ABSTRACT

Title of Thesis:	HOW DO NONPROFITS INVOLVE BENEFICIARIES IN THE DESIGN OF MISSION PROGRAMS AND SERVICES
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Human service nonprofits play an important role in communities across the United States. While existing research has studied how nonprofits engage beneficiaries in the evaluation of services, little research has been done to understand how human service nonprofits involve beneficiaries in the design of services. This research argues participatory design can be used to engage beneficiaries in program design. Through semi-structured interviews conducted with nine human service nonprofit professionals, this research sought to better understand how human service nonprofits involve beneficiaries in the design and development of service programs; and what barriers exist for human service nonprofits to do participatory design. These research findings provide a foundational understanding of how human service nonprofits use participatory design and uncover barriers to help inform the solutions necessary to increase participatory design use at human service nonprofits.

HOW DO NONPROFITS INVOLVE BENEFICIARIES IN THE DESIGN OF MISSION PROGRAMS AND SERVICES

by

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Chapter 1: Introduction

According to the Nonprofit Trends and Impact 2021 report, there are 1.8 million nonprofit organizations in the United States (Faulk et al. 2021). Nonprofits play an important role in providing goods and services to communities across the country. The Nonprofit Trends and Impact 2021 report also found all nonprofits provide services to a diverse and broad range of people. Fifty-five percent of nonprofits reported having programs and services offered to the public (Faulk et al. 2021). This means the recipients of nonprofit services overall, or the end-users, are diverse. With such a large number of diverse users, the nonprofit sector is an excellent industry to study and explore opportunities for participatory design.

This research draws on a core concept of Human-Computer Interaction, “design for all.” When executed through participatory design methods, design for all can be used to inform how all human service nonprofits operate and engage with the people intended to benefit from their services. Human service nonprofits, like software or social media companies, are designing products and services meant for public consumption and they are specifically designing for groups that have been historically marginalized. The HCI pillar of “design for all” explored through participatory design methods in the nonprofit sector allows us to more fully understand how program design does or does not involve service users.

Participatory design in the nonprofit sector could help facilitate deeper involvement and engagement between nonprofits and beneficiaries. Historically, beneficiaries have been perceived as passive recipients of social services and programs (Benjamin, 2020). However, when beneficiaries take on more active roles, it appears both individuals and organizations are positively impacted. For example, researchers found co-production engagement methods helped reframe young people who had interacted with social services as “active participants possessing agency, creativity, and insight rather than the passive subjects of others’ pronouncements (often of their problems and deficits)” (Heron & Steckley, 2020, p. 11). Participatory design could help nonprofits move from perceiving beneficiaries as passive recipients to active players in the services they seek and receive.

Despite the advantages of involving beneficiaries in the design of nonprofit services, most of the nonprofit literature that mentions beneficiaries is focused on the evaluation of services. Studies about nonprofit evaluation seek to understand the influence beneficiaries have over evaluations and program results (Fine et al. 2000; MacIndoe & Barman, 2013). Similarly, researchers have studied how beneficiaries’ program outcomes impact nonprofits’ performance as it relates to funding (Benjamin, 2021; Campbell & Lambright, 2016). There has also been research conducted about the methods used to collect feedback from beneficiaries about programs (Campbell, 2010). Lastly, program evaluation and accountability to beneficiaries has also been examined (Kingston et al. 2020).

The role of beneficiaries in evaluations has been studied in detail. However, evaluation studies look at the role of beneficiaries after nonprofit programs and services have already been developed and launched in communities. The study of beneficiaries’ role in the design of programs and services has not been well-documented in research about nonprofits or nonprofit management literature (Amann and & Sleigh, 2021; Benjamin, 2020; Bopp & Voida, 2020). More recently, researchers who study the nonprofit sector have started to reconsider the role of beneficiaries at nonprofits through the perspective of co-production (Benjamin, 2020), but not specifically participatory design.

The limited focus on the engagement of beneficiaries in the design of nonprofit services is problematic because of the positive outcomes participatory design could offer the nonprofit sector. Participatory design is a method that can be used to empower and involve those people traditionally undervalued in society in decision-making roles. In theory, empowering beneficiaries should be aligned with nonprofit missions to engage with typically underserved groups. In fact, increasing participation of end-users and stakeholders in decision-making processes are both found to increase users' influence over an organization (Vamstad, 2012) and users perceive beneficiaries' influence to have a positive influence on the quality of program services provided (Wellens & Jegers, 2016). Putting beneficiaries in decision-making roles doesn't just benefit the nonprofit, it is also shown to increase the advocacy activities a nonprofit participates in (Guo & Saxton, 2010). Aspects of participatory design could help foster an environment of workplace democracy within nonprofits. Workplace democracy could create nonprofit organizations that are more accountable to the wants and needs of beneficiaries (King & Griffin, 2019).

With those positive aspects of participatory design in mind, this research focuses on better understanding the participatory design landscape in the nonprofit sector. The goal of this research is to also develop a foundational awareness about the barriers nonprofits may face to implementing participatory design. Although nonprofits are often founded with the intention to address certain needs for a specific group of people, the group of people meant to benefit from the services are not always consulted on what their true need is. One Laptop Per Child clearly shows the pitfalls of a top-down nonprofit approach to program design (Janzer & Weinstein, 2014).

To better understand this behavior, I chose to interview nonprofit human service professionals about client engagement practices at their organizations. The type of organization was limited to human service nonprofits because human service nonprofits are more likely to work directly with clients than other types of nonprofits like associations or research and public policy think tanks. In addition, the small number of existing literature examples of participatory design in the nonprofit sector occur at human service nonprofits.

To answer our research questions, I conducted semi-structured interviews with nine human service nonprofit professionals, focusing on the following questions:

1. How do human service nonprofit organizations involve clients in the design and development of service programs?
2. Why are clients not involved? What barriers exist for human service nonprofits to do participatory design?
3. What were participants' reactions to participatory design?

I found human service nonprofits are implementing participatory design at various engagement levels. I also found human service nonprofits are facing barriers to doing participatory design.

This research is organized in the following chapters: Chapter 2 reviews the possible value of using participatory design in the nonprofit sector, documented ways participatory design has been used at nonprofits, and reasons why it may not be used by nonprofits. Chapter 3 discusses the methods used to conduct this research. In Chapter 4 the research results are organized into two main themes: the current state of participatory design in the nonprofit sector and the barriers nonprofits seem to be facing to implementing participatory design. Each theme is organized further by subthemes. In Chapter 5, I discuss the implications of these findings and recommend next steps to further study participatory design in the nonprofit sector.

1.1 Positionality and Standpoint

Based on my real-world experience working for nonprofits and studying Human-Computer Interaction (HCI), I believe there is an opportunity to better support client involvement in the design process of human services through the method of participatory design. I worked in the nonprofit sector for six years before starting my graduate program in HCI. I am familiar with the inner workings of the nonprofit sector and feel strongly that nonprofits can play a positive role in the lives of individuals and communities. I had also previously made a monetary donation to P2/P3's organization. My experience and motivations play a large role in shaping my research questions. The principal investigator is conducting similar research related to democratizing design and has studied how to include marginalized populations equitability and without harm in participatory design practices.

Chapter 2: Related Work

The related work is organized into three sections: the value of using participatory design in the nonprofit sector, examples of how participatory design has been used to date by nonprofits, and the current understanding of why participatory design has not been used by nonprofits.

While the value proposition of participatory design for nonprofits is clear, the understanding of the current nonprofit use of participatory design is unclear. Based on our findings, there are only a few academic research reports about the nonprofit experience of using participatory design. Often when similar processes are studied, they occur during nonprofit evaluations and are more likely related to co-production. One of the largest areas to learn more about then is why more nonprofits are not doing participatory design.

2.1 Participatory Design as a Tool for Nonprofit Organizations

Participatory design started as a tool by and for Scandinavian trade unions to foster the co-creation of democratic solutions in the workplace (Pilemalm, 2018). Participatory design was then adopted in North America. In the United States, participatory design has less of a democratic context and focuses more on user tasks and design processes (Pilemalm, 2018). In this research, I focus on participatory design more in the Scandinavian tradition.

The purpose of participatory design in the Scandinavian tradition is grounded in democratic decision making. When used in the nonprofit sector, participatory design can be used to empower beneficiaries by including them in the design process of services and creating services to better meet their needs. This is valuable for several reasons. When used with intentionality, participatory design can be used as a method for “community accountability and control” (Costanza-Chock, 2020). Participatory design then is a method to help nonprofits become more accountable to beneficiaries and put beneficiaries in positions of leadership.

When beneficiaries are in positions of leadership, they are more likely to have opportunities to influence decision-making. In a 2012 empirical study, researchers looked at how parents and preschool teachers perceived service quality at municipal schools and cooperative schools. Researchers found that nearly 80 percent of parents (78.4 percent) at the cooperative schools saw working at the preschool as a source of influence. A similar number of parents thought ‘meetings with power to decide’ (79.7 percent) and informal talks’ with the staff (75.6 percent) also gave them influence at cooperative schools. Overall, the parents with students enrolled in cooperative schools thought they had more influence than parents with children attending municipal schools (Vamstad, 2012).

When beneficiaries have more influence, they may also be more likely to have influence over program and service decisions. In fact, just the idea of beneficiaries being more involved in decision making processes is perceived to increase service quality levels. In a 2016 survey of 790 nonprofits, 77 percent of respondents said beneficiaries’ impact on decision making could increase the quality of services provided. Seventy-seven percent of respondents also said beneficiaries’ impact on decision making could include better representation of beneficiaries’ interests (Wellens & Jegers, 2016). While this study asked how people perceived service quality levels and did not measure actual impact, it is still a relevant and interesting finding as it relates to participatory design in the nonprofit sector.

Advantages of beneficiary involvement in program decisions can extend beyond an organization's internal operations. In a survey of 174 nonprofits, 33 percent of which were human service organizations, Guo & Saxton (2010) found when beneficiaries are involved in decision making within their nonprofits, nonprofits also tend to be more involved with advocacy efforts including activities like grassroots lobbying. Their findings indicate when "constituent board membership, communication with constituents, and level of constituent involvement in strategies decision making" increases, the advocacy activities of that nonprofit increase and intensifies (Guo & Saxton, 2010).

Overall, utilizing participatory design techniques at nonprofits can create situations that lean toward and support workplace democracy. Workplace democracy at nonprofits is defined as "encompassing features such as collective decision making, equity, and autonomy over and within the workplace to produce good work" (King & Griffin, 2019, p. 914). Based on their analysis of numerous research studies across a diverse range of disciplines, King and Griffin argued that nonprofits' "internal mode of operating could be considered integral to their social mission" and "increasing internal forms of democracy [nonprofit organizations] can be more accountable and representative of their members' needs and interests" (King & Griffin, 2019, p. 923-914). King and Griffin believed workplace democracy could "be considered as prefigurative, reflexive of the types of societal changes that nonprofits seek to bring about."

Participatory design is a valuable research technique to help in the design and development of mission programs. In theory, it is aligned with nonprofits' mission to support beneficiaries, in practice, participatory design creates pathways to put that mission into action. However, despite these benefits, the literature shows participatory design is only happening in the nonprofit sector at a small scale, in specific fields like evaluation.

2.2 How Nonprofits are Using Participatory Design-Like Methods

When participatory design-like methods are used, they are mostly used after the program design phase, during program evaluation. Some studies about nonprofit evaluation are focused on understanding the influence beneficiaries have over evaluations and program outcomes. For example, in a study of 379 nonprofits in Boston, 25 percent of nonprofit manager respondents thought beneficiaries would influence the decision to implement outcome measurements. This was lower than the influence of board of directors (62 percent) and staff (49 percent). Outcome measurements were defined as "organizational practice that seeks to quantify the impact of a nonprofit's programs/services on clients" (MacIndoe & Barman, 2013, p. 717). Similarly, a national survey of 178 nonprofits, indicated that 41 percent of the survey respondents, "fell within the low stakeholder participation level" (Fine et al., 2000, p. 5), meaning they had little to no stakeholder involvement in the evaluation process. Evaluation process activities were defined as: planning/designing the valuation; collecting data; analyzing/interpreting results; and writing a report. While this study defined stakeholders as program staff, funder's staff, board members, and program participants/clients; the participation levels in evaluation activities were not organized by stakeholder role (Fine et al., 2000). Interestingly, 73 percent of respondents said they would use evaluation to change program design or operations even though nearly half, 41 percent, had little to no stakeholder involvement in the design of the evaluation (Fine et al., 2000).

