

Background

“Lived experience” is defined as personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people.

A person with lived experience in the child welfare system—parents, children and youth, resource families/formal and informal caregivers, guardians, and adoptive parents—is someone who has lived (or is currently living) with the impacts of the system.

Those with lived experience may have insight to offer about the child welfare/probation system as it is experienced by the “consumer”—for example, a youth who has experienced failed placements or a family that has completed the Resource Family Approval process can offer insights into those experiences. People with lived experience have awareness of what works, what doesn't work, and what resources (formal and informal) are available or needed in the community.

Organizations that value the perspectives of community members with lived experience are better equipped to offer services that are more focused, efficient, integrated, culturally appropriate, and sustainable.

Lived Experience Survey Summary

Background

During the months of April and May 2022, the Alliance for Children's Rights conducted a voluntary, online survey of people with lived experience, including youth, caregivers, and parents and their advocates. The Alliance's Kinship Caregiver Council and Young Leaders were invited to complete the survey. The survey focused on identifying ways in which those with lived experience would prefer to participate in policy discussions. Specifically, respondents were asked to share their thoughts on how policymakers and advocates should engage people with lived experience during policy discussions. The survey opportunity was shared through partnering organizations' networks and the Alliance's weekly e-newsletter.

An overwhelming majority of respondents noted that they wish to engage in policy discussions as equal partners when discussing the issues and practices that impact them.

Q: What are your expectations when policymakers engage you in discussion?

A: *"Policymakers should be intentional [and more personable] when speaking to foster youth. They should be listening and respectful. Understand that [lived experience] is much needed, so they should compensate [us] for our lived experience because we provide expertise."*

Respondents

Eighty-five people with lived experience in the child welfare system, including youth, caregivers, parents, responded to the Lived Experience Survey, as well as some advocates. Nearly half (39) of survey respondents identified as youth currently or formerly in foster care, 31 respondents identified as caregivers/resource parents, six identified as parents, and nine identified as advocates. Survey responses were sent from various locations across California.

Q1

Describe your role in the child welfare system.

Answered: 85 Skipped: 0

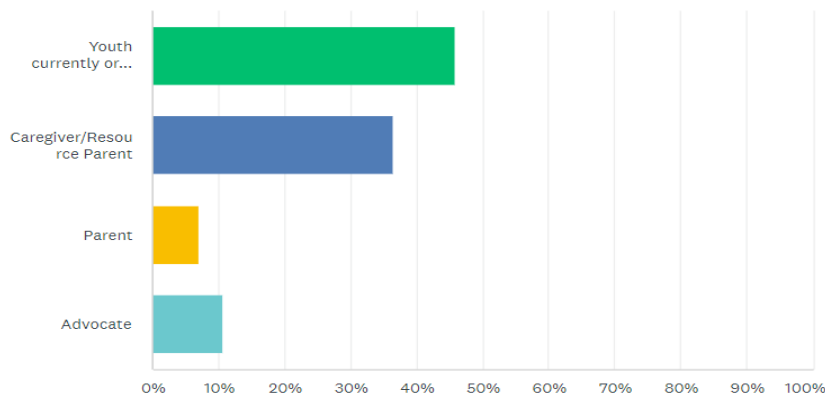


Figure 1: Lived Experience Survey Respondents

Who Should Participate in Decision Making

The survey responses demonstrated a common theme in identifying the voices and viewpoints respondents felt were not sufficiently heard in the decision-making process. When asked which voices were not being heard, survey participants focused in on similar categories such as: youth currently or formerly in foster care, caregivers, and parents. Understanding

that the survey audience was comprised of youth currently or formerly in foster care, caregivers, parents, and their advocates, the responses show that people with lived experience agree that their voices are not currently given sufficient weight in policy development and decision making.

