Exploration of Occupational Barriers of At-Promise Youth with Photovoice

Francis Bie  *Dominican University of California*

Brianna Baisch  *Dominican University of California*

Quyntz Ellenwood  *Dominican University of California*

Kerry Krohn  *Dominican University of California*

Iliana Santellan  *Dominican University of California*

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Francis Bie, Brianna Baisch, Quyntz Ellenwood, Kerry Krohn, and Iliana Santellan
Candidate

Julia Wilbarger, PhD, OTR/L
Program Chair

Karen McCarthy, PhD, OTR/L
First Reader

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Exploration of Occupational Barriers of At-Promise Youth with Photovoice

By

Brianna Baisch, Francis Bie, Quyntz Ellenwood, Kerry Krohn, Iliana Santellan

A culminating thesis, submitted to the faculty of Dominican of University of California in partial fulfilment of the requirements for the degree of Master of Science of

Occupational Therapy

Dominican University of California
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Abstract

Numerous circumstances affect the quality of life of youth including a higher risk for poverty, social exclusion, discrimination, mental health challenges and/or stigma, which effects their ability to engage in occupations (Iwasaki, 2014, p. 317). Through highlighting how photovoice has been utilized in the past with under-represented groups, we wanted to address occupational injustices faced daily by “At-promise” youth. Through utilizing participatory-led research, we wanted to further empower youth to be advocates in their community. Our research aim was to utilize Participatory Action Research and photovoice as a guide for at-promise youth to explore occupational injustices, how to understand the root of barriers to occupation, and how to promote action.

This research study was done in collaboration with the 10th and 11th graders at Huckleberry ACE Academy in San Rafael, CA. Participants took an active leadership role in the research by analyzing their photos together as a group, and guided the research with their exploration of barriers in their occupations. The first stage of data analysis involved the participants analyzing pictures and finding common themes. For stage two, the OT students analyzed the quotes from the meeting transcript and applied it during the third meeting. In the final session, participants found themes and discussed potential call to action. Three themes were found: racism and sexism, anxiety in occupation, and the experience of aspiring first generation college students. Based on these themes, barriers included occupational deprivation, occupational imbalance, and difficulty engaging in occupations in the future. Occupational therapists can further empower at-promise youth to be their own advocates in the community.
Acknowledgements

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Introduction

Youth “at risk” have been marginalized in society by simplified explanations of personal characteristics despite the focus of some literature on the interactions of various external and internal factors (Te Riele, 2006). Numerous circumstances affect the quality of life of youth including a higher risk for poverty, social exclusion, discrimination, mental health challenges, and/or stigma, which effects their ability to engage in occupations (Iwasaki et al., 2014). Fernandes-Alcantara (2018) described youth “at risk” as potentially without parental guidance, access to a safe living environment, and limits to accessing educational opportunities due to socioeconomic status. Policies have been implemented to replace “at risk” with “at-promise” youth. “At risk youth” has been denounced due to setting expectations of failure with the use of a stigmatizing label (Mckenzie, 2019). While changing this label of “at risk” to “at-promise” is only the start, creating a plan of action is what will dive deeper into further empowering youth to have occupational justice.

Occupations for children and youth are activities that enable them to learn and develop life skills such as in preschool and school activities, enabling them to be creative and/ or derive enjoyment through play and thrive as both a means and an end (Handley More, 2015). Occupations are vital for people to live meaningful lives, but they are not always accessible. A significant barrier for youth is racism experienced in everyday forms specifically defined as microaggressions (Roxas & Velez, 2019). The impact of racism in the form of microaggressions was highlighted in Hare and Pidgeon’s (2011) study that explored racism experienced by the Anishinaabe youth in school. This study highlights the importance of understanding barriers to occupation such as racism and the need for further research on further empowering youth for the breakthrough of occupational barriers.
Through the exploration of barriers to occupations we want to explore occupational injustices as a whole. “At-promise” youth experience different types of barriers. Through utilizing the Participatory Action Research (PAR) methodology, it will assist with truly understanding different types of barriers that youth face. This will be a way to encourage participant led research with photovoice, while also giving participants power and leadership in this research. Participatory action research (PAR) with the use of photovoice would be a powerful mechanism for youth to explore barriers and injustices in everyday occupations. The focus of this research paper will be on exploring occupational injustices through focusing on barriers to occupations with the use of participatory action research (PAR) with photovoice.

Mechanisms meant to further empower youth include photovoice and participatory action research (PAR). Photovoice can be used with youth as a way to provide an individualized perspective of their unique experiences with the use of photography (Lam et al., 2020; Wang, 1999). PAR is a community-based research that is meant to advocate for change for communities who are marginalized (Brydon-Miller & Maguire, 2009). For youth who may be at risk the community-based approach is vital. It is important to acknowledge the significance of community because occupations do not happen in isolation. Occupations take place with others signifying the importance of recognizing community in occupations (AOTA, 2020).
Background and Review of the Literature

Occupational Participation

Occupational participation and engagement is an integral part of photovoice and participatory action research. In occupational therapy, occupations refer to the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do (WFOT, 2012). Occupations are so common and engrained in everyday life, it might be hard for participants to consider or it might be difficult to articulate the meaning behind their occupations (Hartman et al., 2011, p. 292). Youth engagement “give[s] voice to youth's concerns, and launch[es] programs and activities that meet the needs of local youth within a community”(Foster-Fisherman et al., 2010, p. 67). Because of this engagement, especially in a visual medium such as photovoice, youth will further empower their voice through new means. They are able to articulate their occupations and voice their concerns to the community, which is essential to bring awareness and promote change. Occupational participation is just giving a voice to the roles, habits, and routines that give youth purpose and a way to tell their story so their community can start listening.

