



“Ask Me What *I* Want”: Community-based participatory research to explore transition-age foster Youth’s use of support services

Saralyn C. Ruff^{a,*}, Kristi Harrison^b

^a University of San Francisco, United States

^b Northcentral University, United States



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ABSTRACT

Transition-age foster youth are a population deserving support, including possible psychological assessment and service provision. The majority of these youth do not receive adequate supports and face difficulties in the transition to adulthood. To understand the challenges and barriers to care, the majority of research relies on adult stakeholders rather than on the voices of youth themselves. This study used community-based participatory research to design and implement a survey of transition-age foster youth to learn about their experiences in foster care, use of professional services, barriers to initiating and continuing services, perspectives on treatment topics and therapist characteristics, and use of informal supports. This study details the methods and application of community-based participatory research with foster youth, and then presents a subset of the results of the survey completed by 84 youth transition-age youth in care. Findings indicate the importance of working towards equitable relationships with youth in care to inform research on youth’s experiences and perceptions. Survey results affirm transition-age foster youth’s desire for autonomy, their resourcefulness, and potential areas where services for these youth could offer more support, particularly during periods of transition.

1. Introduction

The exclusion of young people from the construction of scientific knowledge is prevalent throughout social science research (Jacquez, Vaughn, & Wagner, 2013; Shamrova & Cummings, 2017). This exclusion is not unique to research on foster care, however, the consequences are particularly important for transition-age foster youth. Commenting on research as a form of civic engagement, Shamrova and Cummings (2017) note: “a parallel exists between the lack of children’s participation in research and the level of their participation in society” (p. 400). Preparing transition-age youth for “participation in society” is, arguably, the ultimate goal not just for adolescents in foster care but for all adolescents. Research processes that acknowledge the agency of young people, including foster youth, further the ultimate developmental goals for young people while also contributing to knowledge that is more culturally relevant and more readily translated into action (Jacquez et al., 2013).

Action research frameworks, such as Participatory Action Research (Shamrova & Cummings, 2017) and Community-Based Participatory Research (CBPR; Israel, Schulz, Parker, & Becker, 1998), are methodologies that prioritize genuine participation of the communities that are the focus of the research, as co-investigators. Although specific

CBPR research methods vary widely, these methods value cooperative efforts that engage researchers and community members in equitable decision-making processes to ensure the relevance of the research for communities involved (Israel, Eng, Schulz, & Parker, 2005).

The present study applied a CBPR framework to engage current and former youth in foster care as producers of research, resulting in the collaborative development of a survey on service use among transition-age foster youth. The research team subsequently used the survey to collect data from a separate sample of transition-age foster youth to learn about their use and perceptions of support services designed for youth in care. This article presents both the implementation of the CBPR process and a subset of the survey results that are focused on foster youth’s use and perceptions of support services. Presentation of the CBPR methodology with foster youth paves the way for further application of CBPR with transition-age youth in care, while results from the survey offer preliminary information about youth’s perceptions of support services, framed in terms of the questions that foster youth themselves deemed as important.

Before describing the implementation of CBPR and the results of the subset of the survey focused on service use, we review literature on youth’s participation in research. This review offers some guidance for the use of CBPR with foster youth while also documenting the paucity

* Corresponding author at: University of San Francisco, Psychology Department, 2130 Fulton Street, San Francisco, CA 94117, United States.

E-mail addresses: sruff2@usfca.edu (S.C. Ruff), kharrison@ncu.edu (K. Harrison).

of research studies actively involving foster youth, either as research participants or as research partners. Given the present study's focus on support services, the literature review also examines research that addresses foster youth's use and perceptions of formal and informal support services designed for transition-age youth in care.

2. Literature review

2.1. Involvement of foster youth as collaborators in research

Global children's rights movements, recognizing youth's abilities to speak for themselves, have asked researchers to engage youth as active participants in research about their own experiences (Hart, 1992; Jacquez et al., 2013; Shamrova & Cummings, 2017). Despite this call for inclusion, studies involving youth in general, not just foster youth, vary in terms of the depth and meaningfulness of the youth's role in the research (Jacquez et al., 2013; Shamrova & Cummings, 2017). Recent reviews of action research with children and adolescents indicate that only a small fraction of research actually involves young people as active collaborators in the research process, and youth involvement most often consists of being participants, even among studies explicitly carried out using a participatory research framework (Jacquez et al., 2013; Shamrova & Cummings, 2017).

The lack of research utilizing youth as participants or co-investigators appears to be particularly pronounced in research concerning foster youth. In a review of community-based research with youth between 1985 and 2012, Jacquez et al. (2013) searched for research explicitly applying a CBPR framework with youth. The majority (85%) of the identified articles did not involve youth in any phase of the research process. Not a single article identified in their review utilized CBPR with foster youth (Jacquez et al., 2013). Our more recent efforts to identify CBPR with foster youth, as part of the present literature review, identified just two articles that applied an action research framework with foster youth. Ponciano (2013) applied a participant action research approach to work collaboratively with five foster youth to carry out an interview-based study with 16 foster youth research participants. Ponciano (2013) makes a case for the relevance of action research with youth in care, noting the tendency for research on foster youth to take a deficit-oriented, disempowering approach to studying the experience of youth in care, and provides initial support for the benefits and feasibility of an action research approach with foster youth. Later, Mountz, Capous-Desyllas, and Pourciau (2018) applied CBPR by assembling a community advisory board to guide qualitative interviews with lesbian, gay, bisexual, transgender, queer, and/or questioning foster youth. The researchers describe their use of an advisory board to assist with designing research instruments and recruitment, but specific CBPR procedures are not the focus of the article and are not discussed in-depth.

