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Report on the Peter & Elizabeth Tower Foundation's
Participatory Design Process for Advisory Team Expansion: Methodology and Recommendations from Participants

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Background

Origins of the Tower Foundation's participatory approach

In 2019, the Peter & Elizabeth Tower Foundation conducted a human-centered design project that led the Foundation to explore how the principles of participatory philanthropy could apply to its work. The Tower Foundation partnered with Empower and People, Inc., two agencies in Western New York, to bring seven young adults with intellectual disabilities together as an Advisory Team. Their role was to review and offer feedback on proposals during two grant cycles in late 2019 and early 2020. Plans to expand the Advisory Team to new geographies in 2020 were put on hold as a result of the COVID-19 pandemic.

Members of the 2019-2020 Advisory Team and Tower Foundation staff

What is participatory philanthropy?

Participatory grantmaking has been used by members of the Funding Exchange since the 1970s to make decisions about grants in a way that includes people affected by funding decisions. Cynthia Gibson and Jen Bokoff define participatory grantmaking in Grantcraft's Deciding Together: "Participatory grantmaking cedes decision-making power about funding—including the strategy and criteria behind those decisions—to the very communities that funders aim to serve." **Participatory philanthropy** is a more expansive term that includes participatory evaluation, participatory strategy, participatory design, and advisory models.

The principles of participatory philanthropy are closely aligned with those of the global disability rights movement: "Nothing about us without us." The Disability Rights Fund is an influential practitioner of participatory philanthropy in this space: "The way we do our grantmaking models the inclusive society we aim to achieve. DRF's structure involves persons with disabilities at all levels, from advisory to staffing to governance."

In their recent article "How Funders Can Make Disability Visible" in the *Stanford Social Innovation Review*, Catherine Hyde Townsend and Bess Rothenberg also point to advisory models as an important way funders can include people with disabilities and disabled people: "Advisory groups have the advantage of building relationships between staff and disability leaders, fostering staff learning from members of the disability community, and gathering input directly from disabled people. While you might not be able to achieve everything all at once, it's critical to listen and understand before choosing priorities."

Benefits for funders and participants are plentiful, but funders must be intentional in shaping each process to provide benefits to participants that match or exceed what funders are receiving. Participants should be provided with compensation that recognizes their time and expertise and each process should be designed in a way that prioritizes their goals and needs alongside those of funders.

Expansion of the Advisory Team model

In Fall 2021, the Tower Foundation plans to expand the Advisory Team to include 10-12 advisors (ages 18-30) with lived expertise in one or more of their focus areas (intellectual disabilities, learning disabilities, mental health and substance use disorders) and geographies (Essex County, Cape Cod, Martha's Vineyard and Nantucket in Massachusetts; and Erie and Niagara Counties in New York). The Advisory Team will convene virtually to review a subset of grant applications during the August 2021 grantmaking cycle. The Advisory Team will not have a decision-making role, but advisors will influence decisions and their recommendations may be adopted by grantees and applicants.

Participatory design process for Advisory Team expansion

To align with their participatory approach and values, the Tower Foundation sought to involve young people with lived expertise in the Advisory Team's expansion from the start. The Foundation engaged a "Design Crew" of six youth designers and five agency designers nominated by agency partners across Tower's geographies and focus areas. Youth advisors were compensated for their time and agencies were offered honoraria.

The Design Crew addressed these key questions:

1. How can we create an Advisory Team experience where a diverse team of advisors can be successful?
2. How can we lift up the lived expertise of our advisors in our grantmaking?

After months of preparation, this Design Crew gathered for three facilitated group discussions in May 2021. This report describes the methodology used to convene the Design Crew and the outcomes of this process: the Design Crew's recommendations for expanding the Advisory Team.

Recommendations for strengthening participation

Through this participatory design process and their expanded advisory group model, the Tower Foundation is building a strong foundation for exploring more participatory approaches in the future. Here are some practical strategies that are aligned with the Foundation's values and current approach:

1. The Tower Foundation could bring young people with disabilities and young disabled people into leadership positions within the organization as staff or board members.
2. The Tower Foundation could allocate a portion of their grantmaking budget to a participatory grantmaking pilot that cedes more decision-making power about grants to participants.
3. The Tower Foundation could include participants in other aspects of their work, such as high-level strategy and goal-setting, or evaluation.

Methodology and assessment

Each area includes a brief description of the approach, the evaluator's assessment, and 3-4 recommendations that could be applied to similar processes in the future.

