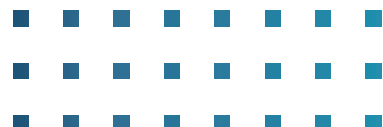


ENGAGING PARENTS AND YOUTHS WITH LIVED EXPERIENCE

Strengthening Collaborative Policy and Practice
Initiatives for Families with Mental Health and
Substance Use Disorders



National Center on
Substance Abuse
and Child Welfare



Building cross-system collaborative partnerships improves outcomes for children and families—especially when serving those affected by mental health and substance use disorders (SUDs) and child welfare involvement. People with lived experience add value to collaboratives by providing personal input on crucial issues and challenges. Integrating the voices of parents and youths helps agencies understand how their decisions affect those receiving services. Although both groups can play an extremely valuable role in terms of feedback and planning, collaboratives must take great care when asking people with lived experience to join.

Lived experience is “the experiences of people on whom a social issue or combination of issues has had a direct impact.” For the purpose of this document, lived experience is defined as an individual (parent or youth) who has firsthand experience with a substance use or mental health disorder and child welfare service involvement or youth affected by their parent’s substance use or mental disorder.¹

The National Center on Substance Abuse and Child Welfare (NCSACW) prepared this document to outline key strategies collaboratives should consider when recruiting and engaging adults and youths with lived experience who were involved with the child welfare system due to a substance use disorder or other mental health challenge. Also included are resources and links to ensure collaboratives have the necessary information to support meaningful partnerships.



INITIAL DECISIONS

RESOURCE HIGHLIGHT

The NCSACW’s *[Building Collaborative Capacity Series](#)* was developed to provide strategies to create cross-systems collaborative teams, communication protocols, and practice innovations.

Consider these questions before involving parents/youths:

1. What is the purpose?

Collaboratives must be able to clearly specify why they seek parent/youth input and how they plan to use their ideas. Otherwise, all involved may wind up frustrated.² Staff and partners should honestly assess their own willingness to accept feedback from those with lived experience, especially if it runs counter to ideas expressed by other members of the group (e.g., staff, leadership). Collaboratives need to be cognizant of power imbalances between staff, partners, and parents/youths with lived experience and work to establish an environment that fosters respect and equalizes power among collaborative members.

RESOURCE HIGHLIGHT

FRIENDS National Center for Community-Based Child Abuse Prevention created *[Meaningful Parent Leadership: Building Effective Parent/Practitioner Collaboration](#)* to enhance engagement of parents. A sample readiness assessment tool can be found on pages 37-40.

2. What level of engagement does the collaborative seek?

Soliciting input from those with lived experience can be viewed along a continuum—with deepening levels of involvement, independence, and effectiveness. Understanding the collaborative’s purpose for involving parents/youths will help identify an appropriate “level of engagement.” Sherry Arnstein’s seminal framework³ is useful to assess different levels of engagement. A version of this model commonly used by child welfare, family services, and mental health and SUD agencies features five distinct levels of engagement:

Level 1: Inform (provide knowledge): Staff inform parents/youths of decisions and plans without soliciting responses (*e.g., presentations, videos*).

Level 2: Consult (receive input): Staff seek parents'/youths' responses (*e.g., surveys, focus groups, interviews*) but may or may not act on them.

Level 3: Involve (shaping): Staff invite parents/youths to assist with some level of planning and decision-making (*e.g., participation in collaboratives and advisory committees, panels for special projects*).

Level 4: Collaborate (partnership): Staff act on parents'/youths' input and make improvements and decisions together (*e.g., participatory action research, board membership, leadership staff positions, collaboratives, and advisory committees*).

Level 5: Empower (ownership): Staff allow parents/youths to set agendas for change while also empowering them to lead programs and communities (*e.g., peer-run advocacy, youth-led development*). This level of engagement is seldom activated in practice.

*If the desired engagement level is to inform or consult (Level 1 or 2) collaboratives can work with local community agencies to connect directly with parents/youths.



MANAGING PARENT/YOUTH INVOLVEMENT

Staff must make additional decisions before bringing parents/youths into the collaborative once the purpose and level of engagement are determined.

Format for Involving Parents/Youths

For Levels 3 (Involve) and 4 (Collaborate) parent/youth engagement, collaboratives must first decide whether to hold a “mixed participant” meeting that brings together *both* staff and parent/youth representatives, or a separate “parent/youth-only” meeting that reports back to the full collaborative.

