (Self), Advisory (System), Leadership Roles	Principles Strategies
Kansas Family Engagement and Partnership Standards for Early Childhood	Guidance for Engagement Families as Foundation, Communicators, Advocates, Partners, Community Members	Principles Standards
Standards of Quality for Family Strengthening and Support	Quality Standards for Family Support Family Centeredness, Family Strengthening, Embracing Diversity, Community Building, Evaluation	Principles Standards Strategies Assessment
A Framework for Understanding the Elements and Developing Interventions and Policies	Continuum of Family Engagement Consultation, Involvement, Partnership and Shared Leadership	Principles
A Framework for Assessing Family Engagement in Systems Change	Assessment Tools for Engagement at the Systems Level Commitment, Transparency, Representation, Impact	Principles Strategies Assessment

More detail on these frameworks can be found in the Appendices.



Engaging for Input, Feedback, or Buy-In

Many programs use this level of engagement to assure they are providing what their families or consumers want and need. This can help you know the services will be utilized by the population they are intended for. Additionally, this can provide ideas for improvement and develop better marketing strategies.

Seeking input or feedback is the most common, and often easiest, way to engage families. In practice, this often looks like a survey, either to identify needs or satisfaction for services received. This can also include community meetings, focus groups, or interviews of a select population among those served, and often does not require a lot of preparation or follow-up on the part of the family/consumer. Engaging in this way is important to show you care and are willing to listen to those you serve.

This type of engagement is the foundation for partnership; each subsequent “level” of engagement builds upon this foundation, supporting purposeful, meaningful, and mutually beneficial partnerships with those served.

The Benefits to Asking for Input

Asking for input provides an opportunity for you to build trust with and loyalty among those you serve. The benefits are widespread and impact everyone.

Agency/Program

- Increases agency’s effectiveness and rapport with consumers
- Increases staff satisfaction to know they are meeting the needs of consumers
- Helps determine training needs/supports

Families/Consumers

- Assured their voice matters and feel heard by seeing input turned to action
- Provides opportunities for them to have an active role in programs they value
- Positive influence/impact in their community

Strategies for Obtaining Input

There are various strategies that fall into this level of engagement. While there are differences, they do all have some simplicity to them and all focus on asking questions to gain a better understanding or clarity around something. Would this be helpful to you? What can we do to be helpful to you? Is there a better way to reach more individuals in the community?

- **Survey:** A set of questions designed to gather information about what most people do or think about something (often paper, phone, electronic)
 - **TIP:** Have surveys available in various formats and utilize QR codes on printed and electronic communication for easy access.
 - **TIP:** To increase return rates, provide the survey at the time of the service or during the visit, give time for them to complete it onsite and place in a secure location before they leave.
- **Focus Groups:** A small group of people whose response to something is studied to determine the response that can be expected from a larger population (often in person or virtual groups, sometimes referred to as “Coffee Chats” or “Parent Cafes”)
- **Interviews:** Discussions with one person at a time to get information (often by phone or virtual meeting)

With any of these strategies, this can be as simple or as complex as needed, which is typically based on the desired goals, outcomes, or output of the activity. Either way, it is about giving opportunity for families/consumers to share experiences or ideas. Having families/consumers involved in the creating the questions and helping to disseminate surveys begins the shift from engaging for input, to engaging in advisory or leadership roles.

It's also important to avoid “tokenism,” such as inviting families or consumers to prevent criticism, at the end of the process, or for optics or appearances. Not engaging at the beginning or throughout the process can send the message that engaging those with lived experiences was an afterthought, or can be perceived that their perspective or experiences do not matter. Families shared this is often how they feel when engaged simply to meet a grant requirement and that it feels as though they are only there to “check a box” and not really as a partner.

Check out the Appendices for resources and examples for each strategy.

Tips for Meaningful Engagement

The following can help families and consumers feel heard, seen, and valued. This creates a meaningful engagement experience and increases the likelihood for future partnership.

Show you value their time.

- Let them know, from the beginning, what to expect (e.g., time commitment, length of survey, scheduled time for activity)
- Offer times that are convenient for them, even if it is not ideal for you (e.g., offer flexible times, multiple opportunities)
- Compensate for their time (e.g., gift cards, survey completion incentives, stipends, travel reimbursement, child care, food)
- Take time to prepare or support their engagement (e.g., explain the process, define or describe acronyms used, offer contact information for more questions)

Be authentic and open to a wide variety of experiences.