I. Preparation and team formation

Description:

1. The Foundation defined and clarified the parameters and limits for the participatory process. For example, the process would need to take place in a specific timeframe and participants would serve as advisors, not decision-makers.
2. The Foundation mapped the potential field of agency partners that could be involved, and prioritized discussions with staff at six key agencies. Tower Foundation staff met with these agencies to gather feedback to inform their approach, to share information, and to invite agencies to nominate designers.
3. After being introduced to youth designers by the agencies, Foundation staff conducted 30-minute orientation calls to provide information about the project, discuss roles and responsibilities, gather feedback, and answer questions.
4. Participants completed an onboarding form (including contact information and accommodations), and signed a release. They shared photos and written statements with the group, to help participants get to know one another.

Evaluator's assessment:

1. Parameters and limits were effectively communicated to participants and participants had a good understanding of their advisory roles.
2. The Foundation's approach to assessing the potential field of stakeholders was attuned to the scale and focus of this pilot. The Tower Foundation focused on established relationships with trusted agencies and drew on knowledge of the field built over many years.
3. Feedback from agencies shaped the design of the process in important ways and ensured that stakeholders were involved in a meaningful way from the start.
4. Relationships and information-sharing was prioritized from the start: one-on-one calls were important to strengthen relationships among participants and facilitators.

Evaluator's recommendations:

1. The parameters and limits set were appropriate for this process, but could be expanded in the future by ceding more power or broadening the scope of the inquiry.
2. Continue the good practice of reaching out to stakeholders during the formation of any participatory group and report back to stakeholders regularly.
3. Continue one-on-one onboarding calls and consider how else you can continue to prioritize relationship-building and information-sharing during onboarding.
4. If future endeavors are designed to increase diversity among participants, a more robust stakeholder mapping exercise could be included.

II. Program and session design

Description:

1. In February 2021, the Tower Foundation began to think about questions to explore with the Design Crew. Staff participated in a "how-might-we" brainstorming session, using a human-centered design approach. Staff organized questions by theme.
2. Staff prioritized areas where input was needed most and where members of the Design Crew would be able to apply their expertise effectively. Staff then used this information to create the goals for each session.
3. Informed by feedback from agencies and participants, staff designed three 90-minute sessions tailored to the needs of this group.
4. After each session, staff conducted a 30-minute debrief to reflect on what went well and what needed improvement, and adjusted future sessions accordingly.

Evaluator's assessment:

1. Openness to feedback and change demonstrated to participants that Tower staff were responsive to their needs, and also led to improvements in the design.
2. Involving more staff (beyond the core team of facilitators) in brainstorming brought more divergent perspectives and allowed more staff to participate.
3. Feedback from agencies shaped the process and outcomes. For instance, a simulation was important for giving participants a concrete idea of what the Advisory Team would be doing, which met participant needs.
4. Agendas for each session were packed, so the Foundation received less information about some priority questions, some topics were too challenging to address in the time available, and a few participants may have felt rushed.

Evaluator's recommendations:

1. Increase the number of sessions, conduct more one-on-one or paired activities outside of sessions, or focus on just one or two priority questions.
2. Build on this emergent approach: be open to changing and evolving the process as you gather feedback, and take time to prioritize learning and reflection.
3. Continue to involve Tower Foundation staff and agencies in process design. Experiment with ways to expand participation by also including the feedback of youth designers, such as calls or focus groups to gather early feedback on process design.

III. Facilitation and engagement

Description:
1. Tower Foundation staff roles: facilitators, technical support, observers, and participants. Three Foundation staff performed the role of active facilitators.
2. Tools: video conference, chat, pre-recorded videos with captions, slides, live surveys, word cloud generator, virtual post-its, and music.
3. Techniques and formats: breakouts, open plenaries, round robins, live surveys, simulations, paraphrasing, reporting, note-taking, clarifying questions, frontloading, framing, share-outs, check-ins/outs, ice-breakers, ground rules.
4. Engagement outside of meetings: gifts, compensation, honoraria, one-on-one calls, addressing accessibility needs, statements and photos from participants, agenda and materials sent by Email in advance of every meeting, one-on-one calls to gather feedback from participants not present during group sessions.

Evaluator's assessment:
1. Participants appreciated the attitudes of the facilitators and other staff. They appreciated that facilitators took an active rather than a neutral role, by sharing and actively participating in discussions and activities, building trust.
2. Facilitators adjusted their approach mid-stream in response to feedback, and included some structured approaches to better meet the needs of this group. For example, facilitators made use of clear speaking orders in Session III.
3. Participation was not even: some participants spoke significantly more than others and their ideas were featured more in discussions and outcomes.
4. Facilitation attitudes, approaches, and techniques were not similar across all three facilitators. This sometimes resulted in very different conversations and results for each breakout conversation, depending on who was facilitating.

