

Promoting Meaningful Partnerships with Lived Experience Experts in High-Quality Research: Considerations for Funders

Brittany P. Mihalec-Adkins

Sandra Killett

George Gabel

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There's nothing new about the idea that ordinary people know and understand their own lives in ways that social scientists (who've been trained to study institutions, social systems, and related phenomena from an external vantage point) are unable to perceive. Indeed, scholars in various fields have long argued that lived experience creates its own kind of "expertise," and that researchers should seek it out, and engage with the unique perspectives and insights that individuals can share. (Similarly, organizational theorists have long called for efforts to promote "consumer involvement," "stakeholder engagement," and the creation of "constituent advisory boards"; see Pecora et al., 2010; Wallcraft et al., 2009).

In recent years, however, lived expertise has come to be seen as particularly valuable for researchers working to inform the design and delivery of social services, such as programs for individuals and families struggling with issues related to mental health (Barr et al., 2020; Tapsell et al., 2020; Vojtila et al., 2021), disordered eating (Musić et al., 2022), substance misuse (Honey et al., 2020; Cheng & Smith, 2009), and suicidal ideation (MacLean et al., 2018), for example.

Indeed, in 2018, the U.S. Department of Health and Human Services (HHS), through its Administration for Children and Families (which oversees child welfare services operations nationwide) released an official memorandum specifying that lived expertise should be incorporated into all of the agency's efforts to improve policy and practice in this area (Milner, 2018), and HHS's Office of the Assistant Secretary for Planning and Evaluation went on to publish an overview of best practices for researchers to consider (Skelton-Wilson et al., 2022). Similar statements have also been issued by leading academic and professional organizations in the field of child welfare, and they, too, have created and updated their guidelines for researchers, recommending specific ways to partner with individuals with lived experience (Casey Family Programs, 2018; Thomas et al., 2022).



“I can imagine because I've been impacted” – Lived Experience Expert

The notion of incorporating lived experience expertise is “rooted in empiricism: the tenet that knowledge comes primarily from sensory experience” (Kuhn et al., 2017, p. 4).

Further, some have noted that while the meaningful inclusion of lived experience in research is necessary to ensure that child welfare services are designed and delivered equitably (taking into account the perspectives and needs of all of the people they are meant to serve), the field has yet to come up with clear guidelines spelling out what it means to engage those research partners in meaningful and ethical ways, while conducting high-quality science that informs policy and practice.

This brief is meant to address these concerns, suggesting specific steps funders can take to support researchers in efforts to engage individuals with lived expertise while meeting various ethical and scientific standards (not unlike the steps researchers must take to meet various standards during participant recruitment, data analysis, and other parts of the research process). Specifically, we draw upon lessons learned and resources identified during the work of crafting a National Research Agenda for a 21st Century Child and Family Well-Being System (an initiative funded and led by Casey Family Programs, the Annie E. Casey Foundation, and the William T. Grant Foundation).

Background

The initiative to create a 21st Century Child Welfare Research Agenda began in 2019 with an effort to identify the most pressing research questions facing the field of child and family welfare. Over the next three years, it grew to include over fifty scholars, lived experience experts (i.e., people formerly in foster care, foster/kinship caregivers, parents impacted by child protective services), Diversity, Equity, and Inclusion (DEI) consultants, policy experts, and representatives from regional and national academic and practice organizations focused on child and family welfare. Team members formed working groups to develop an initial list of over 300 research gaps relevant to the study of child and family welfare and the child welfare system.

