

CCBHC

Toolkit for Meaningful Representation of Lived and Living Experience in Governance

NATIONAL
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Background and Overview

Certified Community Behavioral Health Clinics (CCBHCs) are a promising, effective model to provide access to coordinated, comprehensive behavioral health care, regardless of an individual's ability to pay, residence or age. To reach these goals and establish uniform standards across the country, CCBHCs are required to meet a set of six program requirements with specific criteria developed by the Substance Abuse and Mental Health Services Administration (SAMHSA).¹ This toolkit focuses on the CCBHC Certification Criteria 6.B: Governance, which mandates that a CCBHC's governance includes significant representation of people being served and/or with lived or living experience of mental health and/or substance use challenges and their family members.

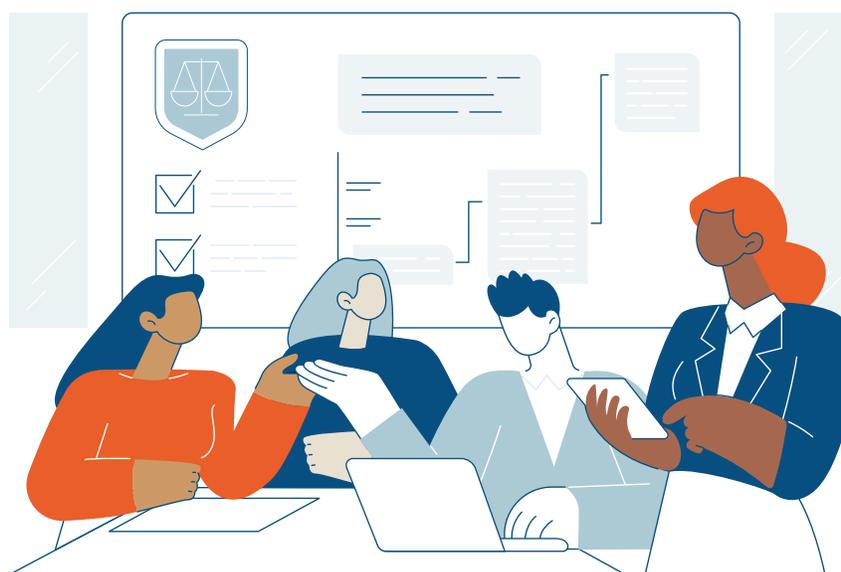
Achieving meaningful recipient and peer representation is not a box to be checked; it is essential to ensuring that CCBHCs work for the people they serve, providing them with safe environments and appropriate services. Yet it can also be challenging for clinics to fulfill this governance criterion, for a variety of reasons.

Toolkit Purpose

This toolkit helps CCBHCs understand the purpose and requirements of Criteria 6.B: Governance and provides guidelines and recommendations to meaningfully incorporate voices of lived and living experience in governing and advisory bodies.

Establishing Shared Language

There is variation across the field in language and terminology used when referring to people who receive and/or provide mental health services and supports. For the purposes of this toolkit, a person with “lived and living experience” is someone who is currently living with or has experienced mental health and/or substance use challenges, and a “peer supporter” is a person who has been successful in the recovery process and provides support to people with lived and living experience and their family members at a CCBHC. A “recipient” is a person who receives mental health, substance use and/or trauma-related services.



¹ SAMHSA. (2023, March) Certified Community Behavioral Health Clinic (CCBHC) Certification Criteria (updated March 2023). <https://www.samhsa.gov/sites/default/files/ccbhc-criteria-2023.pdf>



Acknowledgements

Interviewees

We would like to acknowledge and thank the stakeholders who participated in informational interviews to provide their experiences, feedback and expertise that helped inform this toolkit. Quotes from these interviews are used throughout this document.