The research of Ponciano (2013) notwithstanding, the lack of participatory research involving foster youth is not surprising. As a protected population, there are unique challenges to involving foster youth even as participants in research, let alone as collaborators in research design (Jackson, Gabrielli, Tunno, & Hambrick, 2012). These challenges can include logistical impediments that prevent access, for example, difficulties identifying a legal guardian to complete consent forms (Bogolub & Thomas, 2005), and difficulty accessing youth through institutions that protect confidentiality (Jackson et al., 2012). Barriers also exist in gaining current foster youth's assent, and former foster youth's consent, in part, related to a general mistrust of helping professionals and authority figures (Braciszewski et al., 2018) that may also extend to researchers. Despite these challenges and the lack of research applying CBPR with young adults in general, and with foster youth specifically, it is a methodology capable of generating knowledge readily translated into meaningful action on issues of concern for youth in care (Jacquez et al., 2013; Wallerstein & Duran, 2008).

2.2. Transition-age youth and the need for supports

Given the unique challenges associated with accessing foster youth as both research collaborators and as participants, research about the needs of transition-age foster youth frequently relies on retrospective analysis of county records, therapist records, school data, caseworker report, and foster parent report, generally omitting the voices of the youth (Braciszewski et al., 2018). Of the research that does involve youth as research participants, findings show that many transition-age youth report anxiety about aging out of care, as well as pressure to be self-reliant, a lack of support systems, and concern about their immediate ability to secure basic needs (Cunningham & Diversi, 2012). These concerns reported by transition-age youth are borne out by data on outcomes for transition-age foster youth, which indicate increased difficulty graduating high school and accessing secondary education (e.g., Courtney & Dworsky, 2006), challenges with securing employment and housing (e.g., Osgood, Foster, & Courtney, 2010), and increased rates of teen pregnancy (Dworsky & Courtney, 2010) and incarceration (e.g., Courtney et al., 2011). Research on the wellbeing of transition-age (16–24 years) youth indicates high levels of social-emotional and mental health needs (Courtney & Dworsky, 2006; Leathers & Testa, 2006). Specifically, rates of almost every psychiatric disorder are higher than the general population (Pecora, Jensen, Romanelli, Jackson, & Ortiz, 2009), with some suggesting transition-age foster youth are two to four times more likely to be diagnosed with mental illness than youth not in care (Havlicek, Garcia, & Smith, 2013).

The potential mental health needs of transition-age foster youth warrant support, yet less than half of service agencies require screening for mental health difficulties among youth placed in care (Levitt, 2009), and when youth are identified as being in need of psychological services, the majority never receive care (Burns et al., 2004). For transition-age foster youth, service use declines at precisely the time when many adult disorders are first diagnosed (Kessler et al., 2005), when the prevalence rate of mental health disorders is heightened, and when many experience the greatest challenge associated with their disorder (Davis & Vander, 1997). Service use with transition-age youth varies; in a review of peer-reviewed research on the use of psychological services, reports ranged from 50 percent to 94 percent, and past year rates ranged from 47 percent to 83 percent (Havlicek et al., 2013). Consideration of service use disparities is especially important when looking at the needs of youth of color and those who are sexual minorities, who are overrepresented in the foster care system (Robinson, 2018; Watt & Kim, 2019). There is evidence to suggest that youth with minoritized identities, particularly youth of color, are less likely to receive mental health services, necessitating research to understand why and how to ensure appropriate access and referral to services for particular subgroups of youth in care (Blumberg, Landsverk, Ellis-MacLeod, Ganger, & Culver, 1996; dosRios, Zito, Safer, & Soeken, 2001; Garland & Besinger, 1997).

2.3. Barriers to accessing formal supports

There are numerous barriers to accessing services for foster youth and transition-age youth. One frequently cited barrier to access and use of psychological services among older foster youth is the high likelihood of multiple placement changes (Eggersten, 2008; USDHHS, 2015). Not only does each placement change activate stressors that potentially increase the need for services, but each change can also interrupt the continuity of services while possibly decreasing the likelihood of long-term monitoring by caregivers, who are often the decision makers when it comes to access and use of mental health services (Unrau, Conrady-Brown, Zosky, & Grinnell, 2006). As youth emerge into adulthood, service structure and qualification policies change. Transition-age youth become ineligible for children's support services and must meet new requirements for adult services, which can result in new protocol and eligibility requirements that disrupt care (Davis &

Koroloff, 2006; Sakai et al., 2014).

In addition to, or in response to, the institutional barriers to treatment, youth can be hesitant or unwilling to access or engage with formal support services. Based on their experiences before and during care, some youth may be cautious of helping-service professionals, following maltreatment from past authority figures (Braciszewski, Moore, & Stout, 2014), and this may translate to systems at large (Davis, 2003). Youth may perceive mental health providers as allied with the foster care system, and not acting in the best interest of the youth themselves (Lee et al., 2006). This apprehension may be exacerbated by the frustration of having to tell one's story one more time, the concern that service providers will see them as a foster youth first and as a person second, or a desire to distance themselves from the stigma of foster care (Johnson & Menna, 2017). Even more, youth can express frustration with a system that may default to mental health referrals wherein youth are pushed to access mental health services while in care, and resistant to service after aging out of care (Sakai et al., 2014).

2.4. Transition-age youth and informal supports

Recognizing the barriers to care for transition-age youth, it is important to consider informal supports youth may use in conjunction with, or in place of, formal services. Many foster youth report receiving regular support from friends, and some report reliance on foster parents, mentors, and partners (Rutman & Hubberstey, 2016). Some evidence suggests transition-age youth are more inclined to turn to peers for guidance during this developmental stage than professionals (Brown, 2004). Upwards of 90% of transition-age foster research participants indicate support from birth families (Collins, Spencer, & Ward, 2010); between 17% and 54% of these youth return to living with parents or extended family upon emancipation (Collins, Paris, & Ward, 2008).