Community Involvement

Participation in a wide range of structured leisure occupations is associated with academic achievement and enhanced development in several areas, including personal identity, initiative, emotional self-regulation, social interaction, and teamwork (Bazyk & Bazyk, 2009). Using participation, the community is able to “learn from youth about how young people can become involved...and how the community can support their future goals” (Foster-Fisherman, 2010, p.69). This means that by voicing their concerns, the participants are able to share their problems with the community, while also identifying what needs to be changed.
Barriers to Occupations

Although prior research indicates that occupational importance is correlated with well-being, the access to occupations is unequal (Arnold & Rybski, 2010). There are many barriers to occupational engagement including psychosocial and environmental barriers (Shea & Jackson, 2015). The psychosocial barriers could be from criminal justice involvement, learning or emotional disabilities, or economic disadvantages (Shea & Jackson, 2015). Low-income families deal with the barrier of lack of funds for leisure occupations (sports, camps, etc.). This results in occupational deprivation of structured leisure occupations leaving only passive opportunities (e.g., hanging out) or aggressive opportunities for action (e.g., gang activity, violent computer games), which results in children missing opportunities to seek out and experience health-promoting challenges (Bazyk & Bazyk, 2009).

Environmental barriers could be physical such as a geographical location or lack of social support at home; racial segregation or even lack of belonging to a group or bullying minorities (Goodman, 2018). Based on past research, these barriers to occupations correlate to an unsupportive community (Goodman, 2018). A community that is unsupportive and lacks advocacy and social support will be explored and uncovered. These youth are not receiving the benefits and support experienced through occupational participation, therefore, they need a supportive environment that allows creativity, a safe space to share ideas and emotions, with peer involvement and caring/nurturing group leaders/facilitators (Bazyk & Bazyk, 2009).

Aspiring First Generation College Students

Additional barriers that “at-promise” youth face are unique pressures that come with preparing for college when becoming a first generation college student. First generation college students (FGCS) are defined as being “the first in their family to pursue a 4-year education” (Jehangir et al., 2020, p. 60). Specifically, a first generation college student impacts the student
with unfamiliarity in navigating college along with coming from a family with low income (Jehangir et al., 2020). The overall literature of aspiring first-generation college students emphasize the importance of involving the support of the school staff with the students. The student perspective is vital to incorporate into preparing support in readiness for college. Brookover et al. (2021) looked at how eighteen-year-old high school students prepared before entering college to help inform the school community how to offer appropriate support. This study emphasized the lack in the literature in the perspective of the students as to what their needs are for college readiness (Brookover et al. 2021). This study emphasizes the importance of collaboration among the students and the school staff to create a supportive environment for school readiness. To further strengthen this study, suggestions and evaluation of the current support system in place could have been effective to understand how to best support these students. Acevedo (2021) is another example of supporting college aspirations through the perspective of teachers of color. This study highlights the importance of trust that must be established before any support is offered. It is vital to provide support to aspiring college students, in addition to supporting their mental health, which did not seem to be offered. The teachers understand to a certain extent what the students need to succeed, but sometimes a student may not have that relationship with the school staff to let them know the mental health resources needed. Being the first college student in a family comes with pressures that need to be recognized.

Lastly, the literature indicated barriers to occupational balance when identifying roles and routines surrounding culture. Anastal et al. (2018) recognized the importance of addressing the gap in social-emotional learning among students and their relationship with school counselors and the need for interventions. One of the barriers that stood out was the difficulty for students in
finding a balance between “their familiar world and the college going world” (Anastal et al., 2018, p. 25) Through recognizing this transition, students can be further supported by their school staff. Tello and Lonn (2017) addressed the need to understand Latino/a/x culture in order to provide culturally competent services. Latino/a/x culture has some commonalities but is vital to recognize the intergenerational differences as well when supporting aspiring college students (Tello & Lonn, 2017).

**Imposter Syndrome**

The experience of imposter syndrome negatively impacts the way an individual views themselves or their ability to be successful in school, work, and other occupations that they desire to participate in. Imposter syndrome “refers to an individual who doubts their own skills, abilities, successes, and overall capabilities in their life,” which can significantly impact confidence, resilience, and mental health (Le, 2019, p. 22). Research indicates that imposter syndrome is commonly found in populations that may fall underneath the categories of high achieving, first generation college students, and minority populations (Lane, 2015; Le, 2019). This is because these populations may have many different environments and environmental barriers that are not supportive or apply pressure to pursuing higher education, branching out to new career fields, etc. One example of an environmental barrier for an individual is that the individual may have had negative experiences participating in everyday tasks due to racism or prejudice that impeded their ability to participate in a desired occupation and resulted in them changing their behavior to meet societal expectations (Beagan, 2009).