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- ❏ **Mary Blake**, SAMHSA Center for Mental Health Services
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Overview of CCBHC Requirements for Meaningful Representation of People with Lived/Living Experience (Criteria 6.B)

CCBHC Criteria 6.B explicitly states the requirement of CCBHCs to incorporate meaningful representation of individuals served and with lived and living experience within governance structures:

“CCBHC governance must be informed by representatives of the individuals being served by the CCBHC in terms of demographic factors such as geographic area, race, ethnicity, sex, gender identity, disability, age, sexual orientation and in terms of health and behavioral health needs. The CCBHC will incorporate meaningful participation from individuals with lived experience of mental and/or substance use disorders and their families, including youth. This participation is designed to assure that the perspectives of people receiving services, families and people with lived experience of mental health and substance use conditions are integrated in leadership and decision-making. Meaningful participation means involving a substantial number of people with lived experience and family members of people receiving services or individuals with lived experience in developing initiatives; identifying community needs, goals and objectives; providing input on service development and CQI processes; and budget development and fiscal decision making.”²

The CCBHC Certification Criteria outlines two options for CCBHCs to meet the requirement. Option 2 of the criteria exists because not all CCBHCs have the latitude to choose their own board members.

- ❏ **Option 1:** At least 51% of the CCBHC governing board comprises individuals with lived experience of mental and/or substance use disorders and families.
- ❏ **Option 2:** Other means are established to demonstrate meaningful participation in board governance involving people with lived experience, such as creating an advisory committee that reports to the board. The CCBHC provides staff support to the individuals involved in any alternate approach that is equivalent to the support given to the governing board.
 - Under option 2, individuals with lived experience of mental and/or substance use disorders and family members of people receiving services must have representation in governance that assures input into: 1) identifying community needs and goals and objectives of the CCBHC; 2) service development, quality improvement and the activities of the CCBHC; 3) fiscal and budgetary decisions; and 4) governance (human resource planning, leadership recruitment and selection).



“SAMHSA’s expectation is that CCBHCs will value that the lived and living experience perspective is a critical perspective, and they will take the steps they need to gain value from that perspective, as they would with any other board member.”

- Mary Blake, SAMHSA

² “Certified Community Behavioral Health Clinic (CCBHC) Certification Criteria (updated March 2023)”, SAMHSA, <https://www.samhsa.gov/sites/default/files/ccbhc-criteria-2023.pdf>



“Clinics need to realize what people have gone through and what it took to get there.”

- Sue Abderholden, NAMI Minnesota

Mental health and substance use disorders are uniquely personal experiences for individuals and family members, and often the people who best understand are individuals who have their own stories. Even CCBHC staff and clinicians may not fully understand the experiences of and stigma or discrimination against those with mental or substance use disorders – which can come from behavioral health professionals themselves – or the difficulties of accessing appropriate, comprehensive services. To create a facility that meets people’s needs and promotes a person- and family-driven system, it is imperative that CCBHCs elevate the voices of individuals with lived and living experience and families in their governance.

The purpose of the CCBHC governance criteria is not to check a box; it is to ensure that CCBHCs are truly representative of the communities they serve and to elevate the roles of peers and families at the top of the system design down to the service delivery. The experiences of individuals with lived and living experience and families are not universal; they can vary widely based on race, ethnicity, socioeconomic status, gender identity, sexual orientation, age, disability, co-occurring health concerns and more. As such, SAMHSA requires that “CCBHC governance must be informed by representatives of the individuals being served by the CCBHC in terms of demographic factors.”³



“When we talk about involvement in governance, it’s equally important to speak to all the other ways that the certification criteria require lived experience. When it comes to the community needs assessment criteria, your board is your champion. Members know who to reach out to and how to present your CCBHC to their communities.”

- Mary Blake, SAMHSA

CCBHCs should leverage data and information from their organizational records, community needs assessments and other community demographic factors to assess and inform what representative composition of their board looks like. For example, if the CCBHC serves a predominantly Black or indigenous community, board or committee participation should have similar representation. Similarly, if the CCBHC’s population served is 30% adolescent or 30% older adult, representatives with lived experience should match these age populations. In addition, individuals and family members should not be tokenized. Representation, including that of peers and family members, should not be limited to one individual.

The CCBHC criteria require “meaningful participation” from individuals with lived and living experience and families. Whether a CCBHC achieves compliance through board membership or an advisory committee, members should be fully involved and active in all aspects of the CCBHC’s governance and functions. There should also be processes in place to ensure that recommendations are addressed (see the special considerations for advisory boards section for additional requirements related to this). The strategies and tactics outlined in this document are intended to support those efforts.

Note: CCBHC Criteria 6.B specifically mentions the inclusion of youth in this meaningful engagement by individuals with lived and living experience. Youth engagement is a critical aspect of the criteria, yet serving and engaging youth often require special considerations. Additional resources on youth engagement can be found at the end of this document.