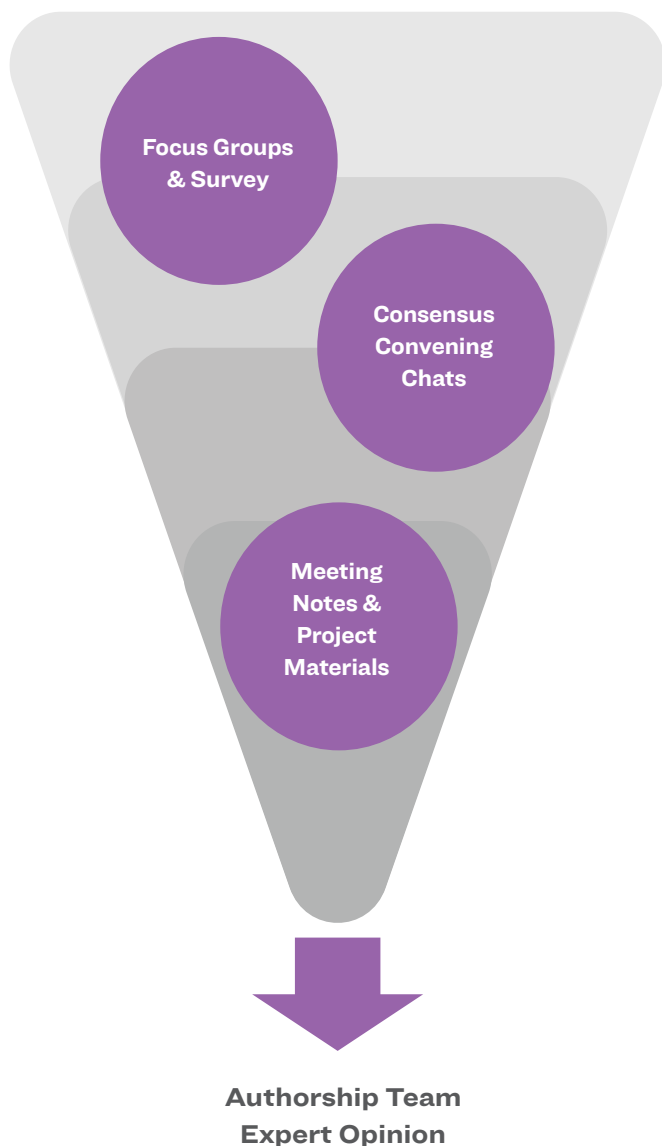
These research gaps were unveiled in a multi-day virtual Consensus Convening in 2021, which drew several hundred researchers, policymakers, practitioners, and people with lived experience from across the U.S. Input from attendees was documented and used to narrow down the initial list to a set of nineteen topics most urgently in need of research. This led to the development of nineteen Requests for Proposals (RFPs), which have been shared with a broad range of research-supporting funders, including private foundations as well as public agencies at the federal, state, county, and city levels.

Throughout the initiative, funders have asked probing questions about what they can do to ensure that their grantmaking activities support meaningful and effective partnerships between researchers and individuals with lived expertise. Further, they asked, could members of the initiative provide clear and concise guidelines to help them as they design their own projects? In response, we (two lived experience experts and a research consultant) set out to develop this brief, relying on guidance from the initiative's steering committee and lived experience advisors, and support from a pair of leading child welfare research experts in leadership at private foundations.

Not only have we strived to respond to funders' request for such guidance, but we have also endeavored to model the kind of meaningful and equitable partnership that we aim to promote among researchers, funders, and lived experience experts. This has included efforts to establish clear roles and responsibilities within our own team of authors and advisors, to discuss our own power dynamics and expectations, to allow for flexible timelines (accommodating our partners' and our own varied life circumstances), and to invite lived experience experts to provide early input on our work and to review and respond to drafts of the brief. Importantly, the authorship team has also maintained primary editorial authority over the content of this document, per conversations and agreements related to power-sharing with the foundations that provided financial support for this work.