In addition, 67 percent of survey respondents who had recently conducted an evaluation, used a mix of qualitative and quantitative data collection methods.

> "For survey respondents, the most commonly reported data collection method was review of program documents (84 percent), **followed by individual interviews (66 percent),** observation (50 percent), written questionnaires (42 percent), **focus groups or group discussions (33 percent),** and tests of knowledge or skills (19 percent)" (Fine et al., 2000, p. 4).

The report results do not state who interviews and group discussions were conducted with; or if they were conducted with beneficiaries.

However, multiple researchers have studied the methods used to collect feedback about programs from beneficiaries and how nonprofits feel about these methods. In a survey of 77 nonprofit leaders and staff, as well as focus groups, a 2010 study found "[nonprofits] perceive the tools they use to gather feedback and the data they collect to be of inconsistent value" (Campbell, 2010, p. 4). Overall, nearly half (41 percent) of leaders and staff said the feedback activities only "sometimes result in organizational change."

The study findings further demonstrated survey respondents were dissatisfied with beneficiary surveys created by funders because the surveys are "imprecise and do not provide useful information" (Campbell, 2010, p. 4). The respondents also felt the surveys didn't provide enough insight for the organization to then make improvements to their programs. However, while study participants were interested in qualitative methods because they "would enable workers to develop greater knowledge of what works and does not work for service recipients," study participants said they often did not use these methods because they were expensive and not supported by funders (Campbell, 2010, p. 5).

When methods used to engage beneficiaries in feedback were studied again in a survey of 14 public charities and interviews with 20 nonprofits, researchers found most nonprofits used satisfaction surveys (67 percent) to seek feedback from beneficiaries, about half (49 percent) conducted interviews with beneficiaries (Campbell & Lambright, 2016). Although this is a different study, six years later surveys were still the main method nonprofits were using to engage beneficiaries in feedback.

In addition to beneficiaries' engagement in nonprofit evaluation, one study examined how staff and beneficiaries could make decisions together through co-determination. Based on 47 interviews with nonprofit staff, Benjamin & Campbell coded 279 "distinct blocks of interview text" in which social agency staff were working with beneficiaries in a way that they called "co-determination." Co-determination was described as "(a) establishing a relationship, (b) working out an agenda, and (c) taking action." Frontline staff used these methods as a way to accomplish the organization's goals and beneficiaries' goals. While these were not explicitly participatory design methods, it is an interesting concept and is an example of participatory design-like methods during nonprofit service delivery, not evaluation (Benjamin & Campbell, 2015).

There are many examples of beneficiary engagement in evaluations, but not many nonprofit organizations are engaging beneficiaries in the design of mission programs and services. Those that do look at beneficiary engagement, do so from the perspective of co-production. For example, Benjamin's review of three well-known nonprofit research journals during a 10-year period found, "only 5% of empirical studies mentioned beneficiaries in abstract, title or keyword; half of these included info about beneficiaries inside nonprofit, and only 5 explicitly discussed co-production" (Benjamin, 2020). Similarly, Amann and Sleigh's review of co-production research conducted with vulnerable populations during a 20-year time found 93-related articles and included 32 articles in their final analysis. While the databases they looked in were not specifically about the nonprofit sector they found, "Articles reporting co-production of healthcare services through research were most common, followed by environmental services (e.g., water resource management), and two articles reporting on social services and public safety services, respectively" (Amann & Sleigh, 2021). In addition, in a systematic review of 145 HCI publications during a 35-year period Bopp and Voida found beneficiaries were "engaged with and considered less than any other stakeholder group" in research where nonprofit organizations were mentioned (Bopp & Voida, 2020).

Although the comprehensive literature review shows there is limited research overall about participatory design in the nonprofit sector, there are some documented instances of nonprofits using participatory design methods to design programs and services. For example, Aboriginal community members in rural Australia were engaged in the design of youth justice programs. Beneficiaries and stakeholders participated in 18 interviews and informed efforts to improve the cultural legitimacy of the youth justice nonprofit program (Butcher et al. 2020).

Researchers in Uganda collaborated with a nonprofit to improve the experience stakeholders were having with a rural water management system. Together, they used co-design methods to engage community members in designing solutions (Ssozi-Mugarura et al. 2016). In Nepal, sex trafficking survivors participating in nonprofit services were asked to take pictures of anything they wanted to inform the nonprofit's support practices (Gauntam et al. 2018). While the individual participatory design examples are helpful, they do not give an overview of the nonprofit and participatory design landscape or help us understand the barriers nonprofits face to using participatory design.

2.3 Understanding Why Nonprofits May Not Use Participatory Design

There are a few clues in the existing literature that hint at why nonprofits do not use participatory design. However, none of these barriers were the focus of the studies I found. Instead, barriers were mentioned as research challenges or limitations throughout the papers, including in the discussion section.

For example, those few research studies that have used methods similar to participatory design noted that limited guidance was a challenge for them during the research studies. In a 2018 evaluation of young cancer patients as co-researchers and collaborators, the study researchers stated, "one of our early challenges was the lack of published guidance or examples of PPIE (patient and public involvement and engagement) in research, particularly when working with young people" (Taylor et al. 2018, p. 2). It is important to note although this was stated in the research paper, additional details around this observation were not provided by the authors.

A study from Isham et al. (2018) explored the role of advisory fora in research. Advisory fora are also called stakeholder groups and are usually organized to provide feedback and oversight of participant involved research. When reviewing literature for their study, the researchers commented,

> "It is difficult to assess what the advisory fore landscape is, or the frequency and complexity of ethical or welfare issues that arise when working in such spaces. In turn, **this makes it difficult to ascertain how researchers go about identifying and supporting advisors and the degree to which this work overlaps with the more visible and narrative practices of working with research participants** or co-advisors, particularly those with complex or additional needs" (Isham et al. 2018, p. 13).

When considering the nonprofit sector specifically, limited guidance was also observed by Benjamin in her 2020 research. In a review of 57 texts over 24 years, she found less than half, 18 or 32 percent, mentioned beneficiaries or a similar term in the table of contents. Furthermore, 33 percent of the books mentioned beneficiaries under evaluation. Likewise, when reviewing the books with indexes, 12 (36 percent) of the books discussed beneficiaries in marketing chapters, 6 (18 percent) in governance chapters, and 5 (15 percent) in evaluation chapters. Benjamin appropriately asks,

> "Although the tables of contents and indexes are imperfect proxies for how well we are preparing nonprofit leaders to understand beneficiaries' roles in their organizations and may miss other types of material educators use in the classroom, this analysis raises the question: **why aren't beneficiaries more central to [nonprofit management] education?**" (Benjamin, 2020, p. 13).

It's not only that there is no guidebook about how to include beneficiaries in participatory design, but nonprofit managers have reported that when organizations want to learn about beneficiaries' needs, they tend to use more informal methods, that may require less time and less advanced training.

For example, Wellens & Jegers (2016) wanted to understand, "which mechanisms do NPOs use to elicit from beneficiaries information on their needs and/or to allow them to have impact on organizational policy making?" (p. 299). Through their survey of 790 nonprofit managers, they found 35 percent of managers (out of 703 who answered this question) used "informal" rather than "formal" mechanisms to gain insight into beneficiaries' needs.

In addition to the lack of structures to support beneficiaries' input, Wellens & Jegers (2016) also found nonprofit managers perceive beneficiaries' impact on organizational policy as less important than other stakeholders' impact. It is difficult to say whether managers feel this way because there are no formal structures to gather insight from beneficiaries, or if there are no formal structures *because* beneficiaries' input is perceived as less important.

Researchers also claim there may be organizational barriers within nonprofits that don't support or align with participatory design. Based on their 2019 literature analysis, King and Griffin, suggested nonprofits feel too many decision makers and people with input power, in this case, beneficiaries, will slow down the organization's decision-making process. Other studies that mentioned organizational capacity as a constraint do not go into detail. Findings about constraints were limited to a line or two in the paper's introduction and discussion sections (Abrines Juame et al. 2015; Aljaberi, 2018; Taylor et al. 2018). Lastly, and more interesting, in Benjamin and Campbell's 2015 study of social workers, they found social workers intentionally and purposefully limit their engagement with beneficiaries because of the training they have received. Front line staff are coached to maintain boundaries and professional working relationships with beneficiaries.

2.2 Summary of Related Work

The current understanding of nonprofit barriers to participatory design is unclear. Some research suggests there are not enough training resources about how nonprofits should do participatory design. Other research points to a lack of formal structures. Finally, constraints like staff capacity are not well documented in existing studies. Through this research, I hope to use empirical data to create a better understanding of the barriers human service nonprofits face when trying to do participatory design. This understanding will contribute to possible solutions and design interventions that in the future could help nonprofits implement participatory design with beneficiaries and as a result could empower beneficiaries at those nonprofits.

Chapter 3: Methods

I interviewed nine human service nonprofit professionals about their experience developing and designing services and programs. During the interviews, I asked participants questions about their nonprofit programs and current client engagement practices. I then presented a stimulus about another nonprofit's experience using participatory design. The purpose of the stimulus was to teach study informants about participatory design methods. Once informants and the interviewer had a shared understanding of participatory design, I asked them questions to better understand if participatory design was something they could see doing at their organization.

3.1 Data Collection

I initially considered conducting a survey of human service nonprofit professionals to learn about their client engagement current practices. However, there were two main concerns about using a survey to collect this data. I wanted to understand the rates of nonprofits doing participatory design and as the research questions evolved, I also wanted to understand the barriers to nonprofit participatory design practices with clients. The data about nonprofit barriers to participatory design would not have been easily collected through a survey because I could not have provided all possible barriers in the form of a multiple-choice question or easily analyzed several open-ended responses.

In addition, and more importantly, because the current literature suggests there are not a lot of nonprofits practicing participatory design with clients, I was concerned there would be a high risk of misinterpretation about the definition of participatory design. With this information in mind, I decided to conduct semi-structured interviews with informants to help to ensure a complete understanding of the participatory design concept by the informants when answering the study questions.

3.2 Settings and Participants

I conducted outreach through email and LinkedIn to find participants for the interview study from September 2021 through January 2022. Potential study participants were limited to individuals with nonprofit program development experience and individuals who were currently working at human service nonprofits or had worked there within the last five years. Study participants also had to be at least 18 years old.

Human service organizations make up 35 percent of all nonprofits (The Nonprofit Sector in Brief, 2019). Human service nonprofits include children's and family services; food banks, food pantries, and food distribution; homeless services; multipurpose human service organizations; rescue missions; social services; youth development, shelter, and crisis services (Charity Navigator).

The informants could be located anywhere in the United States. I did not extend the research pool to include participants from outside the United States because of concerns related to different nonprofit laws and structures.

Table 1 shows the demographics of the participants I interviewed. All the participants were currently employed at a human service nonprofit except one participant, P9, who had been employed at once in the last 5 years. Six of the participants were working in leadership roles, two were in management roles and one was a grant writer. The participants worked at varied kinds of human service nonprofits across workforce development, housing, food insecurity, and sexual assault/mental health domains. The organizations varied in program cost size and age.

Table 1. Participant Demographics

Participant	Participant Role in Organization	Type of Organization	Approximate Organization Age in Years	Location	Approximate Total 2020 Program Service Expenses
P1	Program Manager	Sexual assault survivor and loved one's services	7 years old	Southeast, US	$125,000
P2*	Grant Writer	Workforce services	10 years old	Northeast, US	$500,000**
P3*	Executive Director	Workforce services	10 years old	Northeast, US	$500,000**
P4	Program Director	Food Bank services	40 years old	Northeast, US	$67,000,000
P5	Executive Director	Housing services	40 years old	Northeast, US	$4,000,000
P6	Program Director	Disabilities workforce services	30 years old	Northeast, US	$12,000,000
P7	Executive Director	Homelessness services	More than 50 years old	Northeast, US	$1,800,000
P8	Executive Director	Mental health and sexual assault services	30 years old	Northeast, US	$5,000,000
P9***	Program Manager	Homelessness services	More than 50 years old	Midwest, US	$6,000,000**
*P2 and P3 worked at the same organization. ** Expenses are from 2019 *** Employed at nonprofit within the last five years					

3.3 Procedure and Materials

A semi-structured interview format was used with all participants. During the interviews, I asked informants questions about their roles and organizations' programs. Informants were asked about their current engagement methods with program beneficiaries. I then shared the stimulus and talked about what participatory design was and how it can be used. After reaching a shared understanding of participatory design, I asked about the informants' perceptions of participatory design and how they could or could not see this method fitting into their organization practices. All interviews were conducted remotely using Zoom and usually lasted 40 minutes to 1 hour. Interviews were recorded with the participants' permission and later transcribed using Otter.ai.