Evaluator's recommendations:
1. Especially with a diverse group, prioritize the voices of those least heard within the group: analyze uneven participation and apply specific techniques to correct for it that respect the needs and preferences of participants.
2. Use facilitation techniques more consistently across topics and breakout groups. For example, facilitators should meet to agree on how questions will be framed and how and when techniques like clarifying questions and paraphrasing will be used, and practice these techniques together.
3. Avoid introducing new topics in an "ad-hoc" way, especially when topics are potentially challenging. Have a list of agreed-upon topics or activities on hand for times when conversation lags, or get comfortable with silence.

IV. Analysis and presentation of results

Description:
1. Group sessions were conducted over video conference and participants granted permission to be recorded. Recordings were shared only among staff.
2. Staff took notes using virtual post-its during group sessions, as a facilitation technique and to capture outcomes.
3. Participants were invited to respond to anonymous surveys at session end.
4. An evaluator has been embedded in the process since the project's inception and this report has been commissioned as a way to share outcomes with the Tower Foundation and all participants, as well as assess the process and its implementation.

Evaluator's assessment:
1. Documenting conversations using both notes and recordings was effective. Tower Foundation staff took notes during sessions to support facilitation and to interpret the ideas of participants. This was a useful technique, but recordings were also essential for capturing the words and ideas of participants accurately.
2. Despite the participatory approach to this design process, participants are not meaningfully involved in the analysis and presentation of the results.
3. Response rates to anonymous surveys were good for Session I and Session III, and insufficient feedback was received for Session II. Participants responded positively about their experience with tools, preparation, pacing, and opportunities to share, but little actionable feedback was collected through surveys that could be used to improve future processes.

Evaluator's recommendations:
1. Consistent with a participatory approach, create a process for participants to review and validate outcomes (like those presented in this report) to ensure results accurately reflect their ideas and intentions.
2. Continue to accommodate a range of learning styles and preferences when sharing results. Include video and visual formats in addition to written reports.
3. Respect rules around confidentiality, but consider offering participants the option to have their ideas attributed to them or to share short video or audio clips of them voicing their ideas.
4. Use multiple methods for gathering meaningful feedback on the process, including anonymous and non-anonymous options. Engage in a survey design process to ensure that the feedback you collect will be actionable.

Recommendations from participants

Summary
This report centers the ideas and words of the Design Crew, including both agency and youth participants. It summarizes recommendations for engaging an expanded Advisory Team across five categories:

I. Applying and valuing lived expertise
II. Group culture and dynamics
III. Structure and preparation
IV. Facilitation and roles
V. Sharing information

Program
The Design Crew convened for three group discussions in May 2021:
1. Session One: What makes a good team?
2. Session Two: What makes the Advisory Team worthwhile for everyone?
3. Session Three: What is the best way to review and collect proposal feedback? Where does my lived expertise fit into the grant review process?

Methodology for analysis
The recommendations presented here were produced through qualitative analysis of recordings of participant discussions across the three 90-minute sessions, and including one-on-one calls with participants between sessions when applicable. This analysis centers the words and ideas of agency and youth designers, and does not include the comments of Tower Foundation staff or consultants who will have other opportunities to influence the Advisory Team's expansion. In each category, anonymous direct quotes from participants are also included to bring concepts to life and to center the words of participants.

The results of this qualitative analysis have not been reviewed or validated by participants.

I. Applying and valuing lived expertise

Recommendations from participants:

1. Name and address challenges that may arise for youth that are participating in a process where they are applying their lived expertise to financial decisions:
   a. Be open about difficult emotions that may arise when decisions involve people they may identify with through their lived expertise.
   b. Create space in the process to address trauma around money that participants with lived expertise may carry.
2. Convene a diverse group of participants that bring different types of lived expertise into the process.
3. Value the lived expertise of participants:
   a. Give them real power and real influence over outcomes.
   b. Give them time and space to share their experiences.
   c. Demonstrate how their ideas have had an impact.
   d. Provide them with appropriate compensation.

I appreciate being listened to, and I feel very strong about this.

The emotion that can get pulled into that, if you're saying that these people don't deserve this money: I'm one of those people! Or even just the emotional thing behind how some people feel about not having money or about having been in place at one point in your life you would have been asking for a grant like this or a program you've depended on kind of been asking for a grant like this. Maybe just starting with an acknowledgement of what this can bring up for people.

There's just some fields in life that you have to have the lived experience to be able to relate to the people you're dealing with. You can have the smartest brain in the world, but if you can't relate to people, it doesn't matter. With grants, you got to have folks that come from the trenches, in my opinion.

Everyone has their own lived experience. That's what really brings meaning. Those lived experiences, talking about what you've been through.

II. Group culture and dynamics

Recommendations from participants:

1. Center relationships in facilitation and design, so that participants can build a foundation for meaningful work and connection.
2. A welcoming and respectful culture creates a space where participants can share, ask questions, and express and advocate for their own needs.
3. Agreements about confidentiality and anonymity are important when you are discussing sensitive topics that touch on personal experiences.
4. Participants should share an openness to and enthusiasm for learning about the experiences of others, even when those experiences are different.