³ “Certified Community Behavioral Health Clinic (CCBHC) Certification Criteria (updated March 2023)”, SAMHSA, <https://www.samhsa.gov/sites/default/files/ccbhc-criteria-2023.pdf>



Considerations and Best Practices for Meaningful Participation of Lived/Living Experience in CCBHC Governance

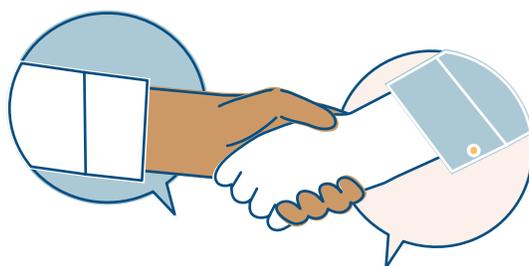
When it comes to board membership and activities, CCBHCs should leverage best practices in nonprofit governance.⁴ The structure of the board, as well as the roles and responsibilities of its members, can largely follow established norms and standards implemented by effective nonprofits. While the following section describes some of these best practices as they relate to CCBHCs and meaningful participation by peers and families, there are additional resources provided at the end of this document.

Membership and Recruitment

The previous section of this toolkit describes the importance of lived and living experience and representation in governance, but not every peer, recipient or family member is the right fit for a board or advisory committee. It is the board or committee members' role and responsibility to represent their communities and ensure that the CCBHC is providing comprehensive and appropriate services to its recipients; therefore, members must be invested in the overall system of care.

To that end, it is important for CCBHCs to consider inclusion beyond just their clientele for board or advisory committee membership. A current recipient may (rightfully) be focused on their own care and services received; governance members should prioritize the experiences of all the CCBHC's recipients. Recent alumni of services may be ideal candidates for board membership recruitment. For current recipients or family members who serve on governing bodies, there should be protocol directing them to recuse themselves should a conflict of interest arise.

While this toolkit is focused on meaningful participation by individuals with lived and living experience and family members, it is important to note that all membership roles, responsibilities and requirements should apply to all members, including those without lived experience. Members with lived and living experience should not be treated differently or held to a different set of expectations. Any needed accommodations should be offered equitably to all members, as touched upon in the engagement section of this toolkit.



“Members should have a real investment in systems change.”

- Mary Blake, SAMHSA

⁴ National Council of Nonprofits. Good governance policies for nonprofits. <https://www.councilofnonprofits.org/running-nonprofit/governance-leadership/good-governance-policies-nonprofits>



Best Practices in Membership and Recruitment:

- ❏ **Have a clear purpose statement and grounding bylaws.** Each CCBHC board or advisory committee should have clearly defined expectations and responsibilities that apply to every member – regardless of whether they have lived experience. The board or committee should also have operating documents and bylaws that are adhered to, which will provide structure and continuity. These documents should be informed and agreed upon by the body’s participants or founding members, including those with lived or living experience or family members, and all participants should be educated and oriented to them.
- ❏ **Have a clear recruitment pitch.** When an individual at a CCBHC approaches a potential board member, they should clearly state the purpose, why it wants that person and what it believes that individual would contribute. People need to know why they are being asked to serve and how their participation will be meaningful. This can include reflecting leadership qualities that are seen by others but may not be recognized by the person.
- ❏ **Ensure members are committed to the mission.** Members must have a stake in behavioral health systems change and be truly committed to providing the best possible services to the CCBHC’s recipients. Members must recognize that they are there to serve the recipients, families and community.
- ❏ **Be creative in outreach.** Think outside of the CCBHC’s current clientele. Conduct an environmental scan of the community, post opportunities in public spaces and leverage consumer surveys. Look to the following to find potential members with lived and living experience:
 - Individuals who have completed treatment at the CCBHC.
 - Peer-run organizations, including Statewide Consumer or Family Networks, 12-step programs or other youth and family organizations.
 - Community-based organizations.
 - Local mental health and substance use organizations, including chapters/affiliates of the National Alliance on Mental Illness (NAMI), Mental Health America (MHA), American Foundation for Suicide Prevention (AFSP), Faces and Voices of Recovery (FAVOR) and Youth Move National.
 - Other peer stakeholders or community partners.
- ❏ **Have alternates.** Maintain board or committee alternates in case a member must step down due to extenuating circumstances. Alternates will ensure the board or committee continues full operations and that the CCBHC does not fall short of the governance criterion in that situation.