To inform the content of this brief, we invited *all* participants of the original research agenda project to provide input via focus groups and online surveys. (Note that we convened a panel of five lived experience experts to help develop the focus-group and survey questions.) In all, we convened two focus groups, with a total of 13 attendees, and received survey responses from 10 additional participants. We also held multiple informal conversations with lived experience experts and with the initiative's steering committee members, taking detailed notes during and after each call. Finally, we drew from Zoom chat records from the project Consensus Convenings in Fall 2021, where over 400 attendees gave input on the agenda and process. We then synthesized these multifaceted data, with support from our research partners, and we solicited input from representatives of the two foundations that funded this brief (William T. Grant Foundation and Casey Family Programs). Throughout this work, we followed all screening and ethics procedures required by Casey Family Programs' human subjects research ethics review process.

Figure 1. Data and Information Sources Informing Brief Content



Considerations and Recommendations

Below, we outline major considerations and recommendations for funders to keep in mind as they design research projects related to child and family welfare, with a focus on creating meaningful, ethically sound, and effective partnerships among researchers and members with lived expertise. Specifically, we highlight six key themes that emerged from our analysis of focus group data, survey responses, Consensus Convening chats, and conversations with partners from the broader project.

Reshaping Power Dynamics

A. Prompt researchers to establish and clarify shared power dynamics among researchers and lived experience experts.

Many comments and conversations centered around power in some way — especially power sharing among researchers and lived experience experts. (By “power sharing,” we refer to collaborative decision making, equitable involvement processes, shared influence in conversations and feedback processes, and other actions that explicitly allocate authority and control over project processes and products.) As one lived experience expert put it, capturing the general sentiment: “We are past the time where we’re just inviting people to the table. We need them to *set* the table.”

To avoid issues or disagreements related to power sharing, project teams should have early and open discussions about how major decisions will be made, with explicit attention to who will have final authority over documents, processes, products, meetings, and so on. In turn, funders should be explicit about these expectations in RFPs and other documents. For the national research agenda project, for example, all six lived experience experts

were invited to serve as full members of the project's steering committee, and therefore had input on important decisions about project directions and products. In this spirit, funders may ask applicants to explain how they will create such formal avenues, meaningful participation, and power sharing by individuals with lived expertise experts.

At the same time, funders should allow for some flexibility in project plans and processes, so that grantees can adjust project details in response to ongoing conversations about power dynamics. For example, during the creation of the national research agenda, project leaders proved willing to make changes in response to concerns and questions raised by participants. At the onset of the initiative, lived experience experts were formally referred to as "constituent *consultants*." This was changed to "lived experience experts" after participants pointed out that the terms "constituent consultants" and "subject matter *experts*" (i.e., researchers) seemed to suggest a difference in status. (Indeed, funders may want to take special note of this issue, making it a point to require grantees to assign equitable titles to researchers and lived experience experts.)

Funders should also require researchers to describe how they plan to provide adequate background information and multi-faceted support for lived experience experts who are not familiar with specific research methods or concepts, such as established approaches to data gathering and or interpreting analysis. For example, researchers should be prepared to explain technical terms and jargon, spell out acronyms, and introduce names or institutions that will likely arise in conversations or whose research might be drawn upon. Further, researchers should anticipate that the content of some project-related conversations may be emotionally charged for some lived experience experts (e.g., discussion of maltreatment, family separation, or risk factors), and that additional time and support may be required to ease frictions. For example, during the creation of the national research agenda, project leadership initiated

monthly check-in meetings to discuss and address any emotional distress that the work might have triggered among participants. In fact, lived experience experts were allowed to set the agendas for these meetings, to ensure that their concerns and needs would be addressed.

B. Provide clarity regarding power dynamics among funders and grantees.

In addition to clarifying power dynamics among researchers and lived experience experts, funders should be mindful of power dynamics in their own relationships with applicants and grantees. As one researcher noted at the 2021 Consensus Convening, "Oftentimes, the funder has a lot of power, or we let them take power over what are the research questions, what will be in the reports, etc. Many of us know the issues we are talking about . . . all the things we know are the barriers [to lived experience engagement], but it's hard for us to overcome them to do this work." In short, funders should be mindful of ways in which their processes, procedures, or regulations might restrict or complicate researchers' ability to meaningfully engage lived experience experts in research, if applicable.