The benefits of informal support are not well documented in research on youth ageing out of care (Rutman & Hubberstey, 2016). Unlike youth not in care, many transition-age foster youth report additional sources of informal support, including community members and professionals with whom they have maintained contact for longer than three years; for those youth who have at least one positive, mentoring relationship they are more likely to report decreased stress, physical aggression, suicide risk, and improved health, educational attainment than transition-age youth without a mentor (Ahrens, DuBois, Richardson, Fan, & Lozano, 2008; Munson & McMillen, 2009). When asked to indicate characteristics of supportive relationships, transition-age youth in care note acceptance, reliability, and encouragement; the desire for such relationships is neither unique to youth in care nor unrealistic, however, the need for such support may be even greater among youth in care due to past relational disruptions and traumas (Ahrens et al., 2011; Rutman & Hubberstey, 2016).

Collectively, the literature reviewed here documents the need for further research on formal and informal supports that not only feature the voices of youth as subjects of research but also that involves youth as collaborators in the design of this research. The present study utilized CBPR with the aim of promoting equitable relationships with foster youth research consultants to gain recommendations on questions to be asked of transition-age youth about formal and informal service use. We hypothesized that study results regarding perceived barriers to care may partially replicate those in the literature, while also shedding light on additional barriers and types of supports, brought to light as a result of involving transition-age youth in the research design. More generally, the inclusion of the foster youth research consultants' questions, which were not typical of research on foster youth (e.g., "What is one thing you would like us to know about you?"), may lead to relevant knowledge to guide future research and the delivery of support services for transition-age youth in care.

3. Methods

Following approval from the Principal Investigator's University Institutional Review Board for the Protection of Human Subjects, trained University research assistants attended monthly meetings at different youth-led organizations in the Bay Area. These organizations included a community organization that oversaw interdisciplinary meetings to share resources for foster youth, a nonprofit focused on training foster youth to share their own stories, and a nonprofit focused on resources (e.g., housing, job training) for transition-age youth in care. During these meetings, the University research assistants focused solely on rapport-building and listening. This cautious, deliberate approach was taken to counter possible perceptions of "top-down" interactions often taken by professionals in the lives of foster youth, which can impede rapport and trust.

Following a period of six months of observation and rapport-building, the Principal Investigator contacted the community partner organizations' leadership to consult about methods to recruit transition-age youth in care for participation in the CBPR project. The Principal Investigator and organizations' leadership jointly determined that the frontline staff would approach youth about the CBPR project on behalf of the University research group. This approach was based on understanding of the challenges that may affect this age-group and, in particular, based on possible variations in decision-making abilities among adolescents and young adults that could directly influence their decision to participate (Merves, Rodgers, Silver, Sclafane, & Bauman, 2015).

The invitation to serve as a foster youth research consultant was open to any current or former foster youth who was between the ages of 16–24 and was interested in being a part of the research project. When recruiting research consultants, frontline staff shared that some youth had hesitations related to the intentions of the research team (e.g., what do they want to know?) and whether the research process might be too personal or triggering (e.g., what if I don't want to answer their questions? What if it's too personal?). Frontline staff also reported that some youth declined involvement due to concerns about the personal investment required for participation (e.g., time, needing to find child-care), or concern about their ability to offer valuable input (e.g., what if I don't have meaningful answers?). The use of frontline staff allowed youth the opportunity to ask questions, deliberate, and make a decision.

Of the seven youth who agreed to serve as foster youth research consultants, two were individuals who had been in foster care and were working for organizations serving foster youth, three were former foster youth affiliated with these organizations, and two were current foster youth also affiliated with these organizations. All foster youth research consultants were compensated at the same rate as University research assistants, were provided reimbursement for their transportation to and from meetings, and were assured that they had the right to stop their involvement at any point.

Youth agreeing to serve as consultants were invited to join research meetings, which were held both at the primary researcher's University and in the community. Planning these research meetings required team flexibility related to scheduling and resources to cover transportation and ensure a location that was private but accessible. Initial meetings with foster youth research consultants focused on establishing research questions, by asking foster youth research consultant what they wish researchers asked/knew about their experiences. Three themes emerged: (1) perceived barriers to support services, (2) use of informal support, and (3) youth's strengths and contribution.

3.1. Measures

To develop the research tool, the research team discussed methodologies most appropriate for the questions and intended sample, weighing the benefits of interview and survey methods. The foster youth research consultants reported hesitancy about interviews,

expressing concern that this may deter potential participants who are uncomfortable in conversation with researchers, particularly about foster care and about mental health services. The youth research consultants unanimously recommended a survey to increase participation and to promote a sense of privacy. They also recommended that the survey be labeled “confidential” on every page, and that the recruitment materials emphasize principles of CBPR, to differentiate the study from youth’s possible perceptions of research.

Over the course of 18 months, the research team co-created a 26-item survey. Youth research consultants advised that the tone and question placement not mirror typical surveys that ask “set” demographic questions. One recommendation involved not including any demographic questions about sexual identity or relationship status, sharing that this information was too personal for youth as young as 16, and that many youth avoid these topics in self-disclosure to professionals, fearing, or having experienced, discrimination based on their sexuality while in care. Foster youth research consultants recommended the inclusion of open-ended questions to capture demographic data where participants could choose what self-disclose, and that would convey general curiosity counter to “set” demographic questions. Additionally, foster youth research consultants recommended ensuring that any forced-choice response sets be inclusive of circumstance. For example, one demographic question inquiring about employment history was written to allow answer choices of “employed,” “not employed and seeking employment”, and “not employed and not seeking employment” to clarify whether youth were seeking employment or were “unemployed,” to challenge some of the common perceptions about high unemployment rates that may stigmatize this population (Cunningham & Diversi, 2012). The question about employment was followed with two questions: the first to inquire about the age when participants started working as well as to learn about reasons for working, and, second, a question about caretaking (“Who do you take care of/have you taken care of?”), to learn about responsibility and contribution through paid and unpaid commitments.