“The missing link is that most people don’t see the power peers hold/peers don’t see their own power. Helping people understand what they bring to the table, helping them see their natural ability and untapped potential can bring people to the table.”

- Peer supporter



Engagement

Ensuring meaningful participation by board members can be a challenge for all nonprofits, but there are additional considerations for CCBHC board members with lived and living experience. This could be their first board membership experience, or even their first opportunity to share aspects of their own stories in a more public setting, and it is important that they feel prepared and supported. It is important to note that some strategies outlined in this section are relevant and applicable to engaging any member of a board or governance structure.



“We say ‘Nothing about us without us,’ but I don’t want to be a token – if I get on a board, I want to have a voice. If it feels like a waste of time, I might leave.”

- Howard Trachtman, NAMI Peer Leadership Council

Best Practices in Engagement:

Provide orientation and training. All members, whether they have lived and living experience, should receive an initial orientation or training when joining the board or advisory committee. The orientation should include an explanation of board responsibilities, the bylaws, conflict of interest disclosures meeting standards and norms and inclusionary practices, such as use of pronouns. It is important to set members up for success at the outset. Additionally, all board members should receive education and training that support their understanding of stigma, implicit bias and internalized beliefs that traditionally exclude those with lived or living experience, and expectations of diversity, equity and inclusion and belonging within governance.

Recommended strategies and tactics:



- Host live orientation sessions for new board members.
- Create and distribute a governance handbook for all members that compiles reference materials on all key information and expectations.
- Hold training or education sessions on considerations for diversity, equity and inclusion and belonging in governance. Topics could include the value of lived and living experience, fostering inclusive environments, understanding stigma and implicit bias, managing conflict and understanding the role and value of peers.
- Provide strategic sharing training to board members to explore and plan for effective use of lived experience stories in a board role.



“Everyone wants a seat at the table, but no one wants to be the only one there.”

- Sue Abderholden, NAMI Minnesota



Establish mentorship or buddy programs. Mentorships can be a highly effective way to orient all new board members. Pairing a new board or committee member with an experienced member, particularly one with similar personal experiences, allows them to establish a meaningful relationship from the beginning and provides them with a trusted resource to ask questions.

Recommended strategies and tactics:



- Assign new members with a mentor or buddy when they start to help them become comfortable in their role.
- Provide guidance and parameters around the relationship, leaving space for the pairing to also incorporate their own preferences. An example could be sharing general goals, the purpose of the relationship and minimum expectations of meeting/connecting, while allowing them to establish their own norms on frequency and communication channels.
- Encourage mentors and mentees to establish debriefing and follow-up connection points following board meetings.

Establish clear structures and processes. Governing business (whether through boards or committees) is generally conducted through meetings that should be organized and well-facilitated to keep participants focused and engaged. Define your processes for setting agendas, soliciting input and conducting follow-up and ensure all participants are knowledgeable on those processes. The roles of those participating and managing activities should be clearly defined.

Recommended strategies and tactics:



- Designate a person responsible for managing governance activities and participants, even if tasks are delegated to others.
- Establish the purpose, priorities and desired outcomes of each meeting and create and distribute an agenda well in advance of the meeting. Build opportunities to acknowledge wins and successes into the culture of board operation.
- Assign someone to record minutes or take notes on key discussion points/action items of each meeting. If operating an advisory committee, establish a process and who is responsible for sharing the minutes with the governing board and how action will be taken and communicated.
- Build a practice of reporting progress and updates on prior board action. Board membership can feel intangible if members are sharing emotionally personal lived experience to promote change, and then nothing seems to happen. Even updates that no progress has occurred on a project can support board members' understanding that the change hasn't been forgotten.
- Assign a clear chain of communication between a board chair and/or CCBHC staff person for questions from board members. This would essentially be an individual who is available for questions between meetings, meeting prep and debrief.
- Keep all members informed, even if they must miss a meeting, by making minutes available.
- Establish an agreed-upon approach for voting or decision-making among all members.