To complicate matters further, one of our focus group participants voiced a concern about whether power can be truly shared when foundations or other funders are closely involved with projects' day-to-day operations. In these situations, especially, it is critically important to clarify roles and establish equitable decision-making processes. Perhaps, as focus group participants suggested, an outside and relatively neutral party should be invited (with input from grantees) to mediate among project team members when needed (though this would likely add to project expenses).

Minimizing the Potential for Tokenism & Promoting Co-Design

A. Require applicants/grantees to articulate how they intend to partner *meaningfully* with lived experience experts.

The potential for tokenism — or symbolic, versus meaningful, involvement of lived experience experts — was raised by many respondents (and often by researchers or funders, interestingly) in our focus groups and surveys. For instance, when asked about potential barriers to meaningful engagement, one survey respondent said: “Avoiding tokenism . . . making sure there is enough time and funding to be authentic and not do harm doing the work.”

In focus groups and informal conversations, lived experience experts also expressed concerns about tokenism, particularly the fear that they will be invited to participate in research projects to

improve the “optics” (i.e., the appearance of inclusion), and not because researchers truly intend to collaborate with them. At the same time, however, they voiced optimism that funders can, with a little forethought, address this problem successfully. For instance, many reported that they have *not* felt tokenized while working on the national research agenda project. Said one lived experience expert, “In the process I have felt heard, respected, etc.”

Thus, one action item for funders is to simply ask grant applicants to describe their plan for meaningfully engaging lived experience experts and avoiding tokenism. They might even require grant applicants to demonstrate that such relationships are already in place, existing since *before* the decision to apply for funding. Indeed, several lived experts argued that the most successful research projects tend to be those that build on long-standing relationships, in which partners have already invested in extended periods of rapport- and trust-building. Additionally, funders could also

Table 1. Co-Design Defined

Co-design has been described as an “approach to designing with, not for, people” (McKercher, 2020). Principles of co-design include emphasizing collaboration, sharing power, and investing in relationships between partners (McKercher, 2020). Co-design goes beyond consulting or partial engagement, and it involves establishing true partnerships and continuous collaboration. Slattery and colleagues (2020) conducted a rapid review of co-design in health research, which may be useful for both researchers and funders. See below for examples of what is and is not co-design:

Not Co-Design	Co-Design
Researchers meet with lived experience experts twice to get input on a research proposal that is nearing submission to a grantmaking agency. Lived experience experts can suggest wording changes and offer ideas for participant recruitment.	Researchers invite lived experience experts to join the research team in the early stages of an effort to develop a research proposal. Lived experience experts help to shape the research questions and project goals.
Researchers convene an advisory board of lived experience experts that meets quarterly to review research project processes and provide input on publications in preparation.	Researchers convene an advisory board of lived experience experts who meet regularly to help make project design decisions, participate in results interpretation, and co-author publications.

request letters of partnership from researchers and lived experience experts (or community organizations) testifying to the fact that the partnership feels meaningful to both parties. Finally, funders can also direct researchers to resources and guidance related to the principles of meaningful co-design (see Table 1).

B. Prompt researchers to develop plans for meaningfully engaging with lived experience experts and their expertise throughout the *entire scientific process*.

Another frequent suggestion from our informants was to ensure that lived experience experts have opportunities to participate in all stages of a research project. For example, funders can require grant applicants to draft and submit plans detailing how they intend to engage their partners in the study design, data collection, results interpretation, product/report development, product revisions, and dissemination. This can also help to minimize the likelihood of lived experience experts feeling tokenized, and it can help establish clear expectations for shared power and decision-making with regard to project planning, task distribution, authorship, and the like.