Furthermore, research has found that when minority populations, such as African Americans, are in a classroom setting, the African American students are more likely to feel shame, distrust, and resent their classmates due to feelings of inadequacy and a sense of not belonging in academia (Le, 2019). Similarly, Asian populations are also more likely to
experience imposter syndrome due to the immense amount of pressure that is placed on them by themselves and others because of the stereotype that they are always at the top of the class (Le, 2019). These populations are significantly at risk for experiencing anxiety and depression, as statistics show they are less likely to pursue mental health resources due to external factors such as distrust, cultural beliefs, and lack of awareness of resources (Le, 2019).

First generation college students are also significantly more likely to experience imposter syndrome and develop mental health conditions due to stressors related to academic expectations and pressures applied to themselves (Beagan, 2009). These high achieving individuals have a tendency to compare their performances to others and can develop a sense of competitiveness within their classes, which can result in a lack of social support and positive experiences with peers (Le 2019). First generation college students are also less likely to seek out mental health services or support; this may be due to the fact that first generation students are typically minority populations, who also are not likely to seek out mental health support (Le, 2019).

**Anxiety**

Mental health disorders and low levels of mental well-being can have a lasting effect on life satisfaction and contribution to society for children and adolescents (Brooks & Bannigan, 2021). Anxiety is a mental health challenge that can be a barrier to accessing occupations among youth. Children and adolescents experiencing anxiety find it challenging to maintain optimal occupational engagement and performance (Anderson, 2013). Anxiety can therefore affect functioning in a number of areas, inhibiting involvement in roles and routines (Anderson, 2013).

Youth’s experience with anxiety also impacts social participation. Leigh and Clark (2018) identifies that socially anxious youth face challenges with social relationships, such as having fewer friends, and peer and romantic relationships being of poorer quality. Youth’s
access to occupations is limited due to anxiety, and an inability to cope and navigate through effective ways of dealing with anxiety can lead to “high risk” occupations.

**Sexism**

Sexism at work gives rise to a sense of alienation, poor self-esteem, frustration, loneliness, poor job satisfaction, contributing to persistently increased stress response, anxiety, and depression (Mukhopadhyay et al., 2021). Women often experience microaggressions in the workplace due to social stereotypes associated with female gender, including domestic role idealization, more emotional sensitivity, concern, and sociability, and lack of assertiveness, independence, leadership quality, and professional competency (Hentschel et al., 2019). Sexist and racially microaggressive experiences were found to have statistically significant negative interpersonal and health outcomes in the areas of occupational self-efficacy, career outcome expectations, and symptoms of stress (McCurdy, 2020). Similarly, Vigod and Rochan found sexism at workplace, compounded with psychosocial stressors including caregiving burden to intimate partner violence, is found to affect women’s general well-being (2020). Sexism in the form of social stereotypes, such as expectations to fulfill the household chores, cooking, taking care of children’s needs, etc., are keeping women from seeking or maintaining higher positions (CEO, manager, editor, etc.) that regularly require more work hours than a regular 40 hour a week position (Cha, 2013). This discrimination is a barrier in occupations outside the workforce as well. For example, research on sexism in golf found that similar to how gender-linked attributes are used to discriminate in employment, the presumption that gender determines driving distance and speed of play subtly contribute to the presumption that only men deserve to be on the golf course (McGinnis et al., 2005). An important point to note is that although the majority of the research is on sexism and its occupational significance in the workforce, it doesn’t start there. It starts with the societal gender role assignment during upbringing and
educational opportunities received by girls as compared to boys. Women often have fewer opportunities and face classroom biases, influencing their risk avoidance, choice of subject, and career in the later life (“How does gender affect educational opportunity?,” 2019).

Discrimination based on sex is seen in individuals upbringing, education, sports, and in the workforce. The effects of discrimination can effect a person’s ability to participate and have success in their desired occupations, but sexism is not the only discrimination experienced by “at-promise” populations. Therefore, it is important to look further into other discriminatory barriers like racism that may potentially affect this population.

**Racism and Occupation**

Access to occupations is more difficult among some racial groups compared to others. Racism takes place in forms of microaggressions which are defined as everyday forms of racism (Roxas & Velez, 2019). For example, for individuals who identify as black living in Nova Scotia, they describe the occupation of “shopping” is different compared to individuals who identify as white, due to needing to be “on guard, vigilant against sudden status reminders, messages that are not welcome” (Beagan & Etowa, 2009, p.287). Thus, occupational engagement is affected by everyday racism. It is described that this prolonged exposure to microaggressions can result in dysfunctional behaviors, but if involved in liberatory activism and community engagement occupations, they can instead develop a positive sense of self, political efficacy, competency and healthy behaviors (Thomas, et al., 2008). In addition to understanding racism and its impact on occupations, it is vital to understand the multiple layers of it consisting of “extra organizational, intraorganizational and personal” (Svetaz et al., 2020, p.323).

Participation in occupations are vital for the well-being of participants, and it is important to recognize that racism has multiple layers that prohibit engagement in everyday occupations. It is important to understand how youth want teachers, students and other members of society to
respond to microaggressions (Roxas & Velez, 2019). Through understanding the point of view of “at-promise” youth experiencing racism will lead us in the direction of occupational justice.