Before conducting the interviews, I designed a stimulus based on a 2016 paper about participatory design at a food pantry in Brisbane, Australia (Snow et al. 2016). I then conducted two co-design sessions with two nonprofit practitioners from different organizations. The purpose of the co-design sessions was to test the effectiveness of the stimulus to support explaining how participatory design may work at a nonprofit organization.

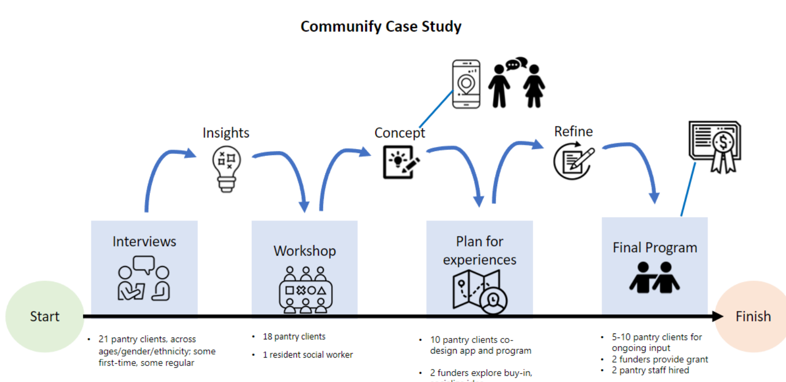
Based on these co-design sessions, I revised the stimulus and study procedure in several ways to improve actual research study outcomes. During the co-design sessions, there was some confusion by one informant about the language used to describe participatory design and related research methods. I changed the language to be less academic and Human-Computer Interaction focused and more reflective of language used by nonprofit practitioners. For example, I did not mention participatory design as the method until after the presentation of the stimulus and instead described the process as an engagement method.

A key piece of understanding for informants is that participatory design outcomes do not need to result in technology. One of the co-design informants shared this was not clear so I revised the stimulus outcome to demonstrate a service program had been created in addition to a new mobile application.

Lastly, one of the co-design informants mentioned they could imagine using participatory design with stakeholders instead of nonprofit clients. In response, I included other sections in the stimulus to show where stakeholders would be involved and clarified the focus of the participatory design was with those individuals receiving nonprofit services.

Following the two co-design sessions, I continued to refine the stimulus and discuss the iterations with the principal investigator. The stimulus went through a total of four versions before it was finalized. A screenshot of the stimulus is available below. A full copy of the final procedure script and stimulus are available in the Appendices.

Image 1. Page 1 of 2 of the Stimulus



3.4 Data Analysis

In total, nine participants were interviewed between September 2021 and January 2022. The interview transcripts were uploaded to Nvivo and analyzed using the grounded theory method. Grounded theory supports analyzing qualitative data to identify reoccurring themes and ideas. During the coding, process transcripts were closely reviewed using initial coding and then intermediate coding. Initial coding is the process of comparing qualitative data and finding patterns in the data. In this cas,e several codes were created first and then combined during intermediate coding once overarching themes and theories had been identified. Intermediate coding "transforms basic data into more abstract concepts allowing the theory to emerge from the data" (Chun Tie et al. 2019). The data in this research was organized with the purpose of identifying key themes about why human service nonprofits do not do participatory design. As the themes evolved, they also included themes about the current state of participatory design in the nonprofit sector.

About six and half hours of interviews were transcribed and analyzed in Nvivo. The interviews were analyzed and supported by writing preliminary analytic memos. The analysis was focused on understanding barriers to doing participatory design. The initial round of codes was focused on the aspiration gap: the gap between nonprofits having a culture of centering clients and the realities of actually doing participatory design to facilitate that engagement. The aspiration gap focused on organizational readiness. The organizational readiness code included organizational phase, staff capacity, and funding as items that fed into whether an organization was ready to do participatory design.

The research team including the principal investigator and lead author discussed the initial codes' strengths and weaknesses. Based on the research team's discussions and iterations of the initial codes, aspiration gap and organizational readiness were thought to be less important as the theme of variations of participatory design surfaced in the data. Likewise, data initially coded to current engagement methods and participatory design excitement were recoded under variations of participatory design. The themes related to staff capacity were initially coded under different codes like lack of skills and time commitment and were eventually all recoded under staff capacity concerns. I then continued to refine and iterate codes until the final codes were determined.

Chapter 4: Results

Table 2: Results

Research Question	Theme	Section
The Current State of Nonprofit Participatory Design	Strong Emphasis on Client Engagement in Human Service Nonprofit Culture	4.1.1
	Human Service Nonprofits are Using Variations of Participatory Design	4.1.2
	Human Service Nonprofits Rely on External Experts and Partners to Fill in Gaps in Order to Practice Participatory Design	4.1.3
Barriers to Nonprofit Progress in the Field of Participatory Design	Participatory Design may Create and add to Staff Capacity Concerns	4.2.1
	Funding less of a Constraint than Expected	4.2.2
	Participatory Design May Disrupt Nonprofits' Narratives About Themselves and Beneficiaries	4.2.3

The research results are organized into two main groups: the current state of participatory design at human service nonprofit organizations and the barriers nonprofits face to doing participatory design. The findings in the first section show that human service nonprofits in this study have passionate organizational cultures that put beneficiaries at the center of all that they do. The majority of the human service nonprofits in this study want to engage with beneficiaries through methods like participatory design and several of the participant organizations are doing variations of participatory design. This is especially interesting because I did not recruit for human service nonprofits that were doing participatory design. I also found that the nonprofits doing participatory design are working closely with external experts and consultants to make participatory design possible.

The second section explores the barriers human service nonprofits face to doing participatory design. I found two barriers related to staff capacity and funding concerns respectively, though the latter turned out to be less of a concern than anticipated. I also found that barriers related to nonprofit narratives around the role of clients in developing solutions (client burden), concerns about mission drift, the role of client trust, and nonprofit's organizational reactionary behavior.

The study results provide an initial understanding of how participatory design currently works at these human service nonprofits and what challenges these nonprofits may face to evolving their participatory design practices.

4.1 The Current State of Participatory Design at Human Service Nonprofits

The findings in this study show human service nonprofits are doing some level of participatory design. This is different than what I expected to find because I found very little existing research on the topic of nonprofits and participatory design.

The following themes appeared during the interviews. First, human service nonprofits want to do participatory design. This shows up in their strong emphasis for client engagement from an organizational cultural standpoint. Secondly and surprisingly, human service nonprofits are doing variations of participatory design. These variations include organizations with high and medium levels of participatory design. The variations also include nonprofits moving toward participatory design, and organizations with no participatory design. I also found human service nonprofits doing high levels of participatory design often work with external consultants or partners.

4.1.1 Strong Emphasis on Client Engagement in Human Service Nonprofit Culture

During my analysis, I found human service nonprofits have a strong emphasis on engaging beneficiaries. This finding was not surprising given human service nonprofits' missions are often developed to focus on the people the nonprofit was created to serve. This was a robust theme echoed across many of our participants (5 out of 9). One of the participants who did not explicitly mention this still went on to describe how their organization did engage beneficiaries in participatory design.

For example, P2, an executive director of a workforce development human service nonprofit, described their organization as having clients at the center and driving all that they do. P2 stated that all the strategic decisions their organization makes are "motivated" by beneficiaries:

> "….Core concept for [organization], probably our most fundamental concept is [clients] in the middle. So all of our strategic decisions are fundamentally **motivated by the perspective of what impact does this have on the [clients]** in our programs."

P3 who works at the same organization as P2 echoed these sentiments about having clients "in the middle":

> "…You know, most, most org charts are like, you know, you got the head person, and then you got the other people and it's like pyramid, **ours is a ball. And it's, it's that the, the [clients] are in the center.** And then we've got these concentric circles, and they're basically like, like ripples. **And, and for us, what that is, is that, you know, that the [clients] are always at the center of what we do."**

This human service nonprofit has strong organizational culture centered on beneficiaries. P6's nonprofit has a similar culture. P6's nonprofit provides workforce development services to adults and young people with disabilities. P6 acknowledged the disability rights community is familiar with involving beneficiaries in decision making and that this informs their client-centered approach:

> **"...Because everything we do is person centered and that is definitely a theme in the focus to disability services in this country**…When it comes to work, the current evidence-based practice in this country is that for people with disabilities to have those good competitive integrated jobs that I described before, people with disabilities do experience barriers to work **and so we really need to include them in that process and find out what their interests are** and, and what their daily schedule requirement are and everybody has their thing, things that they love and hate about where they work, or their environments and that sort of thing. **So we take the time to figure all that out as much as we can, and document that and then use that to line up with businesses that we may introduce them to that seem to match all of the situations,** and will negotiate with them, with the business owner to make sure that that match happens ahead of time, as opposed to some of us figure out how to do that after they get the job."

P6's nonprofit currently engages beneficiaries in their case management process and relies on and values client input to inform each beneficiaries' employment placement plan.

Later when asked to reflect on the study's stimulus, P6 said again how the participatory design process is like the organization's existing approach to program services:

> "…**This kind of value in disability services that you have to include the person into the solution, otherwise, you're going to create something that doesn't work for the person, and then they'll let you know that it doesn't work**.…Think in all of these, just like, **trusting that the customer does know what makes sense to them, right?** And the end user, regardless of what their situation is, so it's not working for them, it's not going to work."

P6's organization may be uniquely positioned to center clients because of their work in the disability rights community.

Like P6, P7 also stressed their client-centered approach to case management at their homeless shelter. P7 said the beneficiaries lead that process and have a lot of input:

> **"It's a thousand percent [the beneficiaries'] input, we're not prescribing anything**, it's them being able to identify where they're at in life and for us to be able to help them put together a case management type plan to, that's going to help them progress within various domains."

P7 then explained the approach their organization takes to case management. This includes using a trauma-informed model of care and tailoring solutions to each beneficiary:

> "… So, a lot of it is even just a trauma-informed model of care. If you're familiar with that, that takes some more of a, you know, **takes a lot of**

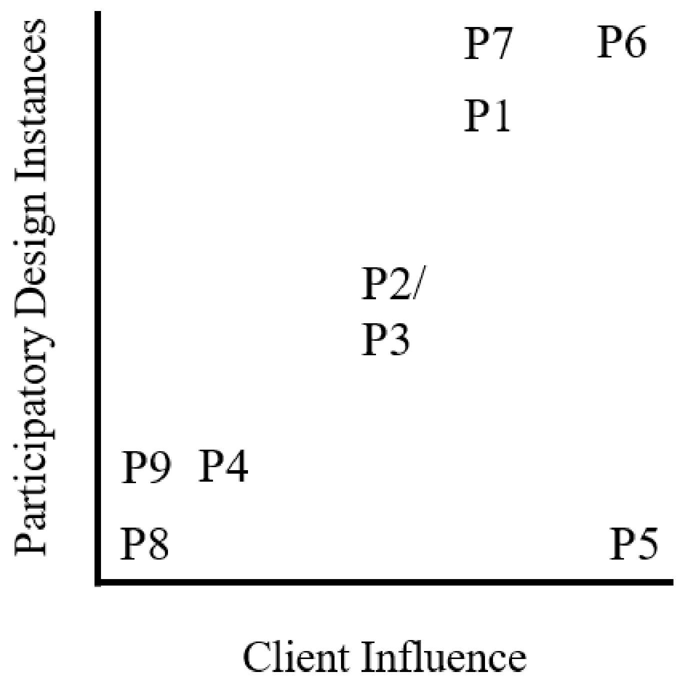
listening, a lot of listening, especially case by case story by story, person after person that nobody's the same….So our transitional housing program in terms of one, one year commitment, we call it the next level, **because we want every man to reach the next level, but that looks so different for every man, it's not a program.** So, there's no set expectation of, of classes or curriculum or goals, objectives, none of that it's basically the self-sufficient, like what how can we layer that across the board on the every single person who comes into our next level program?**"**

P7's case management approach is client-centered and there is no a one-size-fits all solution for beneficiaries seeking services from P7's organization.