- Be open and welcoming to help them feel comfortable
- Avoid always asking the same people for input (e.g., only advisory boards/council members, families who also serve as a professional in the field)
- Assure families or consumers do the majority of the talking
- Identify and seek out voices that are underrepresented

Be transparent throughout the process and close the loop after the input is received.

- Tell them why you are asking for input (e.g., identify gaps, determine service effectiveness, prepare for changes)
- Describe what kind of buy-in you are seeking (e.g., information only, ongoing discussion, advocacy support)
- Share what you plan to do with the information you collect (e.g., project timelines, how they will know the outcome, communication plans)
- Follow-up to share the outcomes of their input (e.g., public comment/review periods, follow-up meetings)
- Share the results of what you received (e.g., email blasts, newsletter, letter to clients, public notices)



Summary

Being intentional in your engagement efforts, taking the time to plan out what you want to do, engaging families and consumers early on, and being communicative throughout the process are important for meaningful and authentic family and consumer engagement and helps families know their time and efforts are valued and not a waste of their time.



Engaging in Advisory Roles

Engaging families and consumers in advisory roles or capacities is a worthwhile investment for programs. Working with families and consumers at this level solidifies one’s commitment and begins to shift from ‘engagement’ to ‘partnership.’ When programs prioritize the experiences of those they serve, take their input under advisement, and make programmatic decisions based on that with that input, this demonstrates that a program is committed to providing person- or family-centered services.

Just as the previous section described, this can help you know the services will be utilized by the population they are intended for, but in a more robust way. This is certainly not as common as engaging for input, but it is not uncommon to engage those with lived experiences in groups referred to as committees, councils, boards, etc. Engaging in this way does require more preparation and commitment on behalf of the agency/organization, and more follow-up on the part of the family/consumer.

The Benefits of Advisory Opportunities

Providing either ongoing engagement opportunities, or one-time events, help families and consumers feel heard and listened to. Providing space for feedback and ideas builds trust and partnership within the communities you serve. In general, we’ve heard from families they love to give feedback on their experiences – both good and bad. However, often they only reach out to share when things did not work out so well – but many have expressed a desire (and joy) in also sharing the difference the services they received made in their lives. Creating advisory opportunities within your agency provides the space for that to happen.

Engaging in advisory roles also creates space to establish organizational champions in the community. If you take family and consumer feedback with an open and honest mindset – your program will be able to build and sustain in ways that profoundly impact those who use it. This can also bring empower families and consumers while strengthening your program or agency.

Types of Advisory Roles

In general, there are two types of advisory roles: self and system. The distinction is slight, but ultimately with regard to the initiative, it comes down to focus. The difference is if the focus of the group is specific to an issue, condition, or population (self) or broad and includes many issues, conditions, or populations (system).

Advisory – Self: Serve on advisory committees and/or task forces typically focused on specific issues, conditions, or populations. Input is provided based upon their own personal lived experiences only.

Advisory – System: Serve on advisory committees and/or task forces that are more general to a system that represents many issues, conditions, or populations. Input is provided based on both their own personal lived experiences and those of others in their communities.

A few examples are outlined in the table below to help show the distinction.

Example	Advisory – Self	Advisory – System
Bureau of Family Health Family Advisory Council	Members represent their own experiences within population-specific work groups to drive change related to a particular population (e.g., children with special health care needs) or objective (e.g., well-woman preventive medical visits)	Work Group Members make up a larger group of families who will collectively discuss and advance broader systems-related issues (e.g., social determinants of health, workforce development, system policies)
Medicaid System	Home and Community Based Service (HCBS) Member Work Groups: Members represent their families' experience regarding the services provided to inform and improve services within a specific waiver program. (specific population)	Managed Care Organizations (MCO) Member Advisory Groups: Members represent their families' experience to with that specific MCO to improve services provided through that MCO. (general population)
Head Start	Local Head Start Policy Councils: parents have a voice in making program budget decisions, classroom activities, and community partnerships (local community)	Head Start Association Board of Directors: Parents serve alongside professionals in a governance role for the KS Head Start Association (broad state programming)

In addition, the group or program may have determined the focus to be at the “system” level, however the family or consumer may still be at the “self” level. This ultimately comes down to the intent of the family or consumer in engaging, or their own goals. Are they hoping to change something with their own family’s impact in mind (self)? Or are they engaging with the goal of changing things for everyone that comes into the system behind them (system)?