When designing questions about formal and informal support services, youth research consultants categorized ‘formal services’ as including any service offered by a professional, clarifying that these need not be strictly psychological. When examining barriers to accessing these formal support services, the research team began the list with barriers identified in extant literature: transportation barriers and mistrust of the system (Sakai et al., 2014). The foster youth research consultants generated additional options, including: fear of diagnosis, stigma of mental illness, and lack of hope about change. The youth research consultants advised that these questions be posed separately with regard to beginning services and continuing services, explaining that many foster youth may begin services but then encounter barriers to continuing in formal services. Youth research consultants also recommended including the question from the CBPR process: “what is one question that you wish someone had asked / would ask you?” to learn what youth may want others to ask, as part of formal or informal support services.

All prospective survey questions were formulated in meetings through discussion, and revised drafts of surveys were provided to the team between meetings for review. Providing drafts of the survey to the foster youth research consultants between meetings appeared to be helpful in allowing them time for review and discussion with other foster youth, and in allowing them the chance to make requests for revision in following meetings. At the start of each meeting, the team discussed proposed revisions.

As noted above, the final survey included 26-items. The complete survey is included as Appendix A. In addition to gathering demographic information, the survey addressed (1) use of and barriers to accessing professionally-provided support services, (2) what youth do to care for themselves, i.e., use of informal supports as opposed to only formal, professional services, and (3) youth’s self-perceived strengths.

3.2. Procedure

Following the development of the survey, the research team advertised the study title, purpose, protocol, and eligibility at foster youth-focused nonprofit, educational, and governmental agencies across four counties in Northern California. Additional recruitment efforts included distributing recruitment flyers through foster youth funding networks and youth-focused conferences. There were no responses to the flyers, and participants were obtained when the research team took surveys to agency sites.

All interested participants completed consent forms; if they were under the age of 18, youth completed assent forms and legal guardians completed consent forms. Participants were then provided the 30-minute pencil and paper survey and were reminded of their right to stop answering questions at any point. Following completion, participants were provided debriefing contact information, a list of clinical resources to support any participants with increased distress associated with survey completion, the Research Participant’s Bill of Rights, and a \$20 gift card to compensate them for their time.

3.3. Data analysis plan

The analysis plan was driven by a commitment to capturing youth’s voices by providing descriptive information about their demographic data, experiences in foster care, and experiences with formal and informal services. When analyzing data on formal and informal service use, *t*-tests and analysis of variance tests were conducted to examine possible group differences in service use, perception of barriers, and comfort discussing specified topics in therapy, by demographic group and by experience in care. A constant comparative coding method was used to examine qualitative response sets, generating codes based on review of data.

4. Results

4.1. Participant demographics & foster care history

4.1.1. Participant demographics

Eighty-four ($n = 84$) participants across the greater Bay Area completed surveys. Most participants identified as female/feminine ($n = 43$, 51.2%) or male/masculine (46.4%, $n = 39$), while 1.2% ($n = 1$) did not identify with either gender and 1.2% ($n = 1$) identified with both genders. The age of participants ranged from 15.98 to 26.03 years ($M = 21.06$ years, $SD = 2.14$ years). Initial inclusion criteria required that participants be transition-age (16–24 years old); however, one 26-year-old participant was included based on their self-description as being “transition-age” and using services designed for this demographic.

The majority of participants were youth of color, including African American ($n = 34$, 40.5%), Hispanic/Latino ($n = 21$, 25.0%), multiple ethnicities ($n = 14$, 15.5%), and Asian/Pacific Islander ($n = 4$, 4.8%). Just 11.9% ($n = 10$) were White and 2.4% ($n = 2$) selected other. Fifty (59.5%) participants were attending either high school, trade school, or college. Fifty-six percent ($n = 47$) of participants were employed, 28.6% ($n = 24$) were seeking employment, and 15.5% ($n = 13$) were not employed and not seeking employment. Thirteen participants (15.3%) reported that they had children; ten of these participants reported one child, three reported two children.

Per the recommendation of the foster youth research consultants, the demographic section of the survey included one open-ended question asking participants to offer one thing that they wanted others to know about them. The intention of this question was to allow youth the autonomy to self-describe. Of the 84 respondents who answered this question, 29% ($n = 24$) reported a positive quality such as “I am amazing and I know that I will complete my goals,” or “I bring positive energy, and lots of it.” Nineteen percent ($n = 16$) of participants

reported an identity statement such as, “I’m a transgender female,” or “I am a teen mom.” Eight percent ($n = 7$) reported a success such as “I graduate in June” or “I am doing well despite my background,” and 8% ($n = 7$) reported a contribution (e.g., “I am trying to break the statistics, stigmas, and stereotypes against me”). Six participants (7.1%) reported about their foster care history (e.g., “my foster parents died 3 months before graduating”) and two participants (2.4%) reported a psychiatric diagnosis (e.g., “I suffer from major depression and signs of PTSD”).