Include and elevate all voices. Ensuring that every member has an active voice can be a challenge but is absolutely necessary. When only select members feel comfortable speaking up or making suggestions, it can isolate other members, resulting in losing critical input. For many people, the experience of living with mental health and substance use challenges results in discrimination and exclusion. In addition, the highly structured culture of a traditional boardroom may be unfamiliar or intimidating. This experience can make participation in boards challenging. Flexibility may be required to accommodate differing styles of expression and decision-making to establish an environment in which each member feels comfortable expressing themselves. Making accommodations for all needs is critical, including for those whose past experiences may impact their engagement.

Recommended strategies and tactics:



- ❏ Lead with establishing trust and respect among group members; conduct relationship-building exercises; co-create norms for interaction with one another, conflict management methods, etc.
- ❏ Connect with all members individually to understand their potential barriers and accommodations for inclusive engagement.
- ❏ Ensure skilled facilitation; whoever is presiding over activities should be experienced in creating an inclusive environment and moderating to ensure all members have space to contribute.
- ❏ Establish procedures that allow for various methods of input and feedback (written, verbal, time after meetings for those who need longer to process their thoughts, etc.).
- ❏ As a group, create language agreements. These could include avoiding use of jargon, avoiding or spelling out acronyms or establishing phrases to call each other in when the conversation becomes too technical and some are left behind without context.

Create a feedback loop. Consider engaging with all board members through brief check-ins or surveys, particularly during transition periods, to gather information about whether they feel effectively included in board processes and decision-making.

Recommended strategies and tactics:



- ❏ Engage in a 360-degree reflection on board processes that considers whether all voices are being heard and identifies improvements for board facilitation and culture. This can be accomplished via group facilitation or a more formal data-collection tool with group reflection of the results.
- ❏ Explore and utilize existing tools that measure level of engagement in an initiative. Examples include Youth Voice at the Agency Level (Y-VAL) and the Family Voice on Council & Committees (FAM-VOC). (Contact FREDLA at info@fredla.org to access the full FAM-VOC tool.)



Accessibility

CCBHCs must address barriers and facilitators to making board or committee meetings accessible to both new and potential members. Members should recognize and accept meeting expectations when committing to the position, but there are common barriers to access that have traditionally excluded people with low and middle incomes from board membership. Addressing these barriers can help governing bodies recruit and engage diverse membership. Just as board or committee members should be invested in their work, CCBHCs must in turn invest in their governing members.



“Boards tend to be very white and middle class. They automatically rule out many people who need transportation, childcare or are caregivers.”

- Sue Abderholden, NAMI Minnesota

Best Practices in Accessibility:

- Consider timing and location.** Work with board members to establish meeting times and locations that work for everyone. Accommodate for work commitments, religious observances and caregiving responsibilities.
- Provide compensation.** Many peers are low income because their mental or substance use disorder has interfered with their employment, whether through discrimination or disability. Even modest stipends can be valuable, as well as compensation or reimbursement for travel to and from meetings. Another option to ease the burden of travel is organizing transportation among members.
- Provide childcare.** Consider providing on-site childcare or working with another community organization who may assist with childcare. Check in with members who are not parents but may have primary responsibilities for sibling or grandchild care as well.
- Provide food and drink.** It's important to feed your members, and time spent enjoying food and beverages before meetings can be a good opportunity for your members to get to know one another.

Special Considerations for Advisory Committees

It is a common misconception that an advisory committee or the alternative option to meeting the governance criterion is the “easier” route to achieving the CCBHC requirements. Neither option in the governance criterion is meant to be “easy” – incorporating meaningful participation by peers and family members should be a priority of each CCBHC. The inclusion of individuals with lived experience should be intentional and take effort. Option 2 of the criterion exists because not all CCBHCs have the latitude to choose their own board members. Every requirement and suggestion outlined in this toolkit applies to advisory committees as well as boards.



“Committees tend to treat peers with kid gloves and don't take them seriously.”