This also encourages researchers to be open to acknowledging the value in different forms of evidence — and to know that funders support this kind of epistemic humility. As in any research collaboration, project members should feel comfortable debating ideas and weighing different pieces and forms of evidence. Both lived experts and researchers in these unique partnerships should be able to respectfully disagree, as is common in the advancement of knowledge in any discipline. Funders can help prepare grantees by providing guidance for lived expert engagement in various project stages, as well as routinely checking in with grantees during and after project completion to assess the extent to which this meaningful engagement was successful at various stages, and compiling and sharing lessons learned. A neutral

mediating party (as mentioned earlier) may also be helpful in solving scientific disagreements between lived experts and researchers, when necessary.

Promoting Diversity in Lived Experience

A. Ensure that researchers meaningfully incorporate lived experience expertise from experts of diverse and marginalized backgrounds, identities, and experiences.

Another key theme from focus groups and surveys was the importance of meaningfully considering *diverse* lived experiences. Of the six lived experience experts who participated in the majority of the research agenda development process, two identified as Black or African American, one identified as Asian American, three identified as white, and all identified as women. (An additional lived expert who began with the project identified as male, Latinx, and Native American, but could not participate for the project duration). They represented five different U.S. states, spanning both coasts and the Midwest. Two were parents with histories of child welfare system involvement, two were young adults with foster care experience, one was a kinship caregiver (grandparent), and one was a foster caregiver. Still, survey and focus group participants raised concerns about whether this group of lived experience experts was *diverse enough* to provide an adequately rich range of perspective. For instance, some worried that most of the lived experience experts held largely negative views of the child welfare system and their experiences therein. On this issue, one survey respondent stated that “the range of voices didn’t get equal time, and the range should have been broader.”

One recommendation for funders is to ask researchers to be explicit about how they plan to recruit diverse experts and solicit diverse perspectives. Funders can also encourage grantees to hold “listening sessions” or offer other means

of gathering honest feedback, early in the project, about whether the range of perspectives included is sufficient. Funders could also require applicants to discuss if and how a DEI framework applies to their proposed project, which might be facilitated by offering guidance from the foundation or funding organization regarding DEI values.

B. Expand the pool of lived experience experts.

Another frequent concern had to do with the process of selecting specific lived experience experts for opportunities to participate in research projects. For example, one organization representative worried that a small circle of lived experience experts has been invited repeatedly to be involved with various child welfare-related efforts: “We’re tapping the same folks.” This issue was also raised by lived experience experts themselves, all of whom had prior experience in similar consulting roles, and some of whom have several years’ experience consulting for one or more of the foundations leading and funding the project.

This is a complex issue, of course, as lived experience experts with prior consulting experience may be more knowledgeable about research methods and concepts, making them easier partners to onboard. However, researchers and funders should be mindful of the potential limitations (and not just the obvious benefits) of repeatedly turning to the same few experts and advocates. For instance, funders could require researchers to engage new or different experts at various project stages, or when projects are renewed, perhaps retaining a subset of the original lived experience experts for continuity. Such a requirement, however, would need to be accompanied by additional funding for such efforts.

Funders can also point grantees and researchers to organizations that broker partnerships between researchers and lived experience experts. For instance, FosterClub, Inc. has brokered relationships between young people with foster care experience and project leadership, Generations United has recruited kinship foster caregivers and

grandparents who have raised children, and the Children’s Trust Fund Alliances’ Alliance National Parent Partnership Council has brokered relationships with parents who have had experience with the child welfare system. These and other organizations also provide support to lived experience experts serving as consultants (e.g., helping with tax form allocation, payment logistics, preparation, and ongoing support, and attending meetings with project leadership when needed). Again, though, funders should be mindful that it may require additional funding to support the work of those sponsoring organizations, and that various forms of contracts may have to be negotiated.