Strategies to Create Advisory Opportunities

Engaging in an advisory capacity can look differently based upon your goals, organizational structure, capacity, and community. Some examples include:

- **Strategic Planning Community Events:** Limited number of meetings; beyond collecting input, rather focused on setting goals and priorities; can be specific or broad
- **Committees or Work Groups:** Groups established with specific outcomes; generally shorter in duration; specific to a program, topic, or activity
- **Councils or Boards:** Groups established with goals of oversight and monitoring; generally long-standing; focus is often on effectiveness, efficiency, and accountability

The duration, goals, and objectives will vary based upon your organization’s needs and desired outcome. For example, you may establish a Council or Board with committees built in, where external community members can be brought in for specific needs. Alternatively, you may begin with community strategic planning and based on those outcomes, establish working groups to assist with setting priorities or strategies. This can lead to the establishment of a broader oversight group, like a Board or Council. Do what is best for your organization and community. This is not a one-size-fits-all engagement strategy. Regardless of the structure, organization, or type of group, here are some crucial tips:

TIP: Establish protocols and policies related to logistics, facilitation, organization goals/needs, and scope of work within the group BEFORE the group convenes.

TIP: Be adaptable based on input received and willing to shift or adjust when possible

TIP: Be open and transparent about goals and objectives. This includes letting families know about boundaries you have (e.g., what you can/cannot change, what constraints, must follow a certain plan or guidelines, barriers you are not willing to push).

TIP: Providing a list of commonly used terms and acronyms can help families feel equipped to engage in discussions.

TIP: Assure you have the capacity to provide support to prepare families and consumers for these efforts and can respond or follow-up based on outcomes of the meetings.

Check out the Appendices for resources and examples for each strategy.

Tips for Meaningful Engagement

All experiences, both personal and professional, add value to an organization. Establishing and building rapport is essential to make lasting change. Building rapport includes viewing families and consumers as equals among staff and professionals and recognizing their preferences. For example, families have expressed feeling “less than” their professional peers in interdisciplinary advisory situations. One way to address this is to refer to them as a “Member” as a standard of practice, at least until you confirm their preference. These things, and the following tips, will help assure families feel their engagement is authentic and genuine – not simply to “check a box” for a grant requirement or “lip service” for community perception.

Strive to build knowledge, increase skill, and assure comfort.

- Establish a point of contact, or liaison, to assure families and consumers know they are an important part of the group. This includes connecting before and after meetings to support participation.
- Create a judgement-free space so people feel comfortable engaging and opening up. This can include establishing ground rules for the groups (e.g., no finger-pointing, avoid politics, use strengths-based language, focus on inclusion).
- Recognize the importance of race, ethnicity, and culture among members and that one’s experiences and culture shape their views and beliefs.
- Expect respect and openness among members of the group, acknowledging that all cultural views bring equal value. Accept and appreciate that practices, perceptions, interpretations, and experiences differ for each member.
- Provide time and guidance associated with meeting preparations (e.g., let them know what to expect, discuss meeting objectives, go over materials or discussion questions to assure understanding).

Engage early. Engage often.

- While it’s never too late to make changes, it’s certainly harder later in the process. Bring in families and consumers early in the process of designing, evaluating, or making changes to your program.
- Allow space for families and consumers to engage at every step (design, implementation, evaluation) and assure they are involved in the whole process.
- Set clear expectations on what you are wanting and what is expected, however do allow for family or consumer brainstorming sessions to finalize plans or set priorities.



Listen with intent and encourage open discussion.

- In all encounters, be sure to allow enough time for open discussion. Ask open ended question and non-committal responses to keep the discussion going.
- Strive for a balanced discussion, assuring all members are sharing ideas and feedback and minimizing time spent hearing from the agency.
- Engage active listening skills and be careful to not “talk at” the families or consumers.
- Be open to what you hear, even if it is not what you think they should think or do. Give space for their perspectives and provide facts as needed to assure understanding.

Actions speak louder than words – make the family/consumer experience special.