Sverez et al (2020) identified the ecological model of anti-racism that is meant to disassemble the racism that exists in the communities. Through the promotion of an anti-racism approach some of the strategies included identifying practicing advocacy, working on terminology that is not stigmatizing and deconstructing racism in the various components (Sverez et al., 2020). Not addressing racism and leaving youth without tools of empowerment can also lead to the participation in more “high risk” occupations to find a community.

**Participatory Action Research (PAR)**

Upon the exploration of barriers to occupations faced by “at-promise” youth such as being first generation college students, having imposter syndrome, experiencing anxiety, racism and sexism, further exploration of PAR proved to be a powerful mechanism in which youth can advocate for social change. PAR combines aspects of popular education, community-based research, and action for social change. Emphasizing collaboration within marginalized or oppressed communities, participatory action research works to address the underlying causes of inequality while at the same time focusing on finding solutions to specific community concerns (Brydon-Miller & Maguire, 2009). PAR has been used with different populations in community and educational settings. Over the past five years, PAR has become much more widely accepted as an effective teaching, learning, and research practice for working with youth. Past research has also used a PAR method to more effectively support youth who live with high-risk, marginalized conditions, by emphasizing youth engagement and development (Iwasaki et al., 2014).

Lee et al. (2020) explored the ways that YouCreate, a youth-led arts-based
Participatory Action Research (PAR) pilot project designed by the International Institute for Child Rights and Development and Terre des hommes, provided a space for youth who have experienced migration and adversity to enhance their experience of meaningful participation. This research revealed the power that an arts-based PAR approach can have on strengthening youth’s wellbeing and enhancing their capacity and opportunities to engage in wider society, including in decision making. Stack and Fei (2018) utilized a school-based youth PAR to make room for students’ voices and engagement within the school curriculum. The study detailed the tensions between what the participants saw as necessary for schools to be places that create a sense of belonging and how the role of students is constructed through policies from the district to provincial levels and through societal attitudes about schooling and young people (Stack & Fei, 2018). Based on these studies, PAR gives youth the ability to engage in critical, creative analysis of their lived experiences, and engage them as full partners in their own learning (Burke & Greene, 2015).

Furthermore, previous research has also used PAR with individuals with physical, developmental, and intellectual challenges. Heffron et al. (2018) utilized a PAR approach to explore participation as defined and experienced by and with people with intellectual and developmental challenges from their insider perspective. This method can facilitate the advocacy of a change in the system for people with intellectual and developmental challenges. Lam et al. (2020) used PAR to support young adults with autism active engagement in the research processes and to encourage meaningful expression of their first-person perspectives. The results of this study revealed an account of well-being reflecting expressions of individuality and growth, the significance of having close relationships, and a sense of connection with the community.
The PAR research method could aid in bridging the gap in understanding between other cultural and ethnic backgrounds as well as geographical locations that have not been previously explored (Roxas, 2017). PAR research has also been found to facilitate empowerment at the community level and may be a key piece to aiding in the development of resolutions to social injustice and other social based barriers. In previously conducted studies it was found that PAR helped with social awareness of participants, specifically in professional and personal aspects (Christensen et al., 2018). The PAR research method allows for these under-represented populations to not only participate in the study, but also have an active role in the interpretation of the findings.

**Photovoice**

Photovoice has been used in a multitude of populations to gather insight and information to better understand the experience of others in their everyday lives. For example, Wang (1999) used photovoice to promote women’s health and to begin to build an understanding of what it is like to be a woman. From an occupational therapy perspective, photographs from women of their first person perspective could aid in the understanding of what key roles women play in their lives, what occupations are important to them, and if there are any barriers to occupational participation. Moreover, because of the simplistic nature of the methodology, Photovoice can be utilized among younger populations. A case in point, Strack, Magill, and McDonagh (2004) utilized the Photovoice method in an after-school program to test the effectiveness of the method with the youth population, and also developed and refined a curriculum for replication.

Though this method has been explored to be useful among youth, this population may benefit from further research with implementation of Photovoice. Photovoice offers individuals the ability to use their voices in environments where they otherwise may not have been able to express themselves previously. With this in mind, it would be interesting to measure and
identify the impacts of utilizing a medium such as Photovoice among an under-represented population to better understand the impact of expression and perhaps uncover occupational deprivation and barriers to occupational participation, as well as occupational injustice. For example, the voice of Indigenous youth is under-represented, and research with mobile Indigenous youth is limited (geographic mobility shapes social relationships) (Goodman et al., 2018). It is essential that these under-represented populations be further explored so that an understanding of the impact of voicelessness may be developed. Moreover, this research may also offer insight on the lived experiences of the participants' and if trauma due to racial and social injustice is present. However, before beginning a study of this nature, it is important to address racism and cultural competence before data collection, so that misinterpretation and assumptions are not wrongly implied (Sethi, 2016). Moreover, the population of youth “at-promise” is a group of individuals that are under-represented and may benefit from the usage of Photovoice, as it may aid in giving these individuals an outlet for expression, a sense of community, and a support system.