Rethinking Budgets

A. Outline equitable compensation procedures.

Another concern raised in focus groups and other conversations has to do with compensation procedures. In projects that include lived experience consultants as well as subject matter consultants or statistical consultants, there is the potential for rates and processes related to compensation to differ or even be starkly inequitable. As one survey respondent said, this issue “is worth unpacking.” Most organizations have various preexisting protocols and processes for determining compensation rates for consultants of all types, which may, for instance, undervalue lived experience experts compared with consultants who have expertise in research design or statistics. These differences should be acknowledged and considered carefully. Funders can provide guidance about compensating consultants in equitable ways, including the need to have transparent conversations and negotiations. In short, lived experience consultants should be compensated fairly and transparently, and they should have the same freedom to negotiate as other consultants.

B. Offer overall budget flexibility.

Budgets must account for the expenses involved in meaningfully engaging lived experience experts as project team members. It is best to anticipate and sufficiently budget for these expenses. Funders should prompt researchers to include these expenses in their budgets and set grant amounts to enable that to occur. Further, funders should be willing to fund each of the necessary stages of meaningful engagement, including orientation and rapport-building, data collection planning, review of initial research findings, and dissemination activities, as well as debriefing sessions. As one focus group participant told us, “You have to be willing to fund the messiness.”

C. Fund (and require) continuous quality improvement processes.

As mentioned above, regular check-in meetings or debriefing sessions with project partners are essential to head off problems and maintain the quality of the work. For example, the research agenda project relied on monthly video calls that included all lived experience experts, project leadership, and representatives from organizations that brokered relationships between experts and the project leadership team. These meetings were important spaces for addressing tensions and disagreements, building rapport, clarifying roles or uncertainties, airing disagreements, and so on. In addition, funders might find it beneficial to hold regular meetings with grantees to check in on their progress and the statuses of their partnerships with lived experience experts.

“I think if it’s not messy at some point, then that could signal that people are not being authentic.” – DEI Expert

Reshaping Timelines

A. Allow (and anticipate) flexible and extended timelines.

To the extent possible, funders should allow for some flexibility in setting and adhering to project timelines. For example, a number of survey and focus group recalled that the research agenda’s project timeline had to be extended and adapted multiple times as the project grew and evolved, and as project leadership worked to engage lived experience experts in more aspects of the project process — this flexibility was important to the project’s overall success, they concurred.

Funders and researchers must be aware that meetings, tasks, and efforts to build rapport often take longer than anticipated in projects that require a true partnership among participants who have little previous experience working together (such as researchers and lived experience experts). As one DEI expert put it, “There’s a balance between moving a project along and having a ‘high level’ of community engagement. In other words, it takes time to build trust, and there are external forces and timelines that don’t always allow for this.”

In addition, true partnership often involves translating research jargon, explaining

research-related concepts, and providing other support to lived experience experts who are not trained researchers — all of which can require significant amounts of time. Finally, efforts to build consensus around research-related issues tends to take longer in such partnerships than in traditional research projects. For instance, one respondent argued that collaboration between lived experience experts and researchers “takes more time, finding ways to synthesize all the perspectives.” Funders should keep this in mind when setting and evaluating research project timelines and deadlines for final products.

B. Invest in planning, relationship building, and other early-stage processes that ideally should occur before the primary research grants are obtained.

Funders should also consider investing in efforts to build strong relationships among community partners and lived experience stakeholders *prior to the start* of the research planning process. It is critically important that lived experience experts are brought into trusting relationships early on, so that they can engage in and contribute meaningfully to a kind of work (formal research) that is new to them. For instance, said one lived experience expert, “If this space is not comfortable, I will be very careful not to be vulnerable.”

During the work of the research agenda project, various participants discussed the need for something like a “Community Planning Grant” to support capacity building, co-design the research agenda, work out details of partnering, and other “front end” work not normally funded by traditional research funding mechanisms. Part of the capacity building will require transfer of some leadership in research to community-based agencies (e.g., trust-based philanthropy). Such a grant opportunity would allow traditional and university partnerships to acquiesce prior to application for research funding.

Modeling Change

A. Solicit feedback from grantees about whether the grant application and administration processes were conducive, in their view, to meaningful involvement of lived experience expertise.