- David Larson, Kansas Statewide Consumer Network



A CCBHC advisory committee must be involved in decision-making and have a close working relationship with the board. Recommendations or feedback from the committee must be diligently deliberated by leadership, with a process for appeals. The CCBHC criteria 6.b specifically outlines that those who choose an alternative approach to meeting the governance requirements must:

- ❑ Establish protocols for incorporating input from individuals with lived experience and family members.
- ❑ Share board meeting summaries with those participating in the alternate arrangement and recommendations from the alternate arrangement shall be entered into the formal board record.
- ❑ A member or members of the arrangement established under option 2 must be invited to board meetings; and representatives of the alternate arrangement must have the opportunity to regularly address the board directly, share recommendations directly with the board, and have their comments and recommendations recorded in the board minutes.
- ❑ Provide staff support for posting an annual summary of the recommendations from the alternate arrangement under option 2 on the CCBHC website.⁵

Other recommended practices include:



Ensuring executive sponsorship. CCBHC executive leadership should participate in all advisory committee meetings, ideally as a lead facilitator, but at the very least as an active listener. The executive should be accountable for ensuring connection between the board and advisory committee and follow through. Advisory committee members should have a clear understanding of their access to decision-makers and/or how communication and decisions are shared with the board.



Establishing clear purpose and structure. As is the case with board meetings, each committee meeting should be meaningful and worthwhile for the CCBHC and the members. Someone should be assigned clear responsibility in managing the planning, facilitation and follow-up of each meeting; this could be a good opportunity for an interested peer staff to cofacilitate with an executive. Each meeting should have concrete tasks to accomplish, as well as at least one generative question requiring input from members that addresses a real issue the organization is grappling with.



Establishing a shared decision-making process for recommendation selection and implementation. Committee members should be able to see the results of their work and input in the CCBHC governance through a well-established feedback loop and follow-up process. As a group, agree upon how final decisions will be made even when there is not unanimous consent.



Ensuring clarity and transparency between governing board and advisory board. Advisory board members should have a clear understanding of when they are advising, making recommendations for or deciding on an issue, and there should be transparency in final decision-making. Communication loops between the advisory board and organizational board should be clear with decisions reported back and forth in a timely manner. The appeals process should be clear and understood by all advisory members.

⁵“Certified Community Behavioral Health Clinic (CCBHC) Certification Criteria (updated March 2023)”, SAMHSA, <https://www.samhsa.gov/sites/default/files/ccbhc-criteria-2023.pdf>



Conclusion

The requirement to elevate individuals with lived and living experience and family members in governance is a concentrated initiative to improve behavioral health services for those who need them most. Establishing effective CCBHC boards or advisory committees that meaningfully incorporate voices of lived and living experience can be arduous and challenging, yet highly valuable and rewarding when implemented well.



“Often, peer suggestions are ignored – not because they’re peers, but because the answer is too hard.”

– David Larson, Kansas Statewide Consumer Network

Additional Resources

- ❏ [SAMHSA Statewide Consumer Networks](#) – CCBHCs can engage their Statewide Consumer Networks for additional tactics, recommendations and recruitment.
- ❏ [SAMHSA Statewide Family Networks](#) – Statewide Family Networks are a great resource for engaging youth and families.
- ❏ [SAMHSA National Consumer and Consumer Supporter Technical Assistance Centers \(CONSTACs\)](#) – The CONSTACS are national peer-run centers that provide training and technical assistance to integrate peers and recovery in behavioral health services and promote evidence-based care for adults with serious mental illnesses.
- ❏ [SAMHSA Peer Recovery Center of Excellence](#) – The Peer Recovery Center of Excellence is a peer-led national center that provides training and technical assistance related to substance use disorder recovery, including the professionalization of peers in the workforce.
- ❏ [SAMHSA National Family Support Technical Assistance Center \(NFSTAC\)](#) – The NFSTAC provides resources, training and technical assistance to families/caregivers and the providers and organizations who serve them.
- ❏ [National Association of Community Health Centers \(NACHC\): Governance](#) – This NACHC resource contains many helpful documents for board recruitment and engagement, including orientation materials; diversity, equity and inclusion; and anti-racism resources.
- ❏ [National Health Care for the Homeless Council \(NHCHC\): Consumer Engagement in Governance](#) – NHCHC provides additional resources on consumer advisory councils.
- ❏ [Youth MOVE National: Youth in Governance](#) – Youth MOVE National outlines broad strategies to involve youth in decision-making.
- ❏ [Raise Center: The Foundation of Youth Engagement and Parent Centers](#) – Raise provides an in-depth look at how to engage youth in programming.