Participants also answered the question: “What is one thing that you wish someone would have asked/would ask?” This question was recommended by the youth consultants to capture topics that youth wanted to discuss in relationship with others, but that people did not ask. Of the 69 respondents who answered this question, 20 (30%) indicated that they did not know (e.g., “Not sure. Too many to count.”). Of the remaining answers, 22 (32%) indicated a desire to have had someone ask them their opinion in decision making processes (e.g., “do you want to be adopted?” “if I agreed with the decisions that were made on my behalf”), 17 (25%) wanted someone to inquire how they are (e.g., “how are you - and actually care” “are you ok, honey?”), and 16 (23%) wanted someone to ask if they needed resources (e.g., “do you need to be signed up for any sports?” “do you need money or clothes?”).

4.1.2. Brief description of foster care history

Survey questions on foster care history addressed the number and types of placements respondents had experienced, as well as their age at entry into foster care. Participants reported an average of 5.74 ($SD = 5.58$, mode = 3.00, range: 1–30) foster care placements, plus an additional three who indicated “too many to count” or “lost count.” The average total duration in care was 7.16 years ($SD = 4.87$, mode = 6 years, range: 0.50–18 years). The majority of youth ($n = 59$, 70%) reported one episode in foster care. Nineteen youth (23%) experienced two separate episodes in foster care; six participants (7%) experienced three episodes. The average age of entry into foster care for the first time was 10.06 years ($SD = 5.11$, mode = 12, range: 0–17 years).

Types of foster care placements reported by participants included non-family foster care (71.4%, $n = 60$), group homes (50.0%, $n = 42$), emergency shelter care (44.0%, $n = 37$), kinship foster care (33.3%, $n = 28$), emergency foster care (35.7%, $n = 30$), relative placement (25.0%, $n = 21$), and/or residential treatment facilities (15.5%, $n = 13$). Six youth (7.1%) lived in a foster-to-adopt family placement while in care. The average number of different types of foster care placement was 3.26 ($SD = 2.09$, range = 1–8, mode = 1 and 2). Those who lived in a group home were more likely to have placed in foster care at a younger age ($t(75) = 6.60$, $p = .01$), and to have spent more time in the foster care system ($t(71) = 5.49$, $p = .02$).

4.2. Formal services

4.2.1. Formal service use

On average, participants reported using 3.64 of the eight types of formal support services named in the survey ($SD = 2.30$, mode = 2.00 and 5.00, range: 0–8). The majority of respondents, 93% ($n = 78$), used at least one formal service while in foster care, including individual therapy ($n = 65$, 77.4%). Table 1 reflects participant’s responses, focused on frequencies of formal services use.

There was a significant positive relationship between the number of placements one had and the total number of different types of formal services used ($r = 0.32$, $p = .005$). There was no correlation between total services used and length in foster care, or age of entry into foster care. There was a noteworthy but not statistically significant relationship between total formal services utilized and ethnicity ($F(5) = 11.32$, $p = .051$), where those who identified as White used more services ($M = 5.20$, $SD = 2.52$) than those who identified as Black ($M = 3.42$, $SD = 2.29$) or Hispanic ($M = 2.86$, $SD = 1.82$). There was no

Table 1
Formal service use $n = 84$.

Formal service	Number	Percentage
Individual therapy	65	76.5%
Case management	50	58.8%
School counseling	37	43.5%
Family reunification	33	38.8%
Family therapy	30	35.3%
Medication management	27	31.8%
Educational treatment	24	28.2%
Group therapy	21	24.7%

relationship between service use and gender ($F(1) = 0.98$, $p = .32$).

4.2.2. Barriers to formal service use

The survey addressed barriers to beginning formal services and barriers to continuing services. When it came to barriers to beginning services, those barriers most likely to be endorsed included transportation ($n = 31$, 36.9%), mistrust of the system ($n = 29$, 34.5%) and the lack of a support system ($n = 29$, 34.5%). The most common barriers to continuing formal support services included a change in living situation ($n = 23$, 27.4%), a lack of time/availability ($n = 20$, 23.8%), a poor relationship with the therapist ($n = 18$, 21.4%), and a change in school situation ($n = 18$, 21.4%). A complete list of barriers to beginning and continuing formal services is reported in Table 2.

On average, those who identified as feminine/female reported an average of 3.29 ($SD = 2.78$) barriers, and males reported an average of 2.16 ($SD = 2.11$) ($t(76) = 2.00$, $p = .049$). There were significant group differences between gender and barriers to continuing services ($t(75) = 2.68$, $p = .009$), wherein again, those who identified as female reported an average of 3.50 ($SD = 2.99$) barriers, and males reported an average of 2.00 ($SD = 2.00$). There were no significant group differences across ethnicity and total number of barriers to beginning or to continuing services.

4.2.3. Therapy topics

Participants were asked to rate their comfort on a 5-point Likert scale about their comfort discussing specific topics in therapy, regardless of use of therapy. Of the 78 participants who responded to this set of questions, forty-two (54%) indicated at least one concerning and/or “off-limits” topic. The majority ($n = 40$) indicated concern in discussing trauma histories, with 14 indicating this topic was “off limits.” Twenty-four participants (31%) indicated some, moderate, or significant (“off-limits”) concern with discussing legal history, 20 (26%) with ethnic identity, 20 (26%) with education, 19 (24%) with sexual

Table 2
Barriers to beginning and continuing formal service use $n = 84$.

Barrier	Beginning N, % sample	Continuing N, % sample
Transportation	31, (36.9%)	17, (20.2%)
Mistrust of system	29, (34.5%)	13, (15.5%)
Lack of support	29, (34.5%)	11, (13.0%)
Time / availability	22, (26.2%)	20, (23.8%)
Stigma mental illness	21, (25.0%)	8, (9.5%)
Lack of hope	21, (25.0%)	12, (14.3%)
Cost of treatment	19, (22.6%)	11, (13.0%)
Fear of diagnosis	17, (20.2%)	13, (15.5%)
Unable to find therapist	15, (17.9%)	-
Cultural competence	13, (15.5%)	3, (3.6%)
Legal consequence	7, (8.3%)	6, (7.1%)
Language	2, (2.4%)	2, (2.4%)
Change of living	-	23, (27.4%)
Poor relationship with therapist	-	18, (21.4%)
Change of school	-	18, (21.4%)
Lack of satisfaction	-	14, (16.7%)
Disagreement with approach	-	10, (11.9%)

identity, 18 (23%) with cultural identity, 18 (23%) with gender identity, and 17 (22%) with class identity.