**Statement of Purpose**

The purpose of this literature review is to understand the significance of occupations in the lives of youth, and to understand barriers to occupation. We will be exploring occupational injustices using PAR and photovoice. Through highlighting how photovoice has been utilized in the past with under-represented groups we want to address occupational injustices faced daily by “At-promise” youth. Through utilizing participatory led research, we want to further empower youth to be advocates in their community. PAR and photovoice have been used in the past for social change. Photovoice has been used to highlight an understanding of an individual through their roles, occupations, or everyday life. Current research identifies the importance of participating in occupation, community participation and highlights structural inequalities in
addition to internal and external barriers. Barriers to engaging in occupation could be detrimental to the participants' health. Our research aim is to utilize PAR as a guide for youth to understand how to understand the root of barriers to occupation and how to promote action. Through utilizing an occupational therapy lens, using PAR methodology and photovoice, our research question is “What are the contexts and barriers that impact the occupations of youth”?

**Theoretical Framework**

We selected the participatory occupational justice framework (POJF) after evaluating the non-linear emphasis it took on identifying occupational injustices with a strong emphasis on context (Whiteford et al., 2018). POJF complimented PAR because we integrated a collaborative approach with the goal to raise awareness (Whiteford et al., 2018). POJF is extremely representative of the unique interactions in a community (Whiteford et al., 2018). POJF relates to our study because through photovoice the youth were able to collaborate and reflect on occupational injustices in the Huckleberry community. Social inclusion was also an important component of the POJF and can be seen as providing the resources to the individuals to ensure access and support in their own community (Whiteford et al., 2018). The goal of this study was to bring awareness and brainstorm how to dismantle these barriers that are present in their community.

In order to even begin the exploration of occupational injustices, we needed to make sure our participants had an understanding of what was meant by occupation and occupational justice. To create a participatory led research we began the study with education on occupation for our participants. The needs of a person are filled with everyday meaningful activities. With the understanding of occupation, we were able to dive deeper into the exploration of barriers in occupation. Occupational justice acknowledges the significance of the ability to participate in everyday occupations (Nilsson & Townsend, 2014). It includes having access to resources to
participate in occupations in order to meet personal, societal, and health needs, opportunities for social inclusion, as well as the accessibility and participation in meaningful occupations granted to others (AOTA, 2020). Murphy et al. (2017) indicated that occupational justice developed from the concept of social justice, which entails the rights of individuals to engage in desired or needed occupation, and to address equity and access. Moreover, occupational justice expands upon the concept of social justice by including issues that relate to OT such as participation, empowerment, and meaningful activity (Arnold & Rybski, 2010; Paul-Ward, 2009). The photovoice project was meant to address what were barriers to this occupational justice.

For the exploration of these barriers to occupation, occupational injustice guided our discussion. The exploration of occupational injustices can be understood through the exploration of context and structure which can highlight the power in government that can build walls in equal access for individuals in everyday activities (Nilsson & Townsend, 2014). Occupational injustices can be categorized as: occupational alienation, occupational deprivation, occupational marginalization, and occupational imbalance” (Townsend & Wilcock, 2004). Our study was focused on occupational imbalance and occupational deprivation. Occupational deprivation is the inability to engage in occupation due to factors outside the person’s control (Durocher et al., 2014). Occupational imbalance was described as the unequal distribution of amount spent in different occupations which results in a negative impact on the life of the individual (Durocher et al., 2014). These concepts were vital in the discussion of barriers to occupations for the youth.

**Ethical and Legal Considerations**

Based on the OT Code of Ethics, there are many ethical considerations to discuss when regarding Photovoice research and PAR methodology. First, it is important to remember the seven principles of the OT Code of Ethics, which are beneficence, nonmaleficence, autonomy and confidentiality, social Justice, procedural justice, veracity and fidelity, when working with
youth and young adults (Scott & Reitz, 2013, p. 36). In any occupational therapy study it is necessary to consider beneficence, veracity and fidelity to allow for a standard, truthful and integral experience for the safety and protection of the participants, professionals and researchers. Throughout recruitment, data collection and presenting the research, ethically, it is necessary to ensure honest cooperation from the participants and honest results. For this study, when working with “at-promise youth”, there is a sensitivity around trauma and social support. Because of this, there is a need to promote a safe space for participants to feel comfortable and comradery, objectivity and respect from authority figures. In regards to this study and the age of the participants, the research is focusing on nonmaleficence, confidentiality and autonomy, and justice.

In regards to nonmaleficence, it is important to not cause harm, physically or emotionally in any way (Scott & Reitz, 2013). This is especially important to consider due to the fact that these participants are “at-promise” youth and may have experienced traumatic events. It is the responsibility of the researchers and occupational therapists to make sure that participants feel safe and comfortable during the group sessions. It is also important to “protect participants from exposure to harm, especially when investigating private occupations” (Hartman, 2011, p.6). This means that the researchers and occupational therapists must consider the effect of certain photographs that might embarrass or expose the participants in any way that could harm them socially, emotionally or professionally.

In order to be confidential and autonomous with the participants, because this research is incorporating participatory action and community involvement, it will be important that the occupational therapists and researchers provide fair and equitable services to the participants. Continuing, because this research is participatory action research, it will be essential that even
though participants are involved in the research, that their identities, quotes and photographs will be strictly confidential, unless requested otherwise by the participant directly. It will be necessary to obtain “signed permission from the participants to use their photographs when disseminating the research” (Hartman, 2011, p. 6). This is explained in more detail in the supportive documentation section of the IRB appendices. Occupational therapists and researchers will also educate the public about occupational therapy and benefit the health status of the community (Scott & Reitz, 2013, p. 64).