Some benefits of mixed participant meetings are the increased ability to promote teamwork and reduce stigma. At the same time, there are challenges, including scheduling, how to protect confidentiality, and avoiding “tokenism”^{4,5} since typically only one or two parents/youths are invited to join these meetings. Still, separate meetings can provide more safety and meetings are easier to schedule. For a separate meeting to be effective, a designated staff member should work specifically with the parents/youths, prepare for additional expenses since there are more parents/youths involved, and devote more care to ensuring feedback and decisions from each meeting are shared with the other. The chart below lists additional pros and cons.

A hybrid option is to nominate several representatives to attend both the “mixed participant” and the separate parent/youth meetings to ensure clear communication of each group’s ideas and decisions. Whether it be a mixed or separate group, collaboratives should create communities that foster an environment of supportive cultural diversity and inclusion that offers support and mutual respect for individuals with a diverse perspective of lived experiences.

	“Mixed participant” meetings of staff and parents/youths	Separate group for parents/youths only
Benefits	<ul style="list-style-type: none"> ▪ Promotes partnerships ▪ Reduces stigma towards parents ▪ Fewer meetings to schedule ▪ Information sharing is easier as everyone has the same access to information shared during meetings ▪ Involves fewer parents/youths, which means a lower cost 	<ul style="list-style-type: none"> ▪ Emotional safety for participants (less likely to feel judged or stigmatized) ▪ Easier to schedule outside of Monday-Friday, 9-5 ▪ Protecting confidentiality is easier ▪ More parents/youths can be involved
Challenges	<ul style="list-style-type: none"> ▪ Special steps may be necessary to protect confidentiality ▪ Concerns about tokenism ▪ Scheduling can be challenging ▪ Parents/youths may feel judged or overwhelmed and contribute less ▪ Requires advance training to ensure parents/youths have the information needed to contribute effectively 	<ul style="list-style-type: none"> ▪ More meeting time required ▪ Need for more attention to transparency and group communication ▪ May require special support from a designated staff contact person ▪ Parents/youths may feel marginalized in a stand-alone group ▪ More participants to recruit ▪ More expensive (reimbursement and compensation)

RESOURCE HIGHLIGHT

The Use of Peers and Recovery Specialists in Child Welfare Settings explores how child welfare agencies and family court programs have integrated peers and recovery specialists into their service delivery to support families affected by substance use disorders.

Liaison Organization

A “liaison organization” is not the same as the lead agency in a collaborative. It is an organization that takes primary responsibility for working with parents/youths. This organization should possess the following qualities:

- An ability to compensate parent/youth representatives in a timely way
- An ability to advance funds or pre-pay for any travel, including transportation, parking, and hotel if required
- Connections with direct service or advocacy organizations that can help recruit diverse participants or provide support to parents/youths if needed
- Strength-based, trauma-informed staff who serve as a designated contact person

Designated Staff Contact Person

A liaison organization typically identifies a staff member to serve as the designated contact person for parents/youths.⁶ Ideally, this person: 1) has a strong understanding of trauma; 2) uses a strength-based, recovery-oriented approach; 3) has the capacity to provide oversight; 4) embraces transparency; and 5) communicates easily with involved parents/youths (i.e., clearly explains official documents and other publications as needed).

The contact person's responsibilities include

- Recruiting diverse parent/youth representatives (with help from other collaborative members) using established protocols to determine eligibility
- Providing orientation for parents/youths new to the collaborative that includes training on equity and diversity
- Ensuring participants understand new plans, initiatives, programs, and policies, while relaying decisions and feedback to the broader collaborative
- Maintaining support for parent/youth representatives including meeting prep or follow-up when appropriate
- Securing accommodations for parents/youths such as translation services, accessible rooms, or alternate sites for virtual meeting participation that allow for privacy
- Creating a supportive and welcoming environment where people with lived experience can openly share their experiences and feel their input is valued
- Talking with an individual parent/youth if there are concerns about their ability to effectively participate in meetings; the contact person may also need to talk with other collaborative members including staff if parents/youths feel stigmatized, marginalized, or judged
- Providing operational support, including compensation, scheduling, and travel coordination



FINANCIAL CONSIDERATIONS

Budget

Collaboratives should determine in advance which organization will cover expenses. Costs for involving parents/youths may include

- Compensation for parent/youth attendance at meetings and training
- Reimbursement for childcare, transportation, technology, or other expenses
- Meeting supplies (e.g., food and IT support)
- Travel, lodging, and per diem expenses for in-person meetings
- Accommodations (e.g., interpretation services, such as ASL or other languages as needed)
- Costs associated with the time commitment of the designated contact person's salary

Parent/Youth Compensation

Compensation demonstrates that the collaborative values parents'/youths' lived experience. Payment is considered taxable income and is part of benefits eligibility calculations, a fact all parents/youths should understand before participating.⁷ Standard compensation ranges from \$20 to \$25 per hour, and may be dependent on locale (e.g., an urban core city versus a rural area) and includes time spent in meetings as well as trainings.