P1, P5, P8, and P9 did not explicitly mention that their organizations have cultures focused on beneficiaries. With exception of P1, these organizations also do not currently have participatory design practices.

4.1.2 Human Service Nonprofits are Using Variations of Participatory Design

Figure 1: Variations in Participatory Design



The participatory design methods discussed by study participants are organized by high, medium, and no levels of participatory design. There is also a category for human service nonprofits moving toward participatory design. Three participants have ongoing participatory design activities (P1, P7, and P6), while one organization had one-time engagements with clients about a specific element of the nonprofit (P2/P3). I also observed two participants that have beneficiaries serving on board of directors, which was considered a high client-influence activity (P5 and P6). There were also two participants with participatory design planned for the future (P4 and P9).

The participatory design activities discussed by the participants are of varying value. The value of the activities was ranked based on the number of participatory design instances reported and the influence clients were perceived to gain through those activities. Figure 1 is meant to visually demonstrate the variations and is not quantitative. For example, P1's human service nonprofit has practiced a full participatory design cycle with beneficiaries using interviews and is planning for additional beneficiaries' input sessions for their new program. On the other hand, P5's human service nonprofit has not planned any participatory design activities, but their organization has two current clients serving on its board of directors.

In total, I found 8 out of 9 participants were using varying levels of participatory design to engage with clients. Only one participant (P8) had no levels of participatory design.

4.1.2.1 High Levels of Participatory Design

P1, P6, and P7 have the highest levels of participatory design. P1's human service nonprofit provides services for sexual assault survivors and their loved ones. Their nonprofit was in the process of designing a new educational curriculum for its beneficiaries. P6 and P7 organizations have beneficiary driven case management services, and both had engaged consultants to run participatory design activities with beneficiaries.

P1's human service nonprofit process for launching the new program was aligned with participatory design practices and consistent with participatory design outcomes. By talking to beneficiaries during the design process, P1's organization discovered that beneficiaries were more interested in connecting with other clients through the program than having a traditional classroom experience. Participatory design helped shift P1's expectations for the new program design.

> "So um, [the consultants] did **a lot of interviews with our clients, our clients' spouses, our clients' friends, different therapists, who [are] in and out of our network as well**. Just really diving deep into the, what would be most useful for the [clients]. And I think what came out of it, which wasn't what I expected, was this idea of kinship. Because in my head, I was always envisioning, like, it's, it's going to be very psychoeducational be very just explaining what [clients] are going through and how to respond to them. And, and just very, almost kind of dry material like that, right? **But what came out of all these interviews on all the research was that the [clients] were what they really need, and what they're really looking for, is a community of other people who are experiencing what they're going through.** So because of that the curriculum is extremely focused on this idea of kinship and how and developing from beginning to end, trying to create a feeling of trust a feeling of rapport, within that one group, we are leading with the intention that after the class is over, they're going to continue connecting with each other and create their kind of own support network in their own community. So that was really eye opening for me because it wasn't at all what I expected. **But it also showed the importance of why it's so important to talk to the people before you really create the design of your program.**"

P1 described a nearly complete participatory design cycle that was operationalized with the help of external consultants. When further discussing the extent of P1's organization's participatory design practice, P1 said they expected their organization will continue to iterate on the program and seek feedback from clients.

> "**We're definitely anticipating making a lot of changes to the curriculum**. Um, we have [the consultants] are going to be reaching out to the clients who have gone through the pilot program and doing another round of interviews. I think our plan was maybe three to six months out just to see where they're at and see if they gained anything through a pilot program, a**nd then taking that information and if we need to revise, whatever we need to revise, for the for the curriculums**."

P1's organization demonstrates an understanding of the usefulness and value of participatory design.

Like P1's organization, P6's human service nonprofit also demonstrated high levels of participatory design. As mentioned earlier, P6's nonprofit provides services for people with disabilities. Their nonprofit's culture is focused on client engagement and their existing services are designed to respond to the client's needs. In addition, P6's nonprofit was also exploring how to engage beneficiaries in planning for the organization's future. When reflecting on the stimulus, P6 said the organization wants to hear from beneficiaries not just staff about how to make the organization better:

> "**So we are having a facilitator coming in and work with a stakeholder group** over the next six months to think about, what did we learn in COVID? You know, what is this future for people that were close to go, we've never quite gotten 100% there to try to get ourselves there. **So we will be coming up with some strategies based on what they're telling us, not what we think**

> **we need to do with staff**…**There's just so many elements to what we do that we can miss the mark if you don't include people in that process."**

When asked why the organization was doing this now, P6 reflected on the importance of including beneficiaries in the conversation when making large organizational shifts:

> **"We got to the point where we feel like we can't do this without everyone. So we didn't want to embark on making some big organizational shifts in the work that we do if we didn't include community support, their family members, and our staff, our frontline staff into the process**."

P6 shared they would be working with external consultants who they worked with before, to host the facilitated workshops.

> "We're gonna use workshops, so these two facilitators have worked with us off and on for I think over five years…**they've got this really great method for designing these kind of real, fun, interactive activities that like get you to the end in mind. And, and they know us, they've been doing leadership retreats with us for many years now**..."

P6 also said their organization plans to keep using these type of engagement practices in the future because they have been received so well by clients and stakeholders:

> "…I think every time we do it, and we have a positive experience with it, that we want to do more. **This year, these consultants, we actually talked about putting them on a retainer, because they came in work with one group and we liked the result in so then other group asked for them. And so and**

> **I think if we hear that more from the people that we support and their families, and if you see that we're actually able to get to the outcome that we're all hoping for**, then it just motivates you to keep doing that practice in the same way."

P6's human service nonprofit has ongoing beneficiary informed case management practices and engaged consultants to conduct workshops with beneficiaries to inform broader organizational decision-making. P6's organization also has a beneficiary sitting on their board of directors, which is an influential position for a beneficiary to hold:

> "And then we also have people, we have one person with a disability who's on our board. So from a board management level, **she participates in helping to drive the strategic focus of the organization."**

P7's organizational model for services is similar to P6's organization. P7's case management practice is heavily informed by client input.

> "…So as it relates to even our own call it, program of emergency shelter, of course, every day, **through our case management and our progressive case management, it's heavily dependent upon [beneficiaries'] input, their contribution…"**

While P7's human service nonprofit has ongoing participatory design activities through their case management process, they also hosted a one-time participatory design project. During this project, P7's organization worked with a consultant and beneficiaries to design a new building expansion for their shelter:

"….In the last year, we used a collaborative, **community collaborative process** like [the stimulus] to come up with our master plan for new construction as well as renovations in our facility. So very similar. So putting together frankly, a team of professionals, architects, engineers, that sort of thing that **listened to our residents, our guests, our staff, our board, even our neighbors, we included our neighbors. So kind of a very community based process to identify what our needs were.** So it's very, it was very similar."

P7 described an activity where the consultant asked beneficiaries to take photos of things and places that made them feel at home to inform the new building master plan and design:

"Every step of the way [beneficiaries were involved]. I mean, even for the designers to ask the residents, what makes you feel at home? **So that the exercise was they gave them disposable cameras and let, asked [beneficiaries] to literally walk throughout the neighborhood, and the facility on the mission as well as the city and take pictures of the things, or the places or the images that made them feel at home."**

This activity of having beneficiaries take photos of things that made them feel at home to inform the building design is a strong example of participatory design.

P1, P6, and P7's human service nonprofits have all done some level of participatory design and have client driven practice in place to continue leaning into participatory design.

While P5 is not doing the same level of participatory design activities as P1, P6, and P7, they are considered to have at least one high-level participatory design activity: beneficiaries serving on their board of directors. Although this is the only participatory design activity P5's human service nonprofit is doing, it is one that is very valuable because of the level of influence beneficiaries would have at the board of directors' level.

> "I'm all for the general idea of of this of this application, because but I just heard we had a board retreat on Saturday, I'm one of my board, **two of my board members are our form our existing [clients].**"

When beneficiaries serve on nonprofit boards, they are in the position to make decisions and have a voice about the direction of an organization. This may be an important action nonprofits can take to move from having a culture of centering clients to having structures of centering clients.

Four organizations in this study were found to have high levels of participatory design. However, what was considered high varied between the organizations.

4.1.2.2 Medium Levels of Participatory Design

Participants 2 and 3 who work at the same human service nonprofit fall in the participatory design level of medium because their nonprofit has done at least one participatory design exercise. Similar to P7's participatory design activity related to their shelter expansion, P2/P3's nonprofit used participatory design when working with an external consultant to design their new headquarters location. P3 described this experience as design charettes:

> "**We did some design charettes around the studio, when we are new studio, because as we were, you know, trying to figure out like, how the new studio should be designed.** You know, we, we really needed to figure out, like, what the, what the user experience was going to be?... So we had different stakeholders come in. **And so from each perspective, what did those stakeholders need?** …You know, in a perfect world, what are all the things that that our, you know, perfect studio would have in it? What are all the things that would accommodate? And you know, we have a really cool studio."

With the help of their external partners, P2/P3's organization involved beneficiaries in the design of their new headquarters. Although this was a one-time participatory design exercise, P2 also noted they want to continue this kind of engagement with other stakeholders and eventually with clients again:

> "…We're coming up on wanting to do another round of experience design. The next one is about the experience of the professionals (teachers and volunteers) who serve…we know that we can unlock even more value for the [clients] and the like, the emerging [clients] at whatever level **by understanding a little bit more about what the professionals in our creative network are getting out of this and also what they wish for, for the [clients].** And then we'll loop back and do the [clients] again, **you know, we've now our, our internal process has feedback, feedback loops. At the quarterly level, we do all team meetings with [clients] and [clients]**

> **quarterly.** So we're kind of regularly asking them what they think about all kinds of things."

P2 and P3 described a participatory design cycle for a specific aspect of their organization supported by external experts. It is important to note unlike P1, this activity was related to designing the location and not beneficiary services. However, since the organization had a positive experience, they want to continue practicing experience design with clients. The experience design session was a powerful way for the organization to turn opening a new headquarters into a client-driven experience.

4.1.2.3 Moving Toward Participatory Design

There were two participants (P4 and P9) whose organizations were planning to do participatory design in the future. Both human service nonprofits also experienced the negative effects of not involving beneficiaries in program design processes, which helped inform their decision to do participatory design activities.

When I talked to P4, their organization was planning new beneficiary engagement activities for the first time. One of these new activities included creating a program to allow staff to hear directly from clients through a client roundtable discussion:

> "…We are looking to have some sort of program established that is going to **incorporate roundtable discussions from clients right out of the community to help us build the programming that we need to best service that particular area.** So yes, it's absolutely something we are going to do and wanting to do. We're just starting to think about how to build it and what it's going to look like and [funder] has kinds of information about food banks

> and all have kind of started to incorporate the lived experience into a lot of their programming."

In addition to the client roundtable, P4 also noted their organization is exploring how to bring clients in to help design a specific program about food safety. P4's organization is starting to build processes to support client engagement at the program level. Part of their motivation is driven by wanting to create a new strategy that is more client centric. P4:

> "But with a lot of the work because we are building new strategy, we are kind of changing the direction of how the [organization] is moving. And as we're doing that, **we are starting to talk about having speaker bureaus for clients with lived experience helping us to define what the programs need to be what the next steps need to be. So it will not just be, it will not be completely [organization] centered, it'll be very client centered, which is a totally new concept for us**…I'm really excited to be able to see, you know, where we can go with a client-centered approach because I think if, if that's who we're serving, we need to know how to serve them best."

In addition, P4's nonprofit experienced what can happen when programs are created without beneficiary input. When discussing a recently launched mobile market program, P4 said they learned that the program was not reaching everyone they intended to reach:

> "…So since going out [launching the new program] in May, we had earmarked 12 locations across all eight of our counties**. And what we have learned is even though we're going into those direct communities,**

individuals are still unable to get to where we are. So trying to figure out how do we do that, you know, how do we really get into the backyard without having to take a truck door to door. You know, 22-foot truck does not always easily go door to door in some of our towns…"

When asked to elaborate on what the organization has learned since launching the program, P4 shared that beneficiaries reported that they didn't know the program was launching or where it would be located:

"Um, you know, we have **some of the clients that I've been able to talk to let, let me know that they didn't even know it was coming.** So the [partners] that we coordinated with at a local level, you know, we know weren't getting didn't get the word out as expected. So, some of it**, obviously real, real insightful, being able to talk to the individuals in the communities that we were serving.** I mean, we were in one area that we went driving around, just to let people know, we were there. And a gentleman drove over a mile his lawnmower to come up. So I mean, even that was like, Okay, are we really positioned in the best place? **And when you talk to the individuals from that community, you know, they're telling us, well, you need to make sure you're posting in the little general store, the liquor store, or the laundromat, because that's where everybody is not just, you know, hope that the community center is going to put something up, because a lot of these people can't get to the community center.** So those are the things we're learning from really being on site, in there, you know, right, right in the moment, talking to individuals. **So that's been very**

important to realizing that we continue to refine what it is that we're doing. And that's why we're thinking about Eventbrite and thinking about changing locations and thinking about, you know, different avenues for getting the word out. So yeah, I kind of look at that exercise [the stimulus], as you know, we built a concept **and now that we've gone out, we've learned some things, and we're coming back to the table to alter the program. So it is better successful, based on some of those clients, some of the client feedback."**

P4's human service nonprofit is now more aware of the value of beneficiaries' input and is using this experience to develop a client speaker bureau, which will help them move toward participatory design.