A significant relationship existed between youth’s total duration in care and their concern with discussing their trauma history ($F(2) = 3.98, p = .023$). Specifically, the average duration in care among youth reporting no concern discussing trauma history was 5.77 years ($SD = 3.15$). Among those reporting neutral responses to discussing trauma, the average length in care was 6.12 years ($SD = 4.18$), and for those indicating moderate concern or that the topic was “off limits,” the average of 9.51 years in care ($SD = 5.98$).

4.2.4. Therapist characteristics

Participants were asked, “What qualities do you look for in a therapist?” Of the 67 who answered this open-ended question, 15 (22%) indicated that the therapist be understanding (e.g., “understanding of basic trauma & relatability”), 13 (19%) a good listener (e.g., “to actually listen and care about me;” “someone who does not care if you don’t talk, they wait”), 13 (19%) educated / knowledgeable (e.g., “for the worker to be competent and rational”); seven (13%) participants indicated non-judgmental (e.g., “someone who understands and won’t judge”) and four (6%) cultural competence (e.g., “unbiased, a person/therapist of color”).

4.3. Informal services

4.3.1. Informal supports

Participants were asked where they turn for informal support; the average number of informal supports, out of 14 total options, reported by participants ($n = 80$) was 3.64 ($SD = 2.54$, range 0–14), with 64.7% ($n = 55$) of participants reporting reliance on friends, and 43.5% ($n = 37$) on siblings. See Table 3.

The vast majority (74%) endorsed between one and four types of supports. There were no significant group differences in how many informal supports were used by gender or ethnicity. There was a significant positive relationship between number of informal supports used and number of placements the youth had while in care ($r = 0.35, p = .001$) and the total number of barriers to beginning formal support services ($r = 0.27, p = .02$).

4.3.2. Support characteristics

Participants were asked what qualities they find supportive in others. Of those who responded ($n = 76$), the most prominent themes included providing emotional support ($n = 30, 39%$) and reliability, dependability, and loyalty ($n = 20, 26%$); many responses addressed the importance of support that is both genuine and reliable (e.g., “they genuinely care about you” or “they are constant and always supportive regardless of the situation”). Being a good listener was also commonly mentioned ($n = 17, 22%$), as was providing good advice or a different

Table 3
Types and frequencies of informal supports use $n = 80$.

Informal supports	Number	Percentage
Friends	55	64.7%
Siblings	37	43.5%
Creative outlets	29	34.1%
Boyfriend/girlfriend	28	32.9%
School	23	27.1%
Parent	21	24.7%
Clubs	19	22.4%
Foster parents	17	20.0%
Spirituality/religion	17	20.0%
Teachers	16	18.8%
Pets	13	15.3%
Social media	11	12.9%
Foster sibling/s	8	9.4%
Partner/spouse	8	9.4%

perspective ($n = 15, 20%$). Many participants addressed qualities associated with authenticity and trustworthiness ($n = 14, 18%$) and with demonstrating understanding and empathy ($n = 11, 14%$).

5. Discussion

The goals of this CBPR study were to elevate foster youth’s voices in the design of research on supports for this population and to report preliminary results from a collaboratively developed survey of 84 transition-age foster youth participants on formal and informal support services. We offer implications and recommendations pertaining to participatory research with foster youth, and to the ways that transition-age youth are encouraged to access supports, including formal and informal support systems.

In keeping with the aims of CBPR—to establish equitable relationships, empower research participants as agents of change, and offer recommendations to make culturally relevant changes (Rodríguez & Brown, 2009)—it is important to begin this discussion with acknowledgement of an important limitation of this research. While youth research consultants participated in the design of the survey, and youth research participants have provided their perspectives via survey responses, the youth research consultants were not involved in the development of the recommendations and implications discussed below. Partnering with our youth research consultants to interpret the survey results and develop recommendations would have been optimal. Acknowledging this limitation, this discussion aims to offer research and clinical recommendations that are grounded in the lived experiences of youth involved in the foster care system, which is especially important when considering how to best connect transition-age youth with supports and services designed to assist these youth with the transition out of the foster care system.

5.1. Increasing collaboration in research and service delivery

Although research about services for foster youth and the actual delivery of these services are distinct endeavors, one take-away from this CBPR process is the insight that both endeavors may be received similarly by youth in care. Extant literature raises the issue of general mistrust of professionals and authority figures among youth in care (Braciszewski et al., 2018; Sakai et al., 2014). Our CBPR partners affirmed this sense of mistrust. Their guidance about the research process, reinforced by established CBPR methods, was largely focused on acknowledging and reducing this sense of mistrust and underscoring the researchers’ commitment to sharing youth’s experiences.

For researchers, helping professionals, and social service providers, it is important to acknowledge that youth may perceive various adult-led endeavors—research, mental health services, and even the foster care system itself—as all connected. Promoting youth’s active engagement in one setting (e.g., research) may help with engagement and empowerment in other settings. Involving youth as active change agents is a fundamental assumption of participatory action research frameworks (Jacquez et al., 2013; Shamrova & Cummings, 2017), making these collaborative, applied research methodologies especially beneficial for work with youth in care, and minimizing the barriers that may otherwise prevent equitable partnerships.