Because not all parents/youths have checking accounts, collaboratives should consider a variety of payment methods including cash, checks, debit cards, or gift cards.

Other Reimbursement

These payments are not considered income and are not taxable:⁸

- **Transportation:** If meetings involve travel, the collaborative should cover anticipated expenses (e.g., parking, hotel rooms, flights) in advance since parents/youths may lack available funds.
- **Childcare:** Some organizations reimburse childcare expenses only from licensed providers; others reimburse unlicensed providers, including family members. Another option is to pay a flat rate for childcare. If using a flat rate, some collaboratives add a supplemental “bump” for childcare if there are several children, younger children, or children with special needs, which may be more expensive.
- **Technology:** The pandemic has forced many collaboratives to meet virtually. Collaboratives may consider partial reimbursement for monthly phone charges, data plans, or other technology expenses.



IDENTIFYING PARENT/YOUTH REPRESENTATIVES

Number of Parents/Youths to Involve

The exact number of parents/youths to involve depends on whether the collaborative uses one “mixed participant” meeting or opts for a separate parent/youth-only group:

- **“Mixed participant” meetings:** Parents/youths have reported feeling uncomfortable when just one or two people with lived experience are expected to represent all people with similar life experiences. This is considered “tokenism” and should be avoided if possible. The best option is to include as many diverse parents/youths as possible without overwhelming the meeting.
- **Separate parent/youth-only meetings:** Many organizations report that a maximum of 12–15 diverse parents/youths are most effective.

Target Population

The collaborative’s goals, as well as any strategic local priorities, will help determine which parents/youths to involve. Some variables to consider include

- Age
- Race and ethnicity
- Gender
- Gender Identity
- Sexual Orientation
- Past experience in child welfare
- Past experience with SUDs
- Past experience with mental health systems
- Parenting experiences (e.g., birth, adoptive, foster, kinship caregivers)

Eligibility Criteria

Many collaboratives restrict participation to those whose experience in child welfare, SUD treatment, or family court is no longer current which also helps to ensure that parents/youths understand their participation is completely voluntary. For example:

- Substance use: Most collaboratives require parents to be in recovery—including abstinence from non-prescribed medications—for at least one year.
- Child welfare experience: Most collaboratives require that parents have not had an active child welfare case for at least one year. This requirement does not extend to youths, foster parents, or kinship caregivers.
- Family Court: Most collaboratives prefer that parents do not have any active family court cases.
- Other potential criteria:
 - No recent involvement in the criminal justice system.
 - Not struggling with active symptoms of mental illness that prevent effective participation in meetings.

Factors *not* used as eligibility criteria include experience in the criminal justice system, lack of a high school diploma, homelessness, or domestic violence (which may require additional attention to confidentiality to facilitate participation).

Many collaboratives request that a relapse, new allegation of abuse/neglect, arrest, or anything else that makes them *ineligible* be disclosed to the designated contact person from the liaison organization. These situations should have a previously agreed upon protocol for responses that are shared by the designated contact person.

Collaboratives should detail how to respond when a parent/youth discloses either a renewed involvement with—or a need for—systems support (e.g., relapse, a new allegation of maltreatment, or a psychiatric destabilization). These guidelines should reflect the fact that although the collaborative is not acting as a direct service provider, members are part of the human services community and must respond appropriately and with compassion.

These guidelines should be developed by the collaborative before *any* parents/youths are recruited and shared as part of orientation. The policy might feature

- Protection of confidentiality
- Referrals to appropriate community services in coordination with partner preferences
- Whether or not the parent/youth may rejoin the group later

Term Limits

If a collaborative has limited time (i.e., focused on developing a new program model or a specific concern) term limits for parent/youth representatives are not an issue. However, when a collaborative focuses on long-term system change, term limits can spark fresh ideas and help maintain a focus on those with more recent connections to current policies, procedures, or services. A typical term limit for participating parents/youths is 2-3 years, sometimes with an option to extend for 1 additional year.