P9's human service nonprofit also experienced what can happen when a program is created without client input. In this case, P9's organization learned in the middle of a client program that the information they were sharing was not relevant to the beneficiaries in attendance:

> "And I feel like we had a similar epiphany [to the stimulus], if you will, um, and realizing, I mean, even, even with the financial literacy, I think, probably, probably assuming that **we assumed everybody had a bank account…** we assumed and the facilitators who came from, you know, one of our, like hunting to make to facilitate these trainings, **they assumed everybody had been accounts and assumed X, Y, and Z.** So we had to, like, go back and be like, no, people, there's a lot of distrust, you know, there's a lot of reasons why people hold onto their money, put their money in their mattresses, like,

that's real. And and so we gotta, we gotta implement another curriculum like something before we even start with lesson one**. Um, but we didn't know that until we got the first rounds of or even feedback in the class. I think I remember a mom standing up be like, well, my money is safest with me and my bra strap right here. And we were like, oh, like it just, again, the privilege that was in the room facilitating the class trying, you know, you didn't, we weren't on the same level. And we didn't know that until someone called it out to us."**

Like P4, P9's organization learned about clients' needed after launching a program without client input first. This feedback influenced how P9's organization moved forward with different aspects of their services:

"…**That was an eye opening, an insightful conversation that then framed, how we interacted with families moving forward, for sure**. And even we, as we evaluated our, the language we use, we did a new family orientation, we participated and helped families get acclimated to who we were and what services we provided, you know, we're here to help you connect you with resources, yada, yada, yada. **But we changed the way we talked about some of these things even just because we were speaking at a level that was not like the need wasn't there, a sense of urgency was not there for these items. It was more for these items that we only spent like a couple minutes on**. So we shifted, less from surveys more just on interaction and experiences we had with families, and **we had a few people who like, told us some hard truths so we could evolve what we were doing."**

P9's organization received informal feedback from beneficiaries that then influenced how their organization operated going forward.

4.1.2.4 No Participatory Design

P8's organization does not have a participatory design process in place. However, like other participants in this study, P8's organization does have an evaluation practice to capture client feedback:

> "Yeah, we do a satisfaction survey. Twice a year, we have a client satisfaction survey that goes out to all of our, all of our clients. We also do a six month follow up phone call for anyone who's discharged from services to understand **what types of services they received, what barriers they found, what was helpful, and how are they doing?** We do that check in with them post discharge."

While evaluation is an important part of how nonprofits review their program and services, evaluation occurs after a program or service has been designed.

The variations in participatory design show the many ways human service nonprofits are practicing client engagement. It also demonstrates participatory design may be more of a journey rather than a destination and human service nonprofits can move between low and high levels of participatory design.

4.1.3 Human Service Nonprofits Rely on External Experts and Partners to Fill in Gaps in Order to Practice Participatory Design

All the participants in this study who reported doing medium and high levels of participatory design are doing so with the support of external experts or consultants. P1, P2/P3, P6, and P7's organizations all engaged outside experts to help run their participatory design sessions. P4, P5, P8, and P9's organizations have not done participatory design exercises and did not report working with external experts for this purpose.

External experts and consultants may fill in a gap for nonprofits when nonprofits do not have formal structures in place to support participatory design on their own. After reviewing the stimulus with P2, I asked P2 if they see participatory design fitting into their organization. They said they do see it fitting in conceptually but that the organization is not a place yet to structurally support participatory design:

> "At the conceptual level, yes, yeah. And um, where we are right now is that it happens very organically, inside [organization] so **it's more a part of our culture than it is a part of our process and structure right now…"**

As noted earlier, participants in this study emphasized their organization's culture of centering their clients. However, as demonstrated by P2, there is not a consistent correlation between organizations being centered on beneficiaries and organizations having their own structures in place to do participatory design. Engaging consultants might be one way nonprofits practice client engagement without creating structures within their organizations.

In addition, consultants may serve to provide participatory design skills and experience that nonprofit staff don't have. When discussing their participatory design activity, P2 explained that the architect partner they engaged "pushed" the organization to do experience design sessions with their clients:

> **"…**We did our experience design sessions with our architect, partner [redacted] and a couple of other experienced design experts. And at the

beginning of that thinking, we thought the kinds of questions we would be asking our kids are like, what kind of wall color do you want? What kind you know, like, what kind of doors should we have? We were thinking in architects' language. And that shifted over to a much more fruitful way of thinking about it. And **our architects pushed us to do experience design, to have a thoughtful conversation with [clients] with everybody but including [clients] about what we wanted the [client] experience to be.** "

P1, P6, and P7 who have high levels of participatory design and worked with consultants did not express similar sentiments about being pushed to involve beneficiaries.

4.2 Barriers to Human Service Nonprofit Progress in the Field of Participatory Design

The interview findings provided a clearer picture about how human service nonprofits are currently doing participatory design. The findings also provided context for the challenges nonprofits might face to doing participatory design. Barriers like staff capacity and funding were mentioned much less than expected during the interviews. On the other hand, nonprofit perceptions of themselves and their beneficiaries showed up throughout the interviews as barriers to participatory design.

Examined together, these themes highlight the narratives human service nonprofits in this study used to explain how their organization can or cannot operate, their organization’s role and responsibility to beneficiaries, and beneficiaries’ role in nonprofit’s services.

4.2.1 Participatory Design May Create and Add to Staff Capacity Concerns

Staff capacity concerns appear to be a reason why nonprofits may be worried about implementing a participatory design practice at their organization. Five participants, from organizations, both doing and not doing participatory design, mentioned this as a concern. P5’s organization is not currently doing participatory design and after reviewing the stimulus, P5 said that creating and sustaining a participatory design practice at their organization would be very resource intensive for staff and would require a dedicated staff person:

“…I think the main thing is, it’s, **it’s heavy resources on staff, you would**

> **definitely need to have a dedicated staff person for something like this and the resources to, you know, keep, stay on top of, you can't, something like this is ongoing.** And that refined stage I think, is always being reviewed and refined. And um and you need to plan for your metrics, you know, how many, how many people are you actually helping through this? **So I do think there's a, there's probably a heavy on the startup, and then that'd be ongoing, making sure that you've dedicated staff you know…"**

P5 also noted they would likely need to hire someone new to take on the responsibility of running all aspects of the participatory design practice:

> "…**I have to really hire somebody who could make sure that all these components are being, you know, being taken care** of like, because there's, it's not as simple as, you know, I've got 10, five to 10 pantry clients for ongoing input, **you need a dedicated person that's going to stay on that, because that's gonna fall low on the priority list** when you're actually out there, in our case, doing the repair [existing program], you know, doing the repairs is going to trump, you know, just ongoing input. So you really need to have a dedicated, and it's different skill sets too."

P5 was concerned that without a dedicated staff person participatory design would "fall low on the priority list" of other mission programs and services. Without having a dedicated person supporting participatory design at P5's organization, participatory design may not have a legitimate place in the organization.

P9's nonprofit was struggling with staff capacity issues and noted that even when additional staff were brought in to support existing services, they still did not have capacity to work on programs beyond the current services they were providing to beneficiaries. While more context around this example may be needed, it begins to point toward a story that no amount of staff will ever provide enough support for the organization to take on new projects.

On the other hand, P1's organization is doing participatory design for a new program. An important part of the new program includes a detailed client intake process. However, P1 shared they didn't have capacity to conduct intake with every client, so they had to limit who was involved in the pilot participatory design program:

> "…But we added on this new program, and **our intention was okay, each person that applies, you know, someone needs to talk to them, talk them through the program,** talk to them the expectations and get a sense of who they are, and if they're ready for the program. **I just really didn't have the capacity to do that**."

Instead of conducting intake with every client, P1's human service nonprofit decided to only accept client referrals in the pilot program. This P1's nonprofit did not have to spend time conducting the detailed intake process with them. Through this client referral process, P1's nonprofit was able to outsource some of the client intake processes which was helpful because P1's nonprofit only has two full-time staff members.

Additionally, P1 is the only human service nonprofit that engaged a consultant and who stated staff capacity as a concern so I cannot consistently say consultants are engaged as a result of staff capacity concerns.

P9, P7, and P8 talked specifically about how hiring the right staff can be challenging. P8 mentioned that staffing overall is a concern for their organization related to hiring trends:

> "…**I absolutely think that there is a growing staffing capacity issue with, with what we've seen within the pandemic, and especially for nonprofits. We're seeing a really an interesting trend and like people not showing up for interviews and not being able to get enough staff.** So I will give you a just a real life example. We've always had an outreach coordinator. And that person left the agency back in July. And so I said to my team, let's reimagine what this position needs to look like. Because it's a clean slate to hire someone. So now, it is an outreach and social media expert. **So I think sometimes it's about reimagining how positions need to look within the agency to meet the shifts and be nimble with what's needed versus always having to hire more staff members."**

P8 explained the staffing shortage in terms of an opportunity to "reimagine" the roles and positions their nonprofit is hiring for, to better meet the needs of the organization. The number of staff and staff roles is another way a human service nonprofit may understand itself as an organization and service provider. In P8's example, the team was able to redefine what type of role they needed and had to hire in support of the organization. If a nonprofit can imagine itself doing participatory design, then it may be more inclined to redefine hiring needs to support participatory design efforts.

4.2.2 Funding is Less of a Constraint on Participatory Design Than Expected

Funding was only mentioned as a concern for implementing participatory design by P1. P1's organization had the smallest total program service expenses of all the informants interviewed at $125,000. When asked about funding, P1 noted that there are many costs associated with kicking off a program. They then shared a story about not having enough money to pay for lunch at a meeting with program leaders:

> "Oh definitely, something is always constrained for kicking programs off. If we have a tight budget, we'll have to. I mean, **it costs money to get group leaders to lead the program.** And it's not only their capacity, but financially compensated, like the compensation is important too, for what we're asking them to lead. And then the supplies and location, and all of that. And **in our last in our last workshop, our executive director was just like, so we have money to pay for you [interviewee] and [consultants'] lunches, but not the rest of the [group leaders].** So I was like, Okay, well, that's gonna be awkward, but I mean, it worked out in the end. The [group leaders] are great. And like, yeah, we'll pay for our lunches. It's fine. You know, there's kind of that awkward piece."

The program leaders in this story ended up being comfortable paying for their own meals, but P1's story demonstrates the challenges their organization faced when launching their participatory design practice.

P1 was the only interviewee who explicitly discussed funding as a participatory design barrier. P2 did not think funding would be a barrier but thought the funder involvement process seemed simplified on the stimulus.

Overall, funding was mentioned in seven interviews but was only a concern in one. The other mentions of funding were related to the role of funders as stakeholders in creating the participatory design program as well as funder expectations for evaluation outcomes.

4.2.3 Participatory Design May Disrupt Human Service Nonprofits' Narratives About Themselves and Beneficiaries

Our analysis also uncovered connections between barriers to implementing participatory design and the narratives the human service nonprofits live with and make decisions based on. The narrative themes discussed in the interviews include:

- Defining who is responsible for developing solutions in client burden
- Deciding who the organization is accountable to in mission drift
- Understanding how client trust impacts nonprofits' ability to provide useful services
- Cultivating awareness of reactionary versus proactive mindset in day-to-day operations

I also argue that narrative expands beyond these themes and can also be used to analyze themes around staff capacity and funding.