One researcher, in one of the national Consensus Convening discussions on transforming research, asked “Do we ask funders for the flexibility we need? Or do we allow them to perpetuate the designs that we know are not working?” Indeed, funders can offer opportunities for grantees and applicants to provide feedback to funding organizations about the application process and grant administration procedures. This would help identify opportunities for change where needed and alleviate concerns from applicants that their feedback may jeopardize their opportunity for funding.

B. Include lived experience experts in funding organization operations.

Funders should consider including individuals with lived experience in the design of funding portfolios. For instance, the research agenda project leadership involved lived experience experts in the development and dissemination of its nineteen RFPs, inviting them to weigh in on the wording of the RFPs, the requirements for grant applicants, and the guidance on projects design — all of which strengthened the RFPs by clarifying the expectation that lived experience experts be defined as full partners in the proposed projects.

Funders can also involve lived experience experts in the grant review process (Rittenbach et al., 2019), which would bring rich new perspectives — grounded in insider knowledge about child and family welfare programs — into the work of assessing the quality of applicants’ plans for creating effective and equitable research partnerships. Feedback from these experts could then be provided to applicants and grantees, helping them to see where their plans fall short and how they might strengthen the roles they assign to their partners. This practice would also help funders to ensure that the research they choose to fund is

likely to have real-world impacts on children and families facing the challenges addressed by the proposed research.

C. Develop and publicize commitments to consistently funding and valuing lived experience engagement in research.

Funders should be clear in their intentions to value and fund research that meaningfully incorporates lived expertise, and they should make it known that they will honor these commitments over time. As one researcher in a consensus convening session explained, “The worry [is] that [lived experience engagement] might be a fad. How do you invest in an intervention if the funding isn’t sustainable?”

Funders can do several things to reassure researchers and potential grant applicants that they are committed to funding research that meaningfully engages with lived experience experts. First, funders can refrain from making applicants argue for the empirical value of lived experience expertise or defend their plans to meaningfully invest in lived experience partnerships using grant funds. (This was a concern for researchers who provided input for the development of this brief, and it was raised many times throughout the research agenda development process.) Second, funders can state clearly to applicants and grantees that they will continue to value, invest in, and prioritize lived experience expertise in research, and that they consider engagement with lived experience to be a social justice issue.

Third, funders can require *all grant applicants* to specify, in their proposal information, whether and how they will meaningfully engage people with lived experience in the proposed work — just as many funding agencies require applicants to specify their plans related to diversity, equity, and inclusion. This communicates to researchers and applicants that the funding organization is serious about this issue and wants every applicant to acknowledge and address it.

Finally, funders can also offer webinars or

other resources related to meaningful incorporation of lived experience in research, further communicating to applicants and grantees that this work is prioritized by the funding organization, as well as providing applicants with tools to address this issue successfully in grant applications.

D. Fund diverse, early-career, and first-time grantees.

Researchers and other project participants also mentioned that funders can promote lived experience involvement in research by diversifying who receives grant funding. For instance, they can state their strong commitment to funding early-career scholars and a more diverse group of researchers, including first-time grantees. This approach to funding a broader array of grantees may promote more lived experience involvement and community-engaged research.

Conclusion

Meaningfully engaging lived experience expertise in high-quality research requires significant determination, time, funding, and flexibility. As such, it can be daunting and difficult for researchers to meaningfully engage with lived experience experts while balancing concerns related to budgeting, scientific rigor, and traditional metrics used to assess successful projects and careers. However, funders are uniquely positioned to influence how the research community engages with and values lived experience expertise. As outlined above, funders can do several concrete things to promote meaningful lived experience engagement in research, including: (1) reshaping power dynamics, (2) minimizing the potential for tokenism and promoting co-design, (3) promoting diversity in lived experience, (4) rethinking budgets, (5) reshaping timelines, and (6) modeling change.

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