Recruitment and Selection

While recruitment for some collaboratives relies on recommendations of former clients from member organizations, many also reach out to a broader base, including agencies separate from the collaborative itself, local advocacy programs, and community groups. Recruitment should be impartial and should not rely on the same individuals for participation but provide opportunities for new applicants to participate and contribute different perspectives.

Although most collaboratives focus on people who are comfortable communicating in English, this practice may leave out those with important feedback to share. Collaboratives should carefully consider what they can do to ensure involved parents/youths reflect the true diversity of the target population or community, such as having the availability of interpreter services.

As a first step, many collaboratives ask interested parents/youths to complete an application asking about past involvement in policy and planning activities, why they're interested in participating, and the scope of their prior child welfare/family court, SUD treatment experience, or other qualifying situations.⁹ Collaboratives then proceed with interviews of those deemed eligible.

During interviews staff should inform potential parent/youth representatives of any confidentiality limitations or concerns as well as the fact that participation is voluntary and will not affect services received by any family member. When recruiting individuals with lived experience, collaboratives need to clearly define expectations and roles that supports meaningful engagement. Finally, there should be a discussion about any participation expectations, such as how many absences are permitted and when meetings are typically held.

Collaboratives may also want to consider parents'/youths'

- Experience working with other collaboratives or serving on an organization's advisory board (e.g., policy and planning experience)
- Geographic, racial, language, and ethnic diversity that reflects the broader client population
- Desired characteristics that align with the strategic vision of the collaborative, such as increased outreach to fathers, LGBTQIA+ families and youth, people of color, or people with disabilities
- Ability to attend meetings in person or virtually as needed



ENSURING PARTICIPANT SAFETY

RESOURCE HIGHLIGHT

For further information and strategies to fight stigma refer to the NCSACW's *Disrupting Stigma* Brief.

Former clients of child welfare, SUD treatment, or family court systems may feel threatened partnering with these same systems. To ensure parents/youths feel comfortable sharing their expertise, collaboratives should consider the following:

Confidentiality

Potential parents/youths may resist working with collaboratives that record and post proceedings for public view or publish documents that list participants' names and affiliations. Collaboratives might want to

- Give parents/youths the option to be referred to in publications, internal documents, recordings, or presentations by their first name only or a pseudonym of their choosing. Make sure this pseudonym (or first name only option) is known by anyone assigned to take notes at meetings, and that name preferences are adhered to in any printed or online documents or audio recordings.
- Make sure parents/youths understand the limitations of any signed media releases and encourage them to speak with the designated contact person about any concerns.
- Ensure participants know in advance if a meeting or event will be recorded so they have the option to opt out.¹⁰
- Decide whether it is essential to maintain audio or video recordings of meetings; written notes may be sufficient and better protect confidentiality.

Professional staff have an obligation to ensure that the confidentiality of parents and youths with lived experience is protected, particularly information available in a digital format now and in the future. It is incumbent on professional staff to safeguard any sensitive information and protect identifying information of people with lived experience.

Staff should discuss confidentiality issues during the recruitment and selection process as well as during any orientation. Potential parents/youths must have a chance to decline participation if they feel uncomfortable identifying themselves as a person with lived experience in systems of care.

Trauma

“Trauma-informed” means staff show *awareness* that trauma is a possible underlying factor in behavior and attitudes, and take steps to prioritize safety, choice, and control for all participants.

Collaboratives can operationalize trauma-informed approaches by ensuring all members are familiar with the core principles and, if not, offering training. Other actions include

- Demonstrating “trigger awareness”
 - If a participant has trouble managing emotions, or seems to dissociate during a meeting, check in with them privately—either during or after the session.
 - Allow parents/youths to decline participation in specific activities or conversations of their choosing.
- Promoting safety, choice, and control
 - Make sure parents/youths have all the information they need for meetings in advance, including agendas.
 - Ask permission before sharing names or statements in any public forum, including online.
 - During virtual meetings, if parents/youths lack privacy in their homes (i.e., no separate space away from children or other family members), work with them to find an alternate location, such as a public library.
 - Provide training on *Strategic Sharing* (a technique developed to provide a trauma-informed way for people with lived experience to tell their stories in short, effective ways that avoid re-traumatization).