4.2.3.1 Client Burden May Be a Concern for Human Service Nonprofits When Considering Participatory Design

Client burden is a theme that came up as a concern during two interviews. It was stated not to be a concern in a third interview. Although only two of the nine participants expressed causing client burden to be a concern, this finding was somewhat expected given human service nonprofits often work with vulnerable and marginalized populations.

When reflecting on the stimulus, P2 noted there is tension between the clients' wants and goals, and the nonprofit's goals. P2 also said there appears to be tension between what the nonprofit can deliver and what the nonprofit expects is possible for that client. P2:

> "…So whenever designing with a group of participants understanding both the opportunities but also **the limitations of perspective of participants** and when I speak to that in our environment, like an [organization] situation it's a tricky thing when a [client] tells you they want to be a celebrity shoe designer. **You know, like an optimistic person or an optimistic mindset says hey, [client] all right you know way to go, grab the ring. Um a different mindset might think, oh, my goodness, what is the opportunity cost of that dream?** And so yeah, just understanding that it's multiple voices that inform solution design at the community level."

P2 also noted that the stimulus outcome in which a food pantry informed by a participatory design workshop created a resource app for clients, could have been developed by other partners, without burdening clients to create the solution:

"So like, this idea got to a bit of a resource list idea of like, of like if someone would just gather all the phone numbers so that when I'm in crisis, I can go to one place and get it. You know, like, that is a super practical resource. What would happen if you took the crack teams at Microsoft, Adobe, whatever, and said, folks, get your regional design together? You know? **It's not down to the service clients to share the burden of solution. Heavily or sometimes even equally.**"

P2 was concerned that asking clients to come up with the service solution was a burden to them. P8 shared similar views about involving clients in participatory design and stated that participatory design should be a benefit to both the organization and the client. P8:

"I mean, I think, you know, especially for our agency, because we are serving mental health clients, we're serving victims of abuse and trauma and sexual assault, **you have to strike the balance as, as an agency of when is it appropriate to have clients involved? And when does it supersede their process of healing? I think it also is really important when you are reaching out to clients that it's not only meeting a need for you as an agency, but it's also meeting a need for them as an individual. And so I think those boundaries come into play, there can be, you know, there can be a power differential that's created…**It needs to be a real clear, almost like a contract, a participation contract so that there aren't unclear expectations on either side."

P8 said they thought it was important to include diverse perspectives in decision making processes and that doing something like participatory design must have a clear benefit to the beneficiary, as well as boundaries.

On the other hand, P1 whose organization is currently doing participatory design said they thought their clients would be very open to sharing their input about what they needed and hoped to get from the organization. Unlike P2 and P8, P1 was not worried about the chances of participatory design burdening clients.

P2 and P8's perspectives and organizational narratives appear to be that nonprofits are responsible for developing solutions on behalf of beneficiaries. Client burden was a reason P2 and P8's organizations might not want to include clients in participatory design. However, this is not a concern for P1's organization as they launch participatory design for a new program. If human service nonprofits believe it is their responsibility to design solutions on behalf of beneficiaries, then this narratives might be at odds with the goal of participatory design to involve end-users in solution building.

4.2.3.2 Mission Drift May Be a Reason Human Service Nonprofits Do Not Do Participatory Design

Mission drift or mission creep, in the nonprofit sector is when an organization starts to take on new roles or activities outside of their declared mission (Vu, 2021). This is generally seen as a risk and something bad for the organization. Three participants in this research mentioned a concern about mission drift.

P2 mentioned mission drift as a concern for incorporating participatory design structures and techniques into their organization. P2 was concerned that the organizations in the stimulus seemed to have shifted from their original mission as a food pantry to a resource hub in response to participatory design findings:

> "Um, the places where I've experienced tricky pivots that I saw come up here is this organization identifies itself as a pantry at the start, but the pantry by the finish sounds much more like a resource hub, and so they're now staffed to play a more, or they're now strategized to play a more central role than just a direct service provider. **And when that isn't working in the mission and spirit of the organization, its mission drift. When it is working, it's evolution. So it occurs to me as a question what did they consciously decide to become something different in service of their clients? And who's doing food pantry?"**

P2 pointed out that the organization in the stimulus changed their organization's goals and decided to become something different for their clients. P2 was concerned about what happened to the nonprofit's original mission of the food pantry.

Similarly, when discussing capacity needed to support participatory design efforts at their organizations, P5 said that they would likely need to hire a social worker and that hiring a social worker might move the organization away from their stated mission:

> "And so social worker, I have to be careful, because, I don't, I don't, I might be rough in the way I say this, but **may get us off the track…** I got a direct call from someone who is about to go onto foreclosure, like the 30^{th}, her home is already up for sheriff sale on November 30^{th}. **So I hear these stories, and I do my best to hand them off. But we really can't get off our plan of providing the housing for another organization to help us get people in**, if that makes sense."

P6 also mentioned mission drift from the perspective of stakeholders. P6's organization works with people with disabilities and noted both beneficiaries and stakeholders (in this case, beneficiaries' parents) may have internalized messages about how independent people with disabilities can be. P6 noted some parents think it is risky for the organization to move away from more staff-dependent services, even if that is what the results of the participatory design practice say to do:

> "So um, people tend to, or I guess society tends to give people with disabilities and their families the message, and then they internalize that, that their disability keeps them from taking care of themselves completely. So a lot of services over time have been based in care and supervision, as opposed to teaching and facilitation so the person can get themselves to work and manage their own money…**So we still have some families who are used to having,**

you know, staff around all the time when their family member was in school or that sort of thing. But, you know, when you show up at work, and you have someone sitting next to you, who's not a worker of the business, it's unnatural, and it still sets people apart, and so we want to be there to train and facilitate for people and not do things for them."

In P6's example, stakeholders are more concerned by mission drift than the organization, but it still impacts the organization's ability to do participatory design. P2, P5, and P6's stories show that concern for mission drift may be a constraint for doing participatory design. This demonstrates the tension between the mission drift narrative and the purpose of participatory design. Mission drift says nonprofits must stay clear and committed to their mission, and participatory design says beneficiaries may say they need or want something that is different from a nonprofit's stated mission, and that's okay.

4.2.3.3 Clients Don't Have Enough Trust in Human Service Nonprofits to Provide Honest Input

Four participants mentioned the role of trust in creating successful engagements with beneficiaries. Two participants shared concerns that beneficiaries may not be comfortable giving the organization feedback (P6 and P9). Likewise, two other participants emphasized the role of trust in staff and client relationships to facilitate more engagement (P3 and P7). Both findings reflect existing structures within the organization that do not facilitate opportunities for beneficiaries to provide honest feedback which could be a barrier to doing participatory design.

P6 and P9 indicated that beneficiaries at their respective organizations were not always comfortable giving their honest and real-time opinions. P6 mentioned their nonprofit was testing a new program. When asked if they thought they could use participatory design to engage beneficiaries in the design of that program P6 said they thought it could be used and acknowledged in other circumstances beneficiaries and stakeholders may not be comfortable sharing their input:

> "…**A lot of families have some challenges around communication and that sort of thing. They don't always feel comfortable like saying that to us. And so this gives us a chance to kind of look at ourselves under a microscope,** and put some practices together as a diverse group, to move forward…and also to give the space for it, because I think it's the people, the services for them, they are a stakeholder…"

In this case, P6 seems to say participatory design could potentially give beneficiaries the space they need to feel comfortable giving honest feedback.

Like P6, P9 noted that given the way their organization's program was currently structured, clients did not always share their experiences until after they left the crisis shelter:

> **"…A lot of [the feedback] came from former family, like after they moved out and they would give us back once they left.** I think there's always that power complex, right? Like as much as they [the nonprofit] try, make it an institution. It, you know, there were times where it felt like an institution, and the staff were the guards, if you will, and you only have access to these things at certain times, you [beneficiaries] can't come and go from

> your room as you please, you are having a hard day, you can't just lay in bed all day, **you know, like there was there was that that limit of power and control that we saw, so once families were out of that space, and often they would feel more comfortable giving feedback**…”

If there is existing mistrust between the organizations and beneficiaries, participatory design may not be easily implemented at these organizations. If beneficiaries are not comfortable giving candid feedback about services they receive, they may not be comfortable giving input about the design of services or they may not believe their input will be valued and used.

Particularly at P9’s organization, tension between partner wants and beneficiaries’ wants may make trust issues worse. In return for an in-kind donation, the partner, a school, wanted to tour the P9’s shelter where the beneficiaries were living. The tour took place and the then beneficiaries reported how this tour made them feel exploited:

> “…I think there were a couple of times where we had partnerships in the childcare center, specifically, there was a partnership with a local school, **and it was really the parents who wanted to provide their children who go to this private school with the experience of, they did a tour of the whole facility so then you have families feel like they’re, you know, they’re zoo animals, right?** Like, it’s not a great, it’s not great…**but the school, donated all of these things, did all these things and then this was kind of like the condition, right? Like, we’re giving you all this stuff, and we’re giving you all of these gifts for the kids. But we also want, we then need to do**

> **this to go along with it. So there were instances where it was kind of like a conditional relationship.** Um, that was several that program does not that does not happen anymore. **They have since realized that was, and that was feedback from the families like we don't, we feel very violated, our**

In this case, the partner's wants were deemed more important than the beneficiaries' experience. This may contribute to eroding trust with beneficiaries. However, P9's organization learned from this experience and realized their role in facilitating trusting relationships with clients.

Contrary to P3, P6, and P9; P7 felt that beneficiaries were responsible for being honest with the nonprofit and did not mention the role the organization has in making clients feel comfortable enough to give feedback. P7 said the biggest problem they have at their organization is getting the people they serve to be honest about their situations. P7 seemed to say beneficiaries were naturally dishonest and that if they were to implement a participatory design practice, beneficiaries' lack of honesty would limit that engagement.

> "…**Here's our number one problem, our number one challenge, number one issue. Honesty. Honesty from those who we serve. I would say, it's the biggest obstacle and hindrance in which I can, I could say, probably 75 percent, if not higher**, of a lot of men that we work with, even after working with them for six, eight months, sometimes a year, and then the realize, like, why weren't you honest with us that the reason that you're homeless, and you're, been unable to find a job. And, and you're unmotivated? Because you owe $32,000, in arrearages for child support and alimony. And, you know, as

> soon as you get that job, the courts are going to discover where you're at, who you are and what you're up to, and you're gonna have to owe that…
>
> … I can't tell you how many times it comes down to that. And so yeah, so here your, your research, like you got the case study, but **then you're going through a whole design phase of what somebody may need or a group of people or clients need. And if throughout that process, there isn't true. Transparency and honesty to what's really going on, right?"**

P7 said the organization might work with a participant and engage them in the design process but that if the participant isn't telling the truth, it won't be valuable. Like P6 and P9, P7 said beneficiaries are not telling staff what's really going on in their lives. Unlike P6 and P9, P7 did not perceive the organization to be responsible for beneficiaries' honesty and instead placed the burden of being honest on beneficiaries.

There are different narrative threads here. There is a narrative that the role of human service nonprofits is to make beneficiaries feel comfortable enough to share feedback and give input, which would be foundational to successful participatory design. Then there is a separate narrative expressed by one participant that clients are not truthful and that it is the client's responsibility, to be honest with the nonprofit, not the nonprofit's responsibility to help facilitate honesty. In both instances, trust may be a barrier to doing participatory design.

4.2.3.4 Human Service Nonprofits Maybe Reactionary and Have a Tendency Toward Fixed Mindsets

Human service nonprofits may be especially at risk of reactionary behavior because they are often trying to be all things to all people including their board of directors, partners, funders, beneficiaries, staff, and other community members. This can create a reactionary culture and an organizational way of working that treats everything like a crisis. Being reactionary may be part of the nonprofit narrative, that a nonprofit must function this way to meet everyone's needs. In this study, about half of the participants talked about their organization in ways that describe them as being more reactionary than proactive. Three participants (P1, P4, and P9) mentioned the urgent or reactionary culture of their work at their human service organization. P8 similarly mentioned how nonprofits including their organization tend to get stuck in certain ways of working.

When discussing why P2's organization does not have organizational structures in place to support a participatory design practice, they described that their organization was just coming out of a hustle phase. P2 said their organization was just trying to "get it done, get it done:"

> "**Because we're just coming out of the like hustle phase, we were like, just get it done, get it done, get it done, you know?** Yeah. And now we're much more at a strategic opportunity moment where what we do, how we do it, and how consistent we are about doing it, really matters to us now. **Where I would say that consistency and continuity, hasn't been a priority in the past couple of years, because of what we've been going through**. **It was**

> **sort of unrealistic to go well, how do you get consistent when you're in your second temporary [location]?** You know, now we're in our permanent studio for 20 years. So there's, it's reasonable to ask people to be more consistent."