Responses to this question emphasized the intersectionalities present within the foster care system, specifically that people of color, members of the LGBTQIA+ community, those with disabilities, unhoused communities, neurodiverse people, and those for whom English is not the preferred language, experience compounded barriers to making their voices heard.

Q: Which voices are not being heard?

A: *"Oftentimes, the ones that are directly affected by certain legislation or policies are the ones that are not a part of the decision making process."*

Several respondents also named children and families involved in the hidden foster care system who are "cut out of judicial council's design of federal funds" as one group they feel is cut out of the conversation. Because there is no standardized way to track diverted kinship families that are not in a formal foster care arrangement or a Voluntary Placement Agreement, these families would likely be overlooked when policymakers and child welfare workers look only to traditional foster care placements in seeking to engage those with experience in the child welfare system.

Opportunities for Engagement are the Beginning

The majority of survey responses indicated that providing subject matter experts with a platform to share their experiences and thoughts on issues is just the start of what should be a more holistic ongoing process. Over half of the survey respondents identified multiple opportunities where they would like to see those with lived experience participate in decision making. The responses encourage policymakers to authentically engage those with lived experience by empowering them as key stakeholders in designing, developing, and implementing policies and practices.

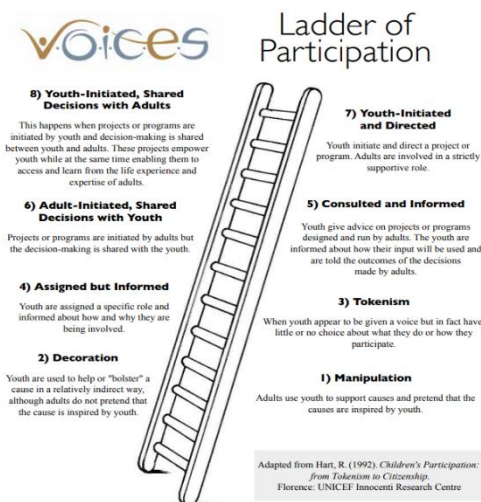
Q: What do you caution policymakers and advocates NOT to do when engaging with those with lived experience?

A: *“Do not tokenize them. What works for one will not work for all. Every single person impacted by the child welfare system should have their experience validated.”*

Authentically engaging those with lived experience is necessary to develop strong and effective policy and practice change. The people directly affected by the system must be the ones providing recommendations in order to create policies that improve outcomes for those in foster care. As one respondent wrote, “the consumers of potential policies know best what supports their need.”

Input from parents, caregivers, and youth in foster care is crucial to fully understanding the practical implications of policies envisioned by advocates and policymakers.

To better receive and absorb input from those impacted by foster care, policymakers and advocates must authentically engage them in the decision-making process. For policymakers and advocates, this means setting aside our own preconceived notions about the best way to achieve a desired outcome to consciously hear the suggestions of experts with lived experience. Many survey respondents expect an ideal interaction with a policymaker in which the policymaker regards them as an “expert” in their field given their unique awareness of policy in practice. When policymakers respect this expertise, they become a more effective partner who can develop and advocate for the systematic changes that “experts” identify and suggest.



Roger Hart’s “Ladder of Youth Participation” is a useful tool that helps groups assess and reflect on the levels of participation that they currently have and ultimately wish to see in their work. It can also be used to identify barriers and solutions to achieving effective participation. There are eight levels of participation and decision-making power in the Ladder model. The top few rungs are achieved when youth and adults work together toward a shared goal. The same concept can be applied to policymakers’ collaborations with experts with lived experience. The transparent and honest assessment of and shifts in policymakers’

efforts to collaborate with subject matter experts can improve the partnership and solutions developed.

Policymakers have ample opportunity to engage lived experience experts as equitable partners. Survey participants stated that they wanted to be in every role in policy discussions. Participants requested more active engagement efforts from policymakers and advocates when it comes to working together on policies and practices.