Lastly, it is also important to focus on justice. Participatory action research also incorporates social justice when working with the community to present the findings from the participants. Social justice is important to consider as an education awareness tool for the research, in addition to the participants' advocacy. When working with “at-promise” youth, procedural justice will need to be considered due to the risky occupations that might be discussed during the group sessions. Based on the OT Code of Ethics, procedural justice means that “rules must be impartially followed and consistently applied to generate an unbiased decision” (Scott & Reitz, 2013, p. 77) Ethically, the researchers and occupational therapists need to consider which occupations are risky, harmful or even illegal to discuss openly (risky occupations-gangs, drugs...etc.) and follow rules for unbiased discussions. In regards to compensation for the participants, it is necessary to pay participants per session, otherwise the researchers would not uphold the justice of the agreement that the participants agreed to, which would be unethical and unfair to the participants, while also confusing and misleading them.
Methodology

Design

A qualitative participatory action research (PAR) method was used to increase the understanding that youth are the experts of their own experiences in identifying barriers, supports, and developing practical solutions related to their occupations and concerns of occupational justice. PAR has both the participants and researchers working together in all stages of the research process to understand social injustice and bring about change in a community (Organizing Engagement, 2020). This method is most appropriate for this study because this initiative is working with youth from the community where their occupations take place. The PAR method is implemented through the use of different phases as the research process continues on. For example, Foster-Fishman et al. (2010) designed a new PAR method that includes three phases: (1) problem identification and initial feedback using Photovoice; (2) data analysis of youth’s narratives; and (3) feedback and community dialogue. These three phases allow for a step by step process that guides researchers and participants throughout the progression of research to ensure that participants are given opportunities to engage in research. Moreover, these three phases keep the PAR research true to its purpose by providing guidelines that remind all involved in the study how PAR research is supposed to be utilized and conducted.

Photovoice was used to allow youth to accurately represent their lives and meaningful occupations through the use of photography. When utilizing Photovoice, participants were able to represent their worlds with their own photographs that they have taken with their own equipment, such as a camera, phone, ipad, etc., which they then can use as a medium of communication. In this study however some participants chose to utilize stock photos instead to visually represent their barriers. Photovoice allows for individuals to communicate details of their personal lives by having a first person viewpoint that others can get a glimpse of through
the photos taken. This allows for the analysis of the photos to highlight important occupations and roles a person may be a part of that would not otherwise be expressed or known (Wilson et al., 2007). Participant-led thematic analysis was applied to provide thematic and structured information on their meaningful occupations and the barriers to their occupations. The participants helped address topics of choice for their photos, as well as help find themes throughout their photographs.

Participants

Huckleberry Youth Program ACE Academy is a community based program in San Francisco and Marin Counties in California that provides social services to the “at-promise” youth. Youth may be referred to Huckleberry ACE Academy because they are facing mental health challenges, impacts from trauma, learning disabilities, social emotional difficulties, drug/alcohol addiction, teen pregnancy, sexually transmitted infections, violence, social and economic inequalities, physical or sexual abuse, and assisting in navigating social welfare, educational and juvenile justice systems (Huckleberry Youth Programs, n.d.). Participants were recruited by the Huckleberry staff via a newsletter and will contact Huckleberry staff by phone or email if interested. The participants were selected through purposive sampling. They included 4 females and 1 male. The inclusion criteria of our participants included youth ages 15 to 17 years old, in the 10th and 11th grade level of highschool and who are clients at the Huckleberry Youth Program ACE Academy, with female, male, and nonbinary being eligible to participate. Participants must also have access to Wifi and a camera. Exclusion criteria included individuals who were not current clients of Huckleberry ACE Academy youth program and individuals who were unable to obtain permission from their parents.
**Data Collection**

A demographic form was completed by the participants to describe the population studied and rule out any interested individuals that do not meet the inclusion criteria (see appendix E). There were a total of three sessions held through a Zoom subscription, a HIPAA compliant telehealth platform, and recorded. Our data was collected during the group in Google Jamboards, Zoom recordings, and notes taken by two of the researchers. Data collection was taken during the first and second sessions as the participants moved through the process of understanding the background of the research, explored their own occupational barriers through photography, and focused group discussions of photos on potential social injustices and barriers to occupations (social, racial, physical, emotional, financial). The other three group members reviewed the Zoom recordings, Jamboards, and added their own verbatim quotes on the word document of participants’ discussions on the photos.

Two researchers in the group sessions were responsible for facilitating group discussions, taking notes during observations and interacting with participants as needed to ask questions to further obtain data. The use of SHOWed questions (Appendix E) by the researchers was the primary means for guiding participant discussions during data collection. The participants' photos were saved on the password protected Photovoice google suite with folders under their alias name to ensure security of information. Finally, the collection of data was kept on a password secure Huckleberry drive. Huckleberry ACE Academy staff was responsible for keeping data initially secure by keeping the confidential information in a password protected google drive, stored on a password protected ACE Academy staff computer, behind a locked office door in the Huckleberry ACE Academy building.
Procedures

Before First Meeting

All youth and parents/guardians received and sent back consent and assent forms to fill out (Appendix C&D). These were filled out using google forms and saved on a private google drive accessed only by the researchers. Five participants completed assent and consent to and confirmed access to a phone, camera or means to take photos. If they did not have access to a camera, the researchers discussed with Huckleberry ACE Academy staff to get them access to a camera. Participants also signed a photo release form before participation in taking photos (Appendix G).