P2 described that it was unrealistic for their organization to have consistency and continuity that would have supported participatory design because they were in the hustle phase of "get it done, get it done." An organization that feels like it is just getting things done may not have the foresight or energy to think strategically about plans, including planning for participatory design.

P4 discussed a similar mantra to "get it done, get it done" when they said their organization is focused on the day-to-day activities of "get food in, get food out" at their food bank. P4 acknowledged that because their organization was so focused on the day-to-day, they may have lost sight of the bigger picture about how they are providing services to beneficiaries. P4:

> "**You're in the motion, you know, you're going through day to day, it's get food in, get food out, service a need. But really standing back and seeing well, how are we servicing the need?** There's this group of population over here that isn't being provided any culturally appropriate foods, what do we need to do to do that? So surveys are becoming tools that we're using. **So yeah, it's just it's, a it's a new way of doing our work. And I think it's a new way of doing the work smartly, with the client in mind, because that's what we're here for, you know, our, our job is to put [organization] out of business,** we want to end hunger, and we need to know

how to do that. And it’s not just going to be getting people donate food or purchasing food, it’s going to be so much more than that.”

P4 discussed that their organization may have lost sight of the bigger mission of providing services to people in the community. When going through the motion of their day, P4’s organization did not pause to think proactively about how they were engaging or not engaging beneficiaries in the design of their services.

While P2 discussed the hustle phase of, “just get it done,” P4 mentioned the daily motion of “get food in, get food out.” Both organizational attitudes show each organization was focused on executing their mission, with less focus spent on planning how to consistently hear from and work with beneficiaries. Like P2 and P4’s organizations, P9’s organization also experienced being reactionary to daily crises and operations. Instead of proactively planning to avoid problems, P9 described responding to problems already happening. When I asked P9 if their organization included participants in the design of programs or if they sought input from beneficiaries before implementing something new, P9 said that they thought the nature of the work for their human service organization was to be reactionary. P9:

> “I think it I think most mostly reactionary...**I think it just the nature of the work for crisis, homelessness, sometimes. There are measures that are in place to try to be preventative, but often I think the change comes from in reaction to as a result of,** you know, we will get we had new leadership, by the time I was leaving at the Family Center, there was new leadership, a new director, and she did have ideas from previous social services, experiences and things she wanted to implement as as preventatives. **Instead of, like, let’s not**

wait until this is a problem, like that's, so there was some, I think it was just a lot of it was, this is the way we've always done it...**But yeah, I don't know. I think I think just nature of crisis, sometimes, is to be reactionary.**

P9 described a culture of addressing problems already in progress rather than spending time being preventative.

In addition to working through crises, P9 also brought up the idea of "this is the way we've always done it." P8 echoed this idea as well. When talking about how their organization could or could not change, P8 acknowledged sometimes nonprofits get stuck in the thinking, "that's just what we've always done."

Human service nonprofits going through day-to-day operations may not only be in the habit of being reactionary, but this may also demonstrate nonprofits' tendency toward a fixed mindset as opposed to a growth mindset. The narrative that nonprofits are stuck in ways of working and cycling through day after day to just get it done, would not make them open to new ways of working. Participatory design would challenge the status quo both because it would be a new way of working for the nonprofit staff and because the act of participatory design would disrupt the nonprofit's reactionary behavior and focus on proactive problem solving.

Chapter 5: Discussion

5.1 Summary and Interpretation of Findings

Human service nonprofits interviewed for this study are doing participatory design that is varied and frequently supported by consultants. I also found human service nonprofits in this study face barriers that may stop them from doing participatory design. These barriers included concerns for staff capacity and funding, though the funding concerns were minimal. Although staffing and funding concerns are repeated over and over again as challenges nonprofits face to accomplishing their goals, I found there is a broader theme about nonprofit narratives that may also explain barriers to doing participatory design.

Based on our findings, human service nonprofits must examine the narratives about their organizations, including how they construct themselves in relation to beneficiaries. Understanding these nonprofit narratives will provide insight about how nonprofits might overcome barriers to participatory design.

For example, staff capacity concerns were reported by about half of the participants. When staff capacity concerns are viewed as a narrative instead of fact, it is easy to see how nonprofits define and redefine their organizational capabilities in the stories they tell about themselves. For example, both P8 and P9 defined their nonprofit's capabilities by the number of staff they had and staff roles. P8 discussed reimagining a role so that they could bring in the type of skills their organization needed, while P9 stated their organization was bringing on more staff but they still didn't think that would be enough to support all the beneficiaries. These were two very different narratives about nonprofit staffing concerns.

Similarly, concerns about funding may be reinforced by stories nonprofits tell themselves. For example, while funding has been cited as having external influence on nonprofit programs (Hetling & Botein, 2010), funding was not heavily mentioned by the participants in this study as a concern for doing participatory design. In a few instances, participants thought participatory design might be a positive thing for funders because it would give funders *more* evidence to support a program: participatory design would demonstrate to funders a new program was participant driven. However, the funding narrative is so all encompassing in the nonprofit community, funding concerns maybe a vague reason used by nonprofits and supporters not to do something. While some organizations with small budgets may experience real concerns about fundraising, it does not appear to be a concern for implementing participatory design in this study.

Nonprofit staff capacity and funding concerns are almost always mentioned when talking about nonprofits, so much so that the nonprofit sector and community at large treat them as fact. However, like other barriers found in this study, staff capacity and funding should be examined more closely with the theme of organizational narratives.

Four additional findings from the study were organized under narratives. While nonprofits may have real concerns about burdening clients and respecting their boundaries, this concern may also reveal nonprofits are viewing clients from a deficit model rather than an asset model. Asset-Based Community Development (ABCD) is a community driven model that looks at the strengths of a community and develops plans organized around community strength (Mathie & Cunningham, 2013). Instead of using Asset-Based Community Development, human service nonprofits may operate from a Community Needs Assessment perspective, looking at what a community *lacks* in terms of assets and capacities instead of what it has. The narrative that beneficiaries are lacking skills and capabilities does not align with participatory design which would ask nonprofits to look to beneficiaries for solutions. This is seen in P2's reaction to participatory design:

> "…Like an [organization] situation it's a tricky thing when a [client] tells you they want to be a celebrity shoe designer. **You know, like an optimistic person or an optimistic mindset says hey, [client] all right you know way to go, grab the ring. Um a different mindset might think, oh, my goodness, what is the opportunity cost of that dream?"**

This participant perceived there was an "opportunity cost" for beneficiaries to think beyond what the nonprofit provider perceived was possible for them. This perception is at odds with participatory design.

In addition to human service nonprofits exploring the use of Asset-Based Community Development, they could also explore the use of co-determination. Co-determination, as mentioned earlier in the related work section, is a method social agency staff were documented to use with beneficiaries to accomplish both the human service nonprofits and beneficiaries' goals (Benjamin & Campbell, 2015). Co-determination was found to have three common scenarios that staff and beneficiaries had to navigate, "(a) establishing a relationship, (b) working out an agenda, and (c) taking action." Working out an agenda, "involves nuanced work to honor client autonomy, even when it runs at odds with program parameters" (Benjamin &

Campbell, 2015, p. 997). If human service nonprofits were to approach client engagement through a co-determination lens, this may serve as a first step to bridging the gap from an organization concerned about client burden to an organization that is client centric. P7's organization which was considered to have high instances of participatory design is already modeling co-determination behavior. When discussing how their homeless shelter engages with clients, P7 said,

> "It's **1,000 percent, [beneficiaries] input**, we're **not prescribing** anything, it's them being able to identify where they're at in life. And for us to be able to help them put together a case management type plan to that's going to **help them progress** within various domains."

P7's human service nonprofit appears to be demonstrating co-determination, stating the case management process is 1,000 percent the input of beneficiaries and that their human service nonprofit is "not prescribing" any specific programs or services for one particular person. The case management processes at human service nonprofits are not always client driven or tailored to a client's situation. Sometimes they are stricter based on what the organization offers. However, P7 demonstrates their organization works with the client to understand their wants and needs. P1 and P6's organizations which also have high instances of participatory design follow similar practices.

I also found tension between the narrative of mission drift and participatory design. In mission drift, there is a tension about who or what nonprofits are accountable to. In this narrative, I found two participants were concerned that participatory design would lead them away from their mission, which they felt accountable to, even though some might argue as I do that as nonprofits, they should be accountable to beneficiaries. If beneficiaries tell nonprofits they want services different from the stated mission, should the nonprofit be accountable to their wants and needs or stay committed to their stated mission?

Four study participants also indicated that there is an existing narrative that beneficiaries do not trust nonprofits and therefore are not honest with their feedback. Although this narrative was stated by four participants, findings also suggest there is little accountability on the part of the organization to do more to become trustworthy in the eyes of the beneficiaries.

Finally, reactionary ways of working can also be connected to narrative. If an organization views itself in reactionary or crisis mode, struggling to keep up with demand, no number of staff will solve the capacity concerns as seen in P9's story:

> "**We brought in additional family support… to just in general, answer questions help guide [beneficiaries] through the shelter.** But when you're trying to man, I mean, I don't know what a good ratio is, though. And I don't know what the ratio was that they had, staff to families. I'm sure there was a perfect number, but, um, if people are not getting along, and that pulls staff into that**, you know, there's not always the opportunity to do more beyond you know, the basic needs care, right and basic services."**

Reactionary ways of working may also be linked more heavily to nonprofit organizational consciousness of working in a fixed versus growth mindset. A fixed mindset at an organization means people may be inclined to believe staff skills and organizational capacities cannot change over time, while a growth mindset is more inclined to believe staff and organizations can get better, in this case, change from a reactionary organization to a proactive organization (Canning et al. 2020). If staff perceive their organizations to be fixed, they are less likely to believe it will be innovative, and possibly less likely to embrace a new behavior like participatory design.

Despite these barriers, it is possible to fully include participatory design in the nonprofit sector. Although it is common now, before the 1990s, many nonprofits were not doing program evaluations or collecting feedback about their programs. As evaluations became more popular and required, tools and resources from funders and consultants were developed to support nonprofits with this process (Benjamin & Campbell, 2020, p. 201). Half of the participants in this study said they are doing evaluations. At some point, these organizations thought evaluations were important and they found capacity to do them. The same could be done for participatory design.

Participatory design could even be used as a tool to support evaluations. In fact, P6 thought using participatory design might improve how funders perceive new services and programs:

> **"I feel like government funded entities and even more so with other funders, especially private dollars, they want to see the outcome**. Right like, they want to know that their money is, is having an impact positively the people supported. **So again, if people are involved in the development process, and it works for them, then it should be better, right?"**

P6 explained that if participants were involved in the design of services that funders might look more favorably on funding a new program.

Removing barriers to participatory design in the nonprofit sector will take time. However, the nonprofits in this study seem ready to take this challenge on now. Four study participants said the impact of the COVID-19 pandemic and recent racial reckoning in the United States inspired changes at their nonprofits, and in some instances these changes meant intentionally engaging more with their beneficiaries. If human service nonprofits were to ever change the way they engage with beneficiaries, this may be the time. Human service nonprofits who mentioned being at a point of inflection given what was happening in society at the time of the interviews seemed ready to improve the way they engage with beneficiaries. This readiness seemed to override concerns about funding or staff capacity that might have been more important at another time.

P4's human service nonprofit is moving toward participatory design and when asked why they decided to engage with beneficiaries now, P4 said that the last year and a half really opened their eyes to a lot of things:

> "I think because of the way that we're assessing, that we need to really solve for hunger, we know, that's not just food, and to really know how to solve for that we need to know what the needs are. **And who better to tell us that and the individuals that we're serving.** And, you know, we're dealing with so many populations, vulnerable populations, seniors, at home, students, children, homeless, are communities of color is something huge, you know, as we're, **we've just started embarking this past year on our diversity, equity and inclusion journey,** which very much needs to be centered also around the clients that we serve. So **I think through this strategic plan, refresh, you**

know, it wasn't time for us to redo our strategic plan. But, you know, the **last year and a half,** I think, **really opened our eyes to a lot of things"**

As P4 said, it wasn't time for them to redo their strategic plan, but they were motivated to do so based on the current climate and movement in the nonprofit sector. P6 was similarly undergoing a strategic plan refresh with the intent to involve beneficiaries more fully in the process.