RESOURCE HIGHLIGHT

For additional information on what strategic sharing is, why it is important, and helpful techniques on sharing ones story, please see [*Strategic Sharing*](#) from the Youth Leadership Toolkit.

Ongoing Support

Parents/youths who participate in collaboratives report that ongoing support from a designated contact person is crucial to their successful involvement. Supports range from meeting preparation (especially if agenda items may be emotionally difficult) to post-meeting debriefings and check-ins if someone is having a personal crisis. Support also includes helping parents/youths connect with local providers who can offer targeted assistance and case management if needed.

Meeting Facilitation

Developing a set of expectations or “rules of engagement” is helpful if participants meet separately. (See [*Attachment A*](#) and [*Attachment B*](#) for sample *Rules of Engagement* and *Letters of Commitment*.) These expectations, which can be developed by participating parents/youths themselves, might include how decisions are made, how disagreements should be expressed, and even suggested time limits when speaking.

To broaden the leadership experience, some groups decide the role of chair will rotate, with parents/youths volunteering in advance for this responsibility. This model requires more training and staff support for those participating but promotes greater shared ownership among all involved. Furthermore, groups should work to ensure that participants with lived experience have more than just a seat at the table, but a voice capable of contributing meaningful dialogue and decision-making.



MAXIMIZING THE QUALITY OF INPUT

Orientation

Making sure parents/youths have vital information at the start helps ensure they can make meaningful contributions. This requires time to be set aside for orientation as well as the budget to cover meeting and training time. Information covered during orientation should be provided in writing and orally, so parents/youths can review it later.

Orientations should include details on

- Compensation and preferred payment options if available
- Confidentiality considerations and limitations including signing of any media release forms
- Expectations and some collaboratives ask members to sign a participation agreement or letter of commitment, so expectations are clear. For sample letters of commitment please see Attachments
- Technology platforms (e.g., Zoom)
- Required paperwork (e.g., for reimbursement or compensation)

Other orientation topics may include

- Background information relevant to the primary purpose of the collaborative
- A list of organizations involved in the collaborative and what each one does
- An overview of guiding legislation, state/federal priorities, and interactions with other systems of care
- Acronyms and commonly used terms
- How to contribute effectively to meetings (e.g., time limits, sharing ideas productively, disagreeing with respect, the difference between data and personal experience)
- Whom to contact with questions

Orientation is also a time to remind participating parents/youths to be sensitive to their own triggers—especially when conversations turn personal. Encourage them to engage in self-care.

Communication

Ongoing transparent communication helps parents/youths build trusting relationships. Regular updates on initiatives or policies are helpful.¹¹ Updates can come via phone, text, emails, or as presentations during meetings. The liaison organization's designated contact person should consider this a primary responsibility.

Technology

Parents/youths may have different skill levels in or access to technology. If so, collaboratives can

- Help them locate free Wi-Fi or offer reimbursement for data plans
- Provide IT support during meetings
- Offer audio-only options for those uncomfortable with video

Evaluation

Collaboratives do not typically conduct formal evaluations of their work. However, they can be helpful for parent/youth-only meetings. Evaluations might include

- An independent annual (or end-of-project) analysis to determine the group's effectiveness, satisfaction level, and areas needing improvement
- Post-meeting assessments after each session
- Collaboratives should consider continuing education opportunities to ensure participants are getting the resources and support needed to be successful in the collaborative and feel valued



SPECIAL CONSIDERATIONS INVOLVING YOUTH

A few additional tips to consider:

- **Youth Panels:** Some young people are reluctant to participate as part of an ongoing collaborative. Youth panels are one solution, in which small groups of young people knowledgeable about a specific topic, such as making the transition to independent living, attend a single session of a collaborative meeting to provide input. To make these meetings most effective, a staff person can meet with youths ahead of time to provide essential background information and help them shape their feedback.¹²
- **Staffing:** The designated contact person should have experience working with youth and understand principles of trauma-informed youth development.
- **Skill Development:** Youths are more likely than adults to need additional support in how to be most effective in meetings and as collaborative partners.
- **Case Management:** Young people not affiliated with other service providers may need help connecting with local resources if they experience personal crises related to housing, school, employment, health, family issues, income/benefits, relationships, or contact with police.
- **Scheduling:** If youths are invited to attend mixed participant sessions, meetings need to be scheduled during their free time.
- **Confidentiality:** Both young people and their family members may be very concerned about confidentiality. Parental consent may be required for youths under 18 to participate in meetings, or to have their name, image, or voice be included in publications of any kind.
- **Recognition:** Certificates, awards, and recommendations are extremely helpful for young people seeking jobs or educational opportunities. Ensure these important documents do not label them as “at risk.”¹³