- Consider the “little things” that you can do to make families feel welcomed, supported, and appreciated.
- Provide reimbursement for out of pocket costs (e.g., child care, travel) and compensation for participation (e.g., stipends). If the professionals are being paid to be there, they should be too.
- Meet families and consumers where they are. Consider their schedules and needs when scheduling (e.g., non-traditional business hours, meetings on weekends).
- Consider making it a point to give family and consumers the first and last opportunity to speak during interdisciplinary groups, this shows their voices are heard, respected and recognized by all members!!

Summary

Ultimately, there is not a “one size fits all” approach when it comes to engaging in an advisory role. Maintaining a focus on strengths and skills provides space to celebrate the families and consumers and show how their engagement and involvement is making a difference for the organization and those you serve. The mantra of “Do for. Do with. Cheer On.” describe the overarching goals in including family and consumers in advisory roles, however in the reverse order. Through cheering on, supporting, and encouraging families and consumers to engage in your organization, you will build partnerships to work together, collaborate to establish and enhance programs to provide services most necessary and valuable to your target population.



Engaging in Leadership Roles

“Leadership is an action, not a position.” This quote from Donald McGannon is the perfect representation of family leadership. Leadership can come from many places and take many forms. Families and consumers can serve in leadership roles or capacities in a variety of ways. Engaging families and consumers as leaders is the ultimate form of engagement. At this level of engagement, the shift from ‘engagement’ to ‘partnership’ has been fully realized and the commitment to family-centered care and services has officially been institutionalized.

Just like the other levels of engagement, engaging families and consumers as leaders can be powerful – shaping programs and bringing betterment to their communities. Engaging families as leaders is not necessarily challenging, difficult, or any more time consuming than the other levels of engagement. It simply requires focus, intent, and commitment.

What Is Leadership?

As stated before, leadership is an action. Leadership is less about what (or who) you know and more about what you do and who you are. Leaders set an example for others. In context of leadership among families and consumer engagement frameworks, this is more about the qualities one might possess, such as effective communication, courage, or selflessness. Families shared with us what they believe it means to be a good leader:

- **Encouraging:** Brings people together and strives to bring out the best in others.
- **Courageous:** Takes informed risks. Isn't afraid to fail and try again. Is willing to be vulnerable.
- **Collaborative:** Gets involved and focuses on building partnerships among all for shared decision-making.
- **Visionary:** Looks broadly at the need and sets clear goals, expectations, and objectives.
- **Honesty:** Shows integrity and accountability in what they do. Trustworthy.
- **Team-Focused:** Focuses on the shared agenda. Looks at things from different perspectives. Strives to hear from all. Shares information, resources, and tools to help others be successful.

The terms “leader” and “leadership” can be intimidating to those who may equate this to access, education, paid or elected positions, or other types of status. When engaging with families as leaders, be clear about what this means to your organization. Use terminology that resonates with those you are serving. If, even after you describe leadership as an action, not a position, the families and consumers are still hesitant or not comfortable with that terminology, use something different. Again, it’s not about a position or a title, it’s about actions.

Families have expressed feelings of overwhelm (“*This feels like too much for me.*”) or inadequacy (“*I don’t have the right credentials, education, or experiences.*”), or lacking the confidence (“*I’m not sure I have what it takes.*”) when they were asked if they wanted to serve as a “Family Leader.” Building rapport can help families overcome these feelings. Organizational messaging around family engagement – that it is expected and part of the organizational culture – can go a long way to helping families and consumers recognize their value and the strengths they bring to the work.



The Benefits of Engaging in Leadership Roles

A key benefit to engaging families and consumers in leadership roles within your organization is that it can provide capacity and support to your organizations’ efforts and services. Family and consumer leaders work along-side staff, community partners, and others towards a collective achievement, as a core part of the team. They can assist with community awareness efforts, represent the organization when staff are unavailable, provide education and advocacy efforts to elected officials or policy-makers, expand your reach and increase numbers served, and lead family and consumer engagement efforts.

Family and consumer leaders provide insight into the services and supports you offer, as their lived experiences provides them the ability to share what staff and professionals simply can’t understand, as they have not “been there.” Certainly, some professionals have entered the workforce or began working in the field because of their own personal experiences, that’s very important. However, a benefit of a family leader, who is not paid staff, they can be completely

focused on the family/consumer perspective and not have to balance their personal experience with their professional role. Generally, family and consumer leaders:

- Bring a true understanding of the program or services provided.
- Can provide insight into the end-user experience to inform how programs and services are delivered.
- Enjoy being involved and feeling like a part of the decision-making process.
- Become more empowered when they feel heard and seen.
- Are willing to take action that professionals may not be able to, particularly in state-level work.
- Have a strong desire to help by sharing their wisdom and experiences with others.