5.2. Acknowledging resourcefulness and promoting youth agency

The foster youth research consultants in the present study provided insights about the importance of autonomy and decision-making in collaborative research with transition-age foster youth. Foster youth research consultants emphasized a need to distinguish the present study from other non-CBPR research studies by prioritizing what youth themselves wanted to share, over adult researcher aims or hypotheses. This request reflected a larger perception that systems and services are not always created with a desire to know what the youth want, but

rather are driven by adults' agendas (Lee et al., 2006). Similarly, youth research consultants shared concern about researchers' typical emphasis on risks and problems, as reflected in studies that only inquire about deficit-based outcomes. Consistent with one key earlier example of action research with foster youth (Ponciano, 2013), youth research consultants in this study emphasized having a balance in the questions posed in the survey of foster youth. They advised: don't just ask if we have a job, but rather ask if we are looking for a job; don't assume we all need services, but rather ask what we already do in our own best interest. This acknowledgement of youth's autonomy and resourcefulness was imperative in conveying that the narrative of the youth's experience is not determined by adults in positions of power, and that research could reflect the stories that youth want to share about their own experiences.

The advice offered by our research consultants to emphasize autonomy and resourcefulness was reinforced by the transition-age foster youth who responded to the survey. Responses to the open-ended question about what participants wanted others to know about them tended to focus on strengths and positive identity characteristics. When asked about what they wanted from formal service providers, answers addressed desires for someone who was relatable and who listened. When asked what question participants wished others would ask them, participants conveyed a desire for others to open space for them to be involved in decision-making about their lives. Participants wanted to be asked about their living arrangements, adoption processes, and visitation schedules, replicating extant findings (Geenen & Powers, 2007), and they also wanted others to simply ask how they were, and to listen to the answer. Collectively, these requests reflected a desire for support and connection that honor youth's autonomy. With transition-age youth in foster care, as with any youth, relationships that support independence and recognize strengths are critical to perceived and exercised agency in adulthood (Shamrova & Cummings, 2017).

5.3. Research and service delivery implications of survey results

5.3.1. Foster care history, service use and barriers, and reconceptualizing 'Need'

The youth responding to our survey had substantial histories with the foster care system and with formal support services. Participants had spent an average of seven years in care and had an average of three different types of foster care placements. There was a positive correlation between age and number of placements, and a negative correlation between age at placement and duration in care; these findings are aligned with other reports of transition-age youth's experiences while in foster care (USDHHS, 2015). These findings indicate that this sample had experienced the marked instability that is common for transition-age youth in care, including multiple placements over long periods of time.

When examining service use, almost all (93%) participants responding to the survey used at least one formal service; 77% had been in individual therapy specifically. As seen in extant literature (e.g., Havlicek et al., 2013), this relatively high service use may be associated with the recruitment of participants largely through non-profit and service agencies, indicating a possible selection bias that may affect generalizability. Despite this potential for selection bias, findings from this study offer important information about perceptions and experiences of services from those in care, and especially from those who have participated in formal services.

One finding of interest from the survey was the correlation between numbers of formal services used and number of foster care placements, but not with length of time in care. In other words, involvement in multiple types of services was associated with changes in placements, rather than with the total time spent in the foster care system. This outcome may be, in part, related to increased transitions that may interrupt services and require new referrals, as noted in the literature (Eggersten, 2008; USDHHS, 2015). A limitation of this study is that our

survey did not inquire about important details regarding formal service delivery, including how many different times the participant used each type of formal service use, what their experiences were with each service, and what the reasons were for stopping. In the context of this survey, and in research on foster youth service use more generally, it may be tempting to view the number of services used as a proxy for a youth's level of need for formal services, however, it is important to recognize that involvement in multiple types of interventions is equally reflective of disruptions in service as a result of placement changes, as opposed to a reflection of youth's need for multiple interventions. Our results suggest the importance of focusing on continuity of formal support services during changes in placement.

Despite a high report of formal service use among the study sample, the majority of the participants endorsed at least one barrier to beginning formal services (78%), and to continuing service use (90%). It is unknown if these barriers prevented access or continued use, but it remains significant that they likely added complication. Additionally, those who identified as female/feminine reported more barriers to beginning and continuing services than those who identified as male/masculine. No differences existed in use of services, or in specific types of barriers endorsed, but future exploration of perceived barriers among those who identify as female/feminine is warranted to support equitable access to formal support services.

Barriers specific to beginning formal services included a lack of transportation, a mistrust of the system, and a lack of support from one's social system—all of which were endorsed by over a third of the sample. Additionally, nearly a quarter of participants endorsed as barriers the cost of treatment, stigma about mental health, fear of a diagnosis, and a lack of hope about change. Thus, there existed both logistical barriers (e.g., transportation issues, cost of treatment) and psychological and/or relational barriers (e.g., mistrust of system, lack of support from one's family) that hindered beginning services. The logistical barriers and lack of support from family and social networks replicate extant literature (e.g., Lee et al., 2006), and suggest the value of allocating resources for transportation and treatment costs. The barriers that reflect the lack of hope about change, fear about diagnosis, and mistrust of the system also warrant action grounded in the building equitable partnerships that acknowledge youth's autonomy and ensure youth's experiences are not determined by adults in positions of power.

Regarding topics participants were resistant to discuss in therapy, the topic endorsed by the most participants was trauma. About one fifth of all participants indicated this topic was "off limits," and notably those who were in care longer were more likely to endorse this as a concern. This finding that youth are hesitant to discuss what they consider trauma presents a conflict with prevailing expectations from adults that youth in care are likely to have backgrounds involving abuse or neglect, and thus are expected to have the processing of trauma be the goal of their therapeutic work. More information is needed to understand how these youth define their trauma and why this may be something they would not want to discuss in therapy. This finding reflects a possible desire on the part of emerging adults to distance themselves from their pasts and to launch into the future, and caution that may complicate accessing services at this age.