Orientation Session (approx. 90 minutes)

Researchers introduced the study, discussed group norms and expectations when creating a safe space for them to speak and feel heard. By the first session, the participants already filled out the demographic form (Appendix F). During this session photovoice and PAR were explained through examples from previous research. Researchers explained how phones and cameras will be used to capture participants’ occupations, identity, and barriers. Then researchers and participants discussed what occupations are and what potential barriers to occupations may look like. Participants then took photos in their environment during an activity on occupations and identity to get experience on describing photos. Participants freely discussed the photos without SHOWed questions. After the students presented the photos in their way, researchers presented the SHOWed questions to use for future sessions. Researchers explained that the next session will utilize SHOWed questions (see Appendix E) to probe discussions on photos and possible barriers to occupations (social, physical, emotional, financial). A verbal discussion was
held to try to find possible themes as a group. Session ended with having the students understand the photos needed for the discussion in two weeks will be barriers to occupations.

*Photo Project Showcase Session (approx. 90 minutes)*

Prior to this session, participants were asked to send their photos to the research specific email so that the researchers could have the photos prepared for the showcase in a shared jamboard document. Three out of the five participants sent in their photos to be used in the showcase and all were informed at the beginning of this session that their participation in discussions will be their valued contribution to this study whether they were able to send in photos or not. This session began by reviewing and agreeing on the group norms list that was created by the participants in the first session. The participants then agreed upon a combination approach to how they wanted to communicate during the photo showcase, which included the options to unmute, write in the chat, write on the Jamboard, and/or use emoji reactions to agree or disagree (thumbs up or thumbs down). The researchers explained how the showcase was going to be in Jamboard, with one picture on each page. It was also explained that with each photo, the person who took the photo would present their photo, potential barriers, and the meaning behind the photo for them. After the participant presents their photo, it will be open for discussion with the rest of the group using SHOWed questions (Appendix E) and communication approach of their choice. Lastly, it was explained that one researcher would be leading the showcase discussions while the other would be taking notes so that any unwritten comments could be documented for our themes discussion at the end. Immediately following this explanation, the showcase presentations commenced, SHOWed questions were used for each photo discussion, and most group discussion was through answering the SHOWed questions by posting sticky notes on the jamboard with the presented photo, while some were unmuted
comments. Due to the 90 minute time constraint, we were only able to present and discuss eight out of the nine photos received by participants. The participants and researchers agreed that within the next two weeks before our last session, if the participants who did not send in their photos would still like to contribute photos, they are able to send them in to be showcased at the last meeting. It was also agreed upon that during the next session we will finish the photo showcase discussions, discuss overall themes, and discuss the participants’ call to action based on these themes.

*Final Session (approx. 90 minutes)*

For the last meeting, the participants who did not finish presenting their pictures finished discussing them. The focus group will categorize the photographs to discover what the themes and/or barriers there are among the group. The focus group then brainstormed potential ideas for the call to action piece. This research group planned a call to action piece, but Huckleberry will implement the selected call to action with the participants.

*End of every session*

At the end of every session, participants and researchers debriefed to check in and discuss any difficult feelings or thoughts that have arisen during the duration of the session. It is important that during the debrief session all participants are aware of their barriers to occupation and that identifying them can be sensitive and/or difficult to discuss. If any of the participants were distressed by this they could stay after the session to debrief further with the ACE Academy Staff member or researchers where they may further request services to support their mental health. In cases where individuals were in need of further support, Huckleberry staff followed their safety protocol to ensure proper support was in place for participants. Another key component of closing the sessions was discussing any changes or talking about any new
information that will be introduced in the following weeks. During this time, participants could discuss any concerns or questions that they may have. At this time, participants also received confirmation that they will be obtaining their monetary compensation by the end of the day.

Data Analysis

Collected data was analyzed by a collaboration of both researchers and participants through use of the PAR research method. The PAR research method emphasizes empowerment and participation, which allows for both participants and researchers to collaborate on the thematic analysis of data.

During meeting sessions, the participants and researchers discussed and analyzed findings of the photos taken so that common themes may be developed and data will be correctly recorded. Prior to interpretation, the data was collected through the use of recordings that were then transcribed verbatim and field notes during zoom meetings. The data collected from recordings and field notes was used to facilitate discussion of themes and then coded by the researchers and participants. The recordings of zoom meetings were used for later reference to ensure that data is recorded correctly and to allow for participants to member check researchers.

The first stage of data analysis involved the participants collectively analyzing and identifying main themes in relation to the research question. During the Photo Project Showcase session, the participants shared and described the photos they took after the Orientation session. Using a similar approach to thematic analysis as Moore and Lynch (2018), the participants were presented with a visual device (Google Jamboard), which was used to organize the data and showcase their photos. The researchers then used SHOWed questions to formulate a discussion, and posted their quotes about each photo using the Google Jamboard sticky notes.