Lastly, when others see the positive outcomes family and consumer engagement efforts bring to your work, more will want to take that opportunity to have their voice heard, invite others to join in, and have a stronger influence on programming.

Strategies to Create Leadership Opportunities

Leadership can come in many forms and an organization's perspective of leadership must be defined early when establishing leadership roles in which families and consumers will serve. Organizations who not only offer the opportunity for families and consumers to lead, but also to build their leadership skills (remember – it's about action, not position) are generally the most successful. In addition to the strategies listed below, it can be very helpful to provide families opportunities to engage in formal leadership programming (such as the Kansas Leadership Center) or informal trainings (such as organizational or programmatic trainings for staff) to help them build their skills, confidence, and knowledge about the organization, services provided, and population served.

- **Assist with Community Presentations:** Have families who have engaged in advisory roles join in developing and delivering community presentations about your organization.
- **Facilitate Family/Consumer Engagement Activities:** Invite families who have an interest in stepping into facilitation roles when hosting community engagement activities or leading peer support groups. Families and consumers are often most comfortable sharing with those they know understand them the best, such as a peer.
- **Advisory Governance/Leadership:** Invite families to lead a committee, work group, or serve as a chairperson of advisory councils or boards.
- **Paid Consultant/Contractor:** Establish a consultant agreement to assure the family voice is represented in various capacities. Develop contractual relationships with those that you'd like to have represent the organization formally or to provide services.

When establishing your strategies for families and consumers to show leadership in your organization, set clear expectations and boundaries. While it's critical they can share their experiences, serving in a leadership role does come with certain expectations, such as accountability, professionalism, mentorship and communication. Be sure your expectations in these areas are clearly defined, regardless of how formal the leadership role is (e.g., volunteer, peer nominated, contract).

Check out the Appendices for resources and examples for each strategy.

Tips for Meaningful Engagement

When it comes to engaging families and consumers in leadership roles it is critical to establish a point of contact, or liaison, to assure ongoing coordination and communication is established. The following strategies can assure success in how you engage leaders in your organization.

Set clear expectations and boundaries.

- Focus on action and assure family leaders are focused on what needs to happen and outcomes they desire to see.
- Partner with families to share short- and long-term outcomes of the shared work (e.g., what has been accomplished, how has it made an impact).
- Encourage families to get involved, learn, and educate themselves. Strive to inspire them to find their deepest passions and identify personal (or professional) goals and help them reach them.
- Ask families to help establish relationships and help make connections with those in their community and your organization.
- Identify your organization's outreach needs and ask families for their help. Provide materials for them to hand out in the community. Share data, resources, and information that can help them identify where their outreach can be most helpful.

Establish clear lines of communication.

- Establish regular connection points to assure your organization and the family/consumer leader are on track and complimenting each other's work.
- Active listening is not one sided and must be mutually beneficial. Assure your organization listens to what the family/consumer leader are saying and the community's needs and concerns.
- Establish trust, rapport, and opportunity to so the family leader is open to hearing input and feedback from the organization on their needs. Together, the organization and families can create a shared plan and articulate that appropriately to programs.
- Follow-through and share back with your families/consumers what has been done from their feedback.

Provide opportunity for personal leadership growth.

- Be sure to provide space and encourage family leaders to ask the hard questions.

- Encourage engagement and involvement at community, regional, and state levels.
- Support family leaders to learn more and grow in their journey by providing opportunities for them to engage in conferences or special trainings.
- Establish opportunities for families to advocate for the issues that are most important to them and their community

Summary

Engaging families in leadership roles is just like any of the other types of engagement. It's not an exact science and it must be

individualized for the organization or community culture. There is no magic curriculum to helping build family leaders, which makes perfect sense – since it is not about education, training, titles, positions, or professional backgrounds. It is about identifying interested families and consumers who strive to make a difference in their community and building relationships through asking for input or feedback and asking for support through advisory roles. It's inviting them in at every stage of a program - planning, implementation, and evaluation.