Additionally, survey respondents identified that they appreciate receiving information about their role in the process and being respectful of their participation. To survey participants, inclusion and engagement looks like:

- actively listening to respondents;
- respecting experts and their experiences;
- using accessible language, and
- follow-up efforts, such as updates informing participants of how their input was operationalized.

Responses sharing advice for policymakers who engage those with lived experience emphasize accessibility and understanding. Many highlighted the use of acronyms and jargon as a disempowerment method, whether it be purposeful or inadvertent, that makes involvement out of reach from many with lived experience. Using readily understandable language makes the process of inclusion more equitable and fruitful in creating avenues for contributions.

Q: What advice would you provide to policymakers or advocates when engaging those with lived experience?

A: *"Use language that the person can understand. Explain why the person is needed and what they can contribute. They should feel valued and accepted."*

Equally important as the engagement itself is follow-up. Participants expressed the expectation that policymakers truly interested in implementing their ideas would work to facilitate ongoing communication in order to create tangible solutions. Expectations for follow-up include a timeline of progress, flexible plans that can change when something is not working, and offering ideas for communication that are "outside the box."

When surveyed about how they would like this communication to continue, respondents conveyed openness to several different methods. A follow-up meeting was the first choice,

with 29 participants indicating that as their preferred method. Phone communication was the second most popular, with 18 indicating that as their preferred method. A report or recommendation was preferred by 17 participants, and text message communication was preferred by 14. A follow up meeting was the clear frontrunner, indicating that participants want a face-to-face opportunity to continue the conversation and create a lasting partnership with policymakers.

Q: What role do you think those with lived experience should play in policy discussions?

A: *“Every role! ... We should be asking people with lived experience HOW to best communicate/interact with those currently in care and actively seek out their input...”*

Engagement Guidance for Policymakers/Advocates

When engaging those with lived experience in policy development and solutions, it is critical to create and maintain an organized, inclusive, and collaborative environment for all. Specific recommendations include:

- Identify goal(s) and anticipated outcome(s).
- Identify how you will use information/insights from people with lived experience to achieve goal(s).
- Identify and recruit community members impacted by the issue.
 - Consider how issues of race, culture, class, LGBTQIA+ identity, etc. may impact engagement and be thoughtful in selecting the individual to perform outreach.
 - Consider reaching out to service providers, advocacy organizations, etc.
 - Clearly communicate expectations: goals, time commitment, processes, etc.
- Meet community members at a time and place that is convenient for them.
 - Use a variety of methods to connect (small groups, surveys, listening sessions, one-on-one interviews) and acknowledge and resolve barriers to connection (access to internet, available resources to attend meetings, etc.).
- Support people with lived experience to ensure they participate as equal partners.
 - Provide level-setting information about systems (e.g., child welfare, probation, local and state government) and community resources.
 - Co-develop resources including public testimony, presentations, reports, documents, etc.

- Jointly identify the issues and co-design solutions.
- Offer fair compensation for time and knowledge.
- Periodically and collaboratively re-evaluate roles, responsibilities, and continued engagement.
- Support growth of skills by offering options to increase level of participation over time, including opportunities for facilitating meetings, public speaking, etc.
- Follow up with members about progress/outcomes.

Other strategies survey respondents think would be useful for engaging people with lived experience include the following:

- Ensure engagement opportunities are more inclusive of people with non-traditional lived experience (i.e., youth and kin caregivers who are not formally engaged with the child welfare system or in a traditional foster care placement, but have had some level of involvement); and,
- Hire employees who have the necessary education and experience in spaces in the child welfare system who can genuinely connect with youth.

Sources

- Jim Casey Youth Opportunities Initiative – [Authentic Youth Engagement: Youth-Adult Partnerships](#)
- [Measuring and Understanding Authentic Youth Engagement](#)
- Voices Youth Center – [Ladder of Participation](#)
- Alliance for Children’s Rights - [Hidden Foster Care: The Human Impact of Bypassing Foster Care](#)