RESOURCES

Substance Abuse and Mental Health Services Administration

[Share Your Story: A How-to Guide to Digital Storytelling – 2016 \(PDF | 1.4 MB\)](#) is an evidence-based guide to help people living with mental or substance use disorders tell their personal stories of recovery in a digital format. It includes key questions and information for individuals and organizations to ensure informed decision-making and consent

Episode 63: Foster Care Alumni

Making Lived Experience Matter, Part 1 shares perspectives, personal stories, and guidance from members and former members of [Foster Care Alumni of America](#) to help agencies understand the value of alumni of all ages, provide information on how to look for and find the right alumni partners, and discuss the impact sharing has on alumni, especially alumni who work as child welfare professionals.

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National Center on
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Future Readings

- Accelerating Change Transformation Team. (2018). [*Engaging Individuals with Lived Experience: A Framework*](#)
- Alberta Health Services. (2020). [*A Guidebook for Engaging Patient and Family Advisors*](#)
- Canadian Centre for Substance Use and Addiction. (2021). [*Guidelines for Partnering with People with Lived and Living Experience of Substance Use and Their Families and Friends*](#)
- Capacity Building Center for States. (2019). [*Family Empowerment Implementation Manual*](#)
- Capacity Building Center for States. (2019). [*Strategies for Authentic Integration of Family and Youth Voice in Child Welfare*](#)
- Casey Family Programs and Foster Care Alumni of America. (2014). [*Strategic Sharing*](#)
- Center for the Study of Social Policy. (2019). [*Parent Engagement & Leadership Assessment Guide and Toolkit*](#)
- Child Welfare Information Gateway. (2021). [*Family Engagement: Partnering with families to improve child welfare outcomes*](#)
- Children's Aid Foundation of Canada. (2019). [*Leading with Lived Experience: Youth Engagement Guidelines for the Child Welfare Sector*](#)
- Children's Bureau Information Memorandum. (2019). [*ACYF-CB-IM-19-03*](#)
- Davis, Cliff (Human Services Collaborative). (2016). [*A Study of Best Practices in Youth Engagement and Leadership Development. Final Report*](#)
- Destination: Home. (2020). [*Establishing and Maintaining Agency Consumer Advisory Boards*](#)
- Domestic Violence Victoria and The University of Melbourne. (2020). [*The Family Violence Experts by Experience Framework: Research Report and Framework*](#)
- Family Voices. (2020). [*Family Engagement in Systems Assessment Tool \(FESAT\)*](#)
- FRIENDS National Center for Community-Based Child Abuse Prevention. (2020). [*Meaningful Parent Leadership: Building Effective Parent/Practitioner Collaboration*](#)
- National Council of Juvenile and Family Court Judges. (2020). [*Strategies for Engaging Youth and Families with Lived Experiences*](#)
- Family-Run Executive Director Leadership Association (FREDLA), National Technical Assistance Network for Children's Behavioral Health (TA Network), and SAMHSA. (2018). [*Supporting Family Participation in Systems of Care*](#)
- National Child Traumatic Stress Network, Family Informed Trauma Treatment Center, and Institute for Translational Research in Children's Mental Health. (2019). [*A Guide to Forming Advisory Boards for Family-Serving Organizations*](#)
- The Young Foundation. (2020). [*Nothing About Us Without Us: Lived Experience Insight and Social Investment*](#)
- Wisconsin Office of Children's Mental Health. [*Lived Experience Partnership Planning Tool for Organizations and Coalitions*](#)