I need mutual respect, general open mindedness to new ideas and active listening that we share with one another. And generally flexibility and understanding of everyone's unique circumstances and how they also work within the team.

I would say something for me would be advocating for yourself, as weird as that sounds. When you deal with things personally, you may not always be able to stand up for yourself or voice those struggles, even in a professional setting, because it feels so professional. You think, why would you bring your personal stuff to the situation? But in reality everyone has this baggage and everyone goes through stuff.

I want to feel more love and more connection to people. Like hear them out, listen to their story. That's what I wanna do.

III. Structure and preparation

Recommendations from participants:

1. Consider structured facilitation formats that make it easy for people to track when they are invited to contribute to a conversation. Consider restorative practices that participants may already be familiar with, such as using a clear speaking order, to create a space where everyone feels heard and valued.

2. Make sure the process is organized and that there are people involved that can help others to track conversations and maintain focus, but balance the need for structure and focus with the need to give participants space to think creatively.

3. Preparation is just as critical as structure for building comfort with the process and ensuring it is accessible to all participants:
   a. Send out orientation materials by mail and digitally well in advance.
   b. Include background on Tower, including case studies featuring past grantees and funded projects. Include additional context about philanthropy that young people can relate to.
   c. Do not assume all participants have the same level of familiarity with the tools and approaches used. Consider providing a group orientation.
   d. Provide participants with agendas, topics, and questions well in advance and continue to connect with them one-on-one.

Sometimes it's hard to know when to jump in and there can be a little hesitation. In a non-virtual setting, it's a lot easier to read people's cues, there's no lagging technology. I think that virtually, it's nice if we have something where one person is facilitating the order, and there's a way to know who's going to speak next.

Sometimes people assume that youth are able to participate in some rituals and methods that we as adults are used to but that is not always the case.

I learned that one of the most important things is being prepared. While it is kind of difficult to keep teenagers engaged, have those questions ready, engage with them and encourage everyone to speak. It really does help the conversation flow and it leads to a lot of meaningful experiences that can come out of those conversations.

IV. Facilitation and roles

Recommendations from participants:

1. Create a role for people with agency experience in the advisory team process in order to include these experiences and foster these connections.
2. Involve facilitators who are skilled in working with groups, who are humble and open to learning, and who express passion about these topics. Ensure that everyone involved in the process is on equal footing and that facilitators and adult participants are sharing and actively participating.
3. Specific tools and techniques highlighted by participants:
   A. Provide participants with structured ways to reflect and share feedback.
      a. A notebook (physical and virtual) that includes space for journaling, note-taking, and responding to prompts.
      b. A structured rubric for participants to reference as they are receiving information, to support them in applying their expertise.
   B. Include breakouts, pair work, and other small group discussion formats that allow participants to form meaningful connections.
   C. Provide opportunities for joy and connection: online games, dance and movement, music, food deliveries, and polling tools.
   D. Consider how the language you are using and the content you are including aligns with the interests and needs of participants.

> *A lot of adults walk around the world with the air of 'I know everything' and that can be very scary to young people. Right from the beginning, being able to talk about an experience can level the playing field or show you've been in their shoes.*
>
> *It sometimes reads as a power imbalance when you have youth and one or two agency folks that are just observing and not contributing to the conversation. Having them be an active part of the conversation promotes more sharing.*
>
> *Having the opportunity to ask kids about their language. What does this mean to you and why do you use it? Why is it important to you?*

V. Sharing information

Recommendations from participants:

1. Present information in multiple formats to accommodate diverse learning styles and preferences within the group.
2. Continue using video to present information and consider these improvements:
    a. Break the video presentation into clear sections.
    b. Include more visuals.
    c. Include lists to organize information.
    d. Include captions and transcripts.
3. Focus on the experiences of people involved with the projects, including testimonials. Consider having advisors connect directly with funds seekers.
4. Consider how presentation formats or performances might insert bias into the process or influence outcomes. Standardize presentations and provide funds seekers with guidelines about what information may be useful to the group.

Maybe resonating more to the outcomes that the students have from that experience rather than what they'll experience while they're there. All the little pictures and little videos were incorporated from some real experience. I think that more of that would be important for people to apply that to their own perception.

I really liked the pictures and when there was a breakdown written out, whether talking about food or transportation. I know that might have just been there to explain the numbers, but I think it would have been helpful to have that visual aid there in general for a lot of what was being said.

So speaking for myself with my learning style, I would need more. I'm a learner that holds things in my hand, highlights, and takes notes. I need to grab certain things out. I need a little bit more time. That's my learning style.

Acknowledgments

The Tower Foundation is grateful to all of the people and grant partners who came together to re-design the Advisory Team.

2021 Design Team

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