For stage two of data analysis, to code the data that has been collected, participants created an alias name that will allow for data to be stored and coded in relation to their name.
During the coding process, researchers and participants specifically looked at finding similar themes from the zoom meeting recordings, field notes, and verbatim so that accurate meaning is made of what is being stored. To maintain trustworthiness of data coding, researchers and participants will work together to derive meaning from data to ensure that what is being stored in records accurately reflects the client's experience with occupational engagement. Moreover, all researchers will be involved with the coding process as well to double check each other’s work to screen for errors and discrepancies. This double checking method will aid in ensuring accuracy, however, researchers will also meet to discuss data outside of designated meetings sessions for participants to review recordings to ensure that meaning of data was developed by the participants and not created by the researchers. Moreover, with the researchers utilizing SHOWed questions during the sessions, this will ensure that the researchers will have guided questions that they will be asking and are not asking questions that will obtain certain findings and themes that benefit the researcher’s agenda.

**Rigor and Trustworthiness**

To ensure trustworthiness, researchers made sure there was credibility, dependability, confirmability, and reflexivity. To enhance confirmability and credibility, data triangulation occurred using data gathered from recordings, observations, and focus groups. Peer debriefing was utilized where focus group information was shared as a team to verify findings. To ensure credibility and dependability, member checking involved the OT-researchers discussing the coding of the transcribed information back to the participants for accuracy and confirmation that the findings reflected their experiences. During team meetings, themes were created with researchers and participants present to reach group consensus and to mitigate bias through active discussion. To ensure reflexivity, there were multiple levels of verification between participants and researchers.
Reflexivity Statement

The research team comprises four women and one man between the ages of 23 and 29 with different socioeconomic statuses, personal biases, and cultural experiences, and are enrolled in a master’s level graduate program. Both group facilitators are female and have personal beliefs of experiencing the stressors faced by many of the youth of being aspiring first generation college students. Additionally, one facilitator shares similar experiences with the participants of being of a similar race and cultural background. This facilitator can relate to the impact race has on occupations. While the other facilitator is white-american, she reflects on the privileges that she has because of her race and how this is not the lived experience of the participants. By understanding her racial differences to the participants, she hopes to reduce personal bias.

Through this study, we believe that we will find barriers associated with the pressures of wanting to succeed and themes associated with imposter syndrome. Our hope for this study is that the youth become further involved in their Huckleberry Community to identify ways to advocate for themselves and others in the community.
Findings

Systemic Oppression: Racism and Sexism

Racism can inhibit the participants’ engagement in occupations. This social barrier can impact various aspects of an individual’s life and result in significant decrease in opportunity to participate in occupations of interest. Participants had the perspective that white individuals had more opportunity and also had the power to stop POC from attempting to engage in desired occupations, such as working. In this group of participants, it can be seen that POC may have a sense that they are set up to fail or have decreased chances of participating in opportunity due to white privilege and systemic oppression, which may have long-term negative impacts on resiliency and willingness to attempt new opportunities. The group discussed the topic of racism after one of the participants showed a picture of a white hand stopping a woman of color who was dressed in professional clothing (see Figure 1). The participant gave an interpretation of their photo:

Race is a big barrier in today’s world. The hand represents society (like a job). The young black lady is ready for the interview but the hand is pushing her away because society favors white people over people of color. (Katie)
Sexism was also discussed as a barrier to youth’s engagement in occupations. Based on the participants’ discussion of the photos, it can be interpreted that women have to work twice as hard as men, if not more. Based on what the participants discussed, there is an inherent advantage to being a white male in this society compared to a white female, or female of color. Furthermore, this led into a comment regarding the wage gap between genders. When discussing the photo of the ladder (see Figure 2), it brought up multiple comments from participants on how the ladder represents life and/or a career which has less opportunities that are more difficult to achieve for women than the ladder with more opportunities that are more easily achieved for men.

The ladder one has made it easier for boys to achieve success. I do not think I have experienced it but I will…. It is hard to accept but I am sure I will work my way around it. (Lisa)

We talked about the pay and the wage between women and men. Women deserve less due to their gender. The people on the top are usually white and you have to deal with their views. (Danessa)
Anxiety in Occupation

The second theme was barriers associated with how mental health impacts participation in occupations. What emerged specifically from the participants was the occurrence of social anxiety. This topic of social anxiety came into light when one participant discussed the experience of anxiety symptoms during a hike (see Figure 3), explaining that when going on a hike with her family for the first time in awhile, she felt:

Anxious, scared...I felt like it was hell at one point, but when I was coming back down. It felt like I climbed Mount Everest….I felt like I was in heaven. (Lily)
This quote describes the experience of social anxiety symptoms and how impactful these symptoms can be on day to day occupational engagement. The participant recognized that though she was with her family, participating in a leisure occupation that she enjoyed, there were significant feelings of fear and anxiety associated with the experience of hiking in a social setting. Despite these symptoms, the participant continued with the hike, indicating that there is a desire to continue with occupational engagement despite feelings of discomfort. Furthermore, the end of the quote could be interpreted as courage and perseverance in