References

- ¹ Sandhu, B. (2017). *The value of lived experience in social change: The need for leadership and organisational development in the social sector*. The Lived Experience. <https://thelivedexperience.org/report/>
- ² Child Welfare Information Gateway. (2021). *Family engagement: Partnering with families to improve child welfare outcomes*. U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau. <https://www.childwelfare.gov/pubs/f-fam-engagement/>
- ³ Arnstein, S. (1969). Ladder of Citizen Participation. *Journal of the American Planning Association*, 35(4), 216-224.
- ⁴ National Child Traumatic Stress Network, Family Informed Trauma Treatment Center, and Institute for Translational Research in Children's Mental Health. (2019). *A guide to forming advisory boards for family-serving organizations*. https://www.nctsn.org/sites/default/files/resources/resource-guide/a_guide_to_forming_advosiry_boards_for_family_serving_organizations.pdf
- ⁵ Canadian Centre for Substance Use and Addiction. (2021). *Guidelines for partnering with people with lived and living experience of substance use and their families and friends*. <https://www.ccsa.ca/sites/default/files/2021-04/CCSA-Partnering-with-People-Lived-Living-Experience-Substance-Use-Guide-en.pdf>
- ⁶ Family-Run Executive Director Leadership Association (FREDLA), National Technical Assistance Network for Children's Behavioral Health (TA Network), and SAMHSA. (2018). *Supporting family participation in systems of care*. <https://www.fredla.org/wp-content/uploads/2018/06/SupportingFamily-2017-Revised2018-newlogo-print-1.pdf>
- ⁷ FREDLA, National Technical Assistance Network for Children's Behavioral Health (TA Network), and SAMHSA. (2018). *Supporting family participation in systems of care*. <https://www.fredla.org/wp-content/uploads/2018/06/SupportingFamily-2017-Revised2018-newlogo-print-1.pdf>
- ⁸ FREDLA, National Technical Assistance Network for Children's Behavioral Health (TA Network), and SAMHSA. (2018). *Supporting family participation in systems of care*. <https://www.fredla.org/wp-content/uploads/2018/06/SupportingFamily-2017-Revised2018-newlogo-print-1.pdf>
- ⁹ For an example of an application, see <https://www.surveygizmo.com/s3/4376441/Collective-Impact-Partner-Parent-Application> from Wisconsin's Office of Children's Mental Health
- ¹⁰ Accelerating Change Transformation Team. (2018, June 11). *Engaging individuals with lived experience: A framework*. <https://actt.albertadoctors.org/file/engaging-lived-experience-framework.pdf>
- ¹¹ Capacity Building Center for States. (2019). *Strategies for Authentic Integration of Family and Youth Voice in Child Welfare*. Children's Bureau, Administration for Children and Families, U.S. Department of Health and Human Services. <https://capacity.childwelfare.gov/states/resources/strategies-for-authentic-integration-of-family-and-youth-voice-in-child-welfare>
- ¹² Davis, C. (2016). *A study of best practices in youth engagement and leadership development*. Human Service Collaborative. https://endowment-assets.nyc3.digitaloceanspaces.com/resources/Early-Childhood/Youth_engagement_best_practices.pdf
- ¹³ Children's Aid Foundation of Canada. (2019). *Leading with lived experience: Youth engagement guidelines for the child welfare sector*. https://www.cafdn.org/wp-content/uploads/2019/02/Leading-with-Lived-Experience-Youth-Engagment-Guidelines-for-the-Child-Welfare-Sector_Feb_2019.pdf

Attachment A – Rules of Engagement and Letter of Commitment



COLORADO
Department of Human Services



Letter of Commitment for Family Voice Council Members

Member Term: XX/XX/XXXX to XX/XX/XXXX

The Family Voice Council is committed to the community and represents Colorado families with Colorado Department of Human Services lived experience and other government assistance.

My role as a Council member is to provide feedback on CDHS planning, policies, and procedures in order to improve the design and delivery of high-quality human services. I understand that the Council is consultative and advisory; it is not always a decision-making body for CDHS, but my voice is extremely valuable in the process. I will strive to uphold the mission of the Family Voice Council and advocate for more equitable and accessible human services for all.

I am committed to the following rules of engagement and procedures as established by the Family Voice Council.

Expectations

- I understand that I am committing to one term of service, XX/XX/XXXX to XX/XX/XXXX, with the option of renewing for a second year. I will attend the meeting once a month, as scheduled by the Family Voice Council. I will arrive on time and participate until the meeting is adjourned.
- Council members are expected to respond to email requests, including reviewing documents before the next meeting, and attending to council logistics.
- If I have a concern regarding the council, I will share the concern on the monthly meeting feedback form or speak directly to the Director of Family and Community Engagement for Community Partnerships.

Rules of engagement

- Respect other viewpoints and perspectives.
- Honor members' realities and life experiences.
- We all are human. Focus on other's strengths.
- Respect the process. Practice patience.
- Be aware of bias. Focus on the issue not the person or presenter.
- Provide a safe and positive culture. Always assume positive intent.
- Step back to allow others to step forward.
- Actively contribute to FVC meetings. Try to avoid side conversations in the chat.
- Be on time.
- Two minute speaking limit. Practice self-awareness.
- Practice the raise hand functionality in zoom to be added to the speaker's queue.