Drawing on guidance from foster youth research consultants, this study also examined informal supports, with the assumption that youth may seek these supports, either in addition to or in place of formal services. Interestingly, informal supports were endorsed with less frequency than formal supports. The survey did not address length or intensity of these supports, limiting the conclusions we can draw. Across the sample, 65% indicated that they relied on friends for support. While this is the majority, it stands out that 35% did not endorse indicate that they rely on friends for support at a critical time of development when youth are likely to turn to peer relationships for support (Brown, 2004). Survey respondents also reported they used siblings for support, an area that is under prioritized in the foster care system and in research. About a third also indicated using biological parents for support, in line with

extant research with transition-age youth in care (e.g., Collins et al., 2010; Rutman & Hubberstey, 2016). Still, considering these relatively low numbers, and the high endorsement of non-relational supports (e.g., creative outlets), additional research ought to consider possible barriers to initiating and maintaining these informal supports.

5.3.2. Marginalized populations in foster care and the importance of youth empowerment

The sample responding to this survey included transition-age foster youth, ages 16–26 years, who identified as female/feminine ($n = 43$, 51.2%) or male/masculine (46.4%, $n = 39$), and who were predominantly youth of color ($n = 75$, 89%). These percentages of youth of color in our sample were higher than those in a large national sample selected to be representative of the population (Watt & Kim, 2019).

Youth from minoritized backgrounds, including youth of color, are disproportionately represented in the foster care system nationally (Watt & Kim, 2019), arguably making issues of agency and autonomy more salient when considered in light of the systems of oppression that persist in the United States. When foster youth's experiences of adults in power are situated within a critical consideration of race specifically, issues of power, voice, and identity become paramount. The race and ethnicity demographics of our sample bring into relief the importance of participatory research methods and add import to conclusions regarding mistrust of adults in power.

When examining the results of the survey, a mistrust of the system was clearly indicated among youth of color. When examining barriers to beginning services, 96% ($n = 24$ of 25) of those who endorsed mistrust of the system as a barrier to formal services were youth of color; by comparison youth of color were 89% of the study sample. When examining specific topics that participants were hesitant to discuss in a therapeutic context, a fifth of participants endorsed each of the following: cultural identity, ethnic identity, sexual identity, gender identity, and class identity, further signaling that participants did not feel comfortable discussing identity-related topics in therapy. These findings demand attention, in terms of awareness, research, discussion, and service provision. We have known about differential service provision and use for long enough (Blumberg et al., 1996; dosRios et al., 2001; Garland & Besinger, 1997); repeated inquiry into why, centered on the youth's perspective, is imperative to understanding and addressing barriers that may otherwise prevent access to services and perpetuate inequitable service delivery (Watt & Kim, 2019).

When discussing sexual identity and orientation, foster youth research consultants raised critical issues for consideration. Specifically, the foster youth research consultants recommended that the survey not ask participants about sexual orientation when inquiring about demographics. This may be considered a limitation of this study, and the distinct experiences of sexual minority youth in foster care do merit further exploration, including through the use of CBPR practices. However, acknowledging that youth in the foster care system who lesbian, gay, bisexual, transgender, queer, and/or questioning are sexual minorities experience elevated rates of victimization (Robinson, 2018), it is important to note that inquiries about sexual orientation and gender identity in research may exacerbate fears about discrimination, particularly if researchers are perceived as outsider adults affiliated with systems of power. It is possible that the fear of discrimination based on sexual orientation and gender identity may serve as a barrier to participating in research, and that concerns about research being deficit-focused may be even more pronounced among sexual minority youth who have already experienced discrimination. Inclusion of open-ended questions that allow the opportunity to self-disclose (e.g., "what is one thing you want us to know,") may be one means to support autonomy around disclosure.

This study is not without limitation, as noted throughout this discussion. The sample size was relatively small, and most participants were recruited through nonprofit organizations in the Bay Area, limiting generalizability. While CBPR studies are generally limited in

generalizability (Israel et al., 1998), replication is necessary to confirm findings, possibly in the form of interviews that may offer significant detail and context. Additionally, although the survey questions developed were the result of collaboration and reflect a process that worked to facilitate equitable relationships, further refinement of the survey may be needed. Specifically, it is of value to learn whether subsequent foster youth research consultants would also recommend the exclusion of sexual orientation when learning about participant's demographics, and to refine questions about gender so they do not conflate gender and sex. It would also be important to reconsider questions about formal service use, as many of the survey questions sought general perceptions and did not capture detail about length or frequency of service use, perceptions of efficacy, or reasons for starting or stopping services. Further inquiry into questions, ideally utilizing a CBPR framework, is critical to supporting foster youth in identifying and framing questions that they themselves deem important.

The aim of this study was to enter into equitable relationships with foster youth as research consultants to seek out their recommendations on conducting research about their experiences, and to implement these recommendations in a collaboratively developed survey focused on transition-age youth's perceptions of formal and informal services. Through both processes, we heard the clear message that youth may distrust systems and adults in power, and that they often desire a deconstruction of the assumptions of that drive these systems, including a shift from assumptions about deficits and problems, to assumptions about autonomy and resourcefulness. We learned that youth in care want more command of the narratives that are told on their behalf, not only in research but also in formal support services like therapy. Participatory research methods are optimal ways of honoring youth's agency, autonomy, and resourcefulness while generating knowledge that is relevant and empowering to youth in care.

Declaration of Competing Interest

The authors declared that there is no conflict of interest.

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Appendix A. Supplementary material

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