Perhaps this is the time for well-established nonprofits to improve their engagement practices, while newer human service nonprofits are engaging beneficiaries in participatory design practices from the start. For example, P1's organization is seven years old and actively committed to using participatory design to create programs and services. P1's nonprofit is doing this despite having the smallest program service expense budget. P1 is a program manager and stated that funding, as well as staff capacity, is a concern, but P1 also stated that their organization's goal is to be methodical and intentional with all of their service offerings. The way P1's organization works with beneficiaries is aligned with their mission, it is their mission in a sense, and there is no concern for mission drift. Likewise, P1 was not concerned about causing client burden, P1 felt participants would have no problem saying how they felt or what they wanted or needed from their organization. Concerns about trust and an urgent work culture did not come up when speaking with P1. P1's approach to participatory is the counternarrative to the barriers other human service nonprofits may face to doing participatory design. P1's organization demonstrates participatory design is possible and worth doing.

5.2 Limitations and Future Work

There are several next steps future research could explore to better understand participatory design use at human service nonprofits and in the nonprofit sector. First, it would be valuable for future research to involve beneficiaries. Through research with beneficiaries, we can learn about their experience engaging with nonprofits and learn about their perspective on giving input to the design of programs and services. Future research with beneficiaries could include a focus on power dynamics, a theme that came up in both narratives about client burden and client trust. Both P8 and P9 mentioned privilege and power dynamics as a concern when engaging beneficiaries. When discussing client burden, P8 said:

> **"There can be, you know, there can be a power differential that's created…**It needs to be a real clear, almost like a contract, a participation contract so that there aren't unclear expectations on either side."

Likewise, when reflecting on feedback from a participant about a program, P9 said:

> "I think I remember a mom standing up be like, well, my money is safest with me and my bra strap right here. And we were like, oh, like it just, again**, the privilege that was in the room facilitating the class trying, you know, you didn't, we weren't on the same level. And we didn't know that until someone called it out to us."**

Both instances indicate a power dynamics theme that could be explored more deeply from the nonprofit side but also the beneficiary side.

Design Justice (2020) by Sasha Costanza-Chock details how organizations like nonprofits can both better work with beneficiaries and support beneficiaries to lead the design of nonprofit programs and services. Design Justice may be especially valuable to help human service nonprofits to address the barrier of client burden. P2's concerns about client burden revealed that they perceived beneficiaries to have a limited perspective on what was possible. Design Justice asks organizations to examine their biases in design, which may be an important step human service nonprofits can take to overcome the barrier of client burden.

Other possible next steps include understanding how barriers to participatory design are being addressed during nonprofit evaluations. In a 2022 paper, Campbell and Lambright argued for the "meaningful role" of beneficiaries in performance analysis. In their analysis, they present a six-element framework to move beneficiaries from a passive role in nonprofit evaluation practices to an active role (Campbell & Lambright, 2022). This argument is parallel to one I am making for beneficiaries' involvement in the design of programs and services.

Additionally, it would be valuable to consult participatory design experts to learn how similar barriers have been addressed in other industries. Once barriers are better understood, a checklist to help human service nonprofits understand what it would take them to move from low levels of participatory design to high levels of participatory design could be valuable. This may also help inform how human service nonprofits can create their own organizational structures to support participatory design and rely less on external experts. This is important because organizational structures, not just client-centered cultures may strengthen participatory design processes at nonprofits. Dodge and Ospina (2016) argue wanting to engage participants is not enough. Organizational structures must be in place to support these practices:

> "We find that what matters for civic engagement is not just promoting the civic activism "impulse" that Salamon (2012) describes, but whether or not a nonprofit intentionally advances active citizenship. Across the literature, we observe that nonprofit organizations exhibiting various "impulses" can support or inhibit active engagement. Collectively, t**his research suggests that *organizational practices*, not impulse, generate different experiences for citizens, with implications for how citizens take up democratic participation**" (Dodge & Ospina, 2016, p. 493).

In addition to the findings from this research, the study's participant demographics may also be used to inform future work on participatory design. This study was limited to nine participants from eight organizations. Finding participants to sign-up for the interviews was difficult. All interviews were conducted virtually due to the COVID-19 pandemic. While this small study sample cannot be applied broadly to the nonprofit sector, aspects of the participant demographics can be transferred to other studies.

Four of the participants were executive directors, two were program directors, two were program managers, and one was a grant writer. Future research could examine the role nonprofit leaders in executive director or high-level director positions at organizations play in supporting participatory design efforts. The type of organizations in this study were all human service nonprofits, specifically the programs offered at these organizations included: three workforce development services (one specific to people with disabilities), three housing and homeless services, two sexual assault services, and one food bank service. Additional research could be conducted on human service nonprofits and participatory design, or additional nonprofits could be explored to see how they use participatory design (like advocacy or membership associations).

The organizations in this study varied in age from seven years old to more than 50 years old. The participant organizations also varied in total program service expenses from $125,000 to $67,000,000. Although the findings in this study did not find funding to be a barrier among most participants, the participant with the smallest program expense budget, P1, did mention this as a concern. Future research could also explore a narrower range of program service expense budgets.

Appendices

Appendix A: Procedure Script

A. Introduction 1-2 mins

1. Confirm have signed consent form
2. Confirm comfortable with video and audio recording and note taking
3. Start with a few interview questions, then share case study, then follow up discussion
4. Provide basic context about research and study
    a. I am a graduate student studying human-computer interaction at the University of Maryland and I have a background of working at nonprofit organizations
    b. The goal of my research is to understand how your organization currently engage beneficiaries in the design of mission programs and if practices from human-computer interaction can support that work

B. Interview questions about current experience engaging clients (10 mins max)

5. Can you describe the organization you work for

a. Programs

b. Mission

c. Location

6. Tell me about your role
7. Tell me about your organization and the organization's programs
    a. Probe about current client engagement methods

C. Presentation of stimulus (5 mins)

Will be walking through a case study and will be given option to read and go back through for main points if want that

1. Walk through the Communify case study
    a. Communify is a food pantry in Maryland, anyone may seek services from them
    b. They serve many different clients who range in age, gender and race
    c. New and regular clients

2. They had some initial assumptions that their clients struggled with managing their finances and that they might need help with foundational budgeting skills and techniques. Wanted to confirm this and learn more.
    a. Decided to do interview. During interviews asked about how families budgeted their money, saved money, and how they envisioned technology that might support their budgeting supports
    b. Found that getting by on a low income involved a wide range of innovative and sociable practices, including sharing and pooling resources, bartering and use of available support services.
    c. Participants most skilled at budgeting money and the social processes involved with getting by on less actually had little to do with tables or spreadsheets. The importance of social connections in managing money illustrated to us the need to look beyond money itself.

d. Decided to explore that further through a workshop

3. Workshop – any questions?
   a. Go over workshop demographics – paid them
   b. Activities (second slide)

4. Outcome of activities (back to slide 1)
   a. Four activities
   b. Initially the focus of this study was on technology to support people to manage their money.
   c. What the leaders found out, less about the technology and more about human connectedness
   d. However, over the course of this process we now understand the problem (and thus the direction of our future work) to be less about actual money management and more about making connections with people and with goods and services.
   e. Participants left our workshop with notes and connections to follow up with- i.e. tangible useful information and several said that was the most valuable outcome of the workshop

5. Planning for experiences – questions?
   a. Came up with concept for Crisis Phone. Purpose of crisis phone to have services and support available by zip code so person experiencing a crisis

could type in their zip code and be connected to free services in the surrounding area.

   b. Wishing to ultimately design and prototyping a technology akin to the Crisis Phone, we plan to first map out the journeys of those, for example, leaving jail, their information needs and the services they access.
   c. Refine – computers at pantry, mobile phones, charging stations, free wifi
   d. Continue gathering retrospectives from those who have made such a journey in the recent past and have become stable (rather than those in the midst of such a transition) and those who are eager and able to discuss their experiences.

6. Final program
   a. Continue engaging participants to support whole program that will support app
   b. Pursue grant to hire staff person to lead efforts to seek feedback from clients, make sure app stays up to date
7. Confirm informant has accurate picture of story board
   a. PD can be varied in terms of level of time and effort ("lift")
   b. Contributions can come from anyone, even those who seem to lack "traditional" capacity
   c. Final concepts of what should be designed can be quite different from what the "design team" started out with

d. Often is most valuable if integrated throughout design process; not really a "eval" thing

8. What it should not consist of

   a. It's not just about designing a product or piece of technology, but could be broader

- Any confusion or didn't see that?
- This method is called participatory design, have you ever used a method like this before?
- Do you have any prior exposure to this method? (5 sec answer)

D. Discussion of whether/how PD could integrate into the informants' (organization's) program design process (30 mins or more)

Now that we have shared understanding, we would like to understand whether/how a process like this could fit into the way that new programs are developed in your organization.

1. Can you tell me your overall thoughts on whether/how something like this could be done in your organization?

2. Follow-up / probe questions:
   - It sounds like X… can you elaborate? Tell me more about…
   - What parts of this process seem like they could fit well with what you do? Is there anything in here that seems promising/exciting?

- (if mention constraints) What do you think would have to change in the way things are done in your organization to be able to do this?
- Are there particular stakeholders who would need to be involved to make something like this work?
- How do you think the goals of this exercise align with how you measure success in your program development process?

Appendix B: Stimulus

Communify Case Study

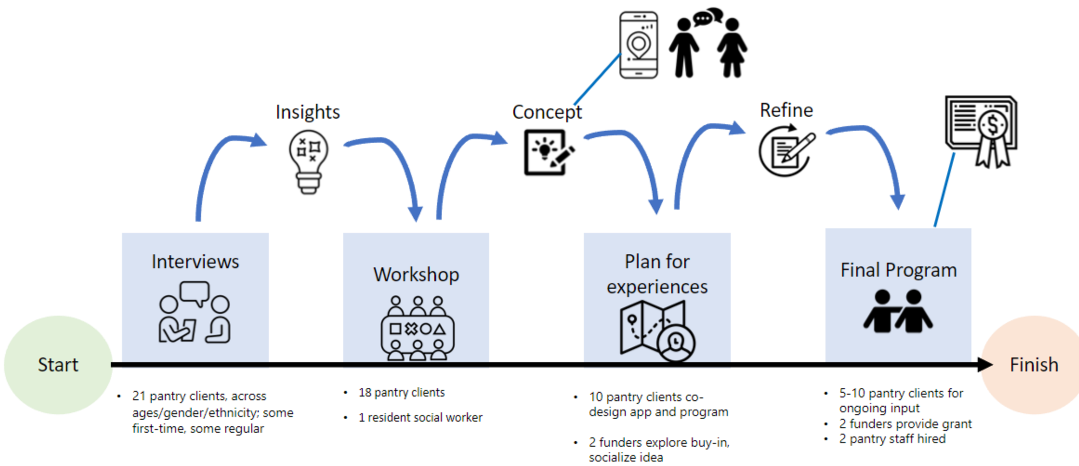


Figure 1: The workshop prior to group formation.

Activity 1: Post-it Exercise

Write five answers to each of the following questions: On your present income, how do you: (a) eat healthy (b) stay fit or active (c) have fun (d) What stops you from doing any of the above?

Aims:
•Encourage **honesty** and **participation**
•Build a **shared understanding** of constraints and opportunities

Activity 2: Design a pamphlet

Groups generated content to be included in a pamphlet to be given to all new Communify users.

Aim:
- Give participants a relatively **structured design task** to get them accustomed to working in their group and **ideating novel designs**

Figure 2. Design concepts shown to the participants.

Activity 3: Four ideas for assistive technology

Cardboard mounted images of potential design concepts that the nonprofit considered might be helpful to save money and organize finances were circulated among participants.

Aim:
- Give participants **examples of possible designs** and solutions

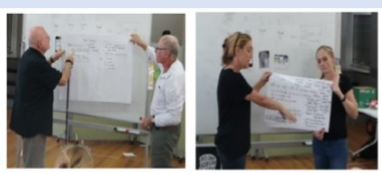


Figure 3a and 3b. Design Ideas

Activity 4: Design your own assistive technology

Using the previous exercise as inspiration, participants in their groups were asked to design their own assistive technology.

Aim:
- Ideate, and map out an idea for a technology that would **assist them in the context of managing finances.** All groups were encouraged to think far beyond current technology, monetary and engineering constraints.

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