- Please mute yourself when you're not speaking.
- Feel free to move and take a body break.
- Please pronounce your name before speaking.
- Review boundaries and triggers as needed. If triggered, please send a private message to the facilitator.
- If you are able, or choose to do so, please have your camera on when speaking.

CDHS will provide Family Voice Council Members with:

- Compensation for your time at each monthly meeting. Payment options will be provided.
- Reimbursement for cost of mileage, RTD bus pass and/or childcare expenses for each meeting if applicable
- Parking reimbursement/validation if applicable
- Breakfast and lunch, which will be served during the council meeting if meeting in person
- Professional development through speakers who will present at the council meetings and through other opportunities in the community
- An evaluation and conversation with each council member at the end of the first year term to gather the council member experience and options for a second year term
- Frequent communication and support with other engagement opportunities

In becoming a member of the Family Voice Council, I release from liability and waive my right to sue the Colorado Department of Human Services, their employees, or other members from any and all claims resulting in any physical injury, illness (including death) or economic loss I may suffer or which may result from my participation in the Family Voice Council, travel to and from or any events incidental to my membership on the Family Voice Council. I have read this letter of commitment and signed it freely.

Signatures:

Name of CDHS Director Date

Family Voice Council Member's Name Date

Attachment B – Rules of Engagement and Letter of Commitment



Group Acknowledgement

The Nebraska Department of Health and Human Services (DHHS) is engaged in a process of improving outcomes for children and families impacted by substance abuse disorders through the Nebraska Plan of Safe Care (POSC) Project. As a part of this project, this workgroup has been created to facilitate discussion and develop action items around the implementation of Plans of Safe Care (POSC). As a part of this workgroup, you bring immeasurable value to the team through your professional expertise, personal experience, and desire to see improved outcomes for the families of Nebraska.

To accomplish this, the Nebraska POSC Project will be providing opportunities for people to share their personal experiences, professional expertise, and recommendations through participation in the Nebraska POSC Project. Through your participation in the Nebraska POSC Project, your experiences could be shared in several different forms (i.e. verbally, written). This form is to help ensure that every group member understands how their experiences could be shared, and how the group has agreed to create a protected space for the sharing of experiences for the safe participation of all members in the Nebraska POSC Project.

Please read the following carefully regarding your participation in the Nebraska POSC Project.

I understand that:

1. I can withdraw my participation from the group at any time, for any reason by contacting Nebraska Department of Health and Human Services (DHHS).
2. I have full control over what experiences I share, be they professional or personal in nature.
3. I do not have to answer any question from any group members or attendees about any experience that I am not comfortable with.
4. Not answering a question about any experience shared will not in any way negatively impact my participation in the Nebraska POSC Project.
5. Other group members may share experiences that may be triggering or involve past substance use or neglect.
6. Any past substance use or neglect discussed is considered as having been addressed and not active unless explicitly mentioned.
7. As a result of the Nebraska POSC Project being conducted in a public forum, any information I share has the potential of being discoverable in Google searches or other public domains.
8. Any information communicated may be shared with other Nebraska POSC Project participants, which could result in friends, family members, and/or other community members having access to the details I share about my experiences and expertise.
9. Activities that include my participation in the Nebraska POSC Project may be recorded, unless I contact Nebraska Department of Health and Human Services (DHHS) to request that they not be recorded.

Your participation in the Nebraska POSC Project will make an important contribution to the Project Name, and we thank you for your willingness to be a part of this group. Your willingness to participate in the Nebraska POSC Project and share your expertise and experience will greatly help create a product that will increase outcomes for the children and families of Nebraska.

The Nebraska POSC Project wants to ensure that you are completely comfortable with sharing your experience and expertise and are fully aware of the impacts of your participation.

I hereby confirm my understanding of my participation in the Nebraska POSC Project and release the Nebraska POSC Project from any and all claims, demands, rights and causes of action of whatever kind that I may have, caused by or arising from participation in the Nebraska POSC Project, including all claims for libel and invasion of privacy or infringement of rights of copyright and publicity.

Signature

Date

Printed Name, Title

Email

Organization Name (if applicable)

Phone Number

Street Address

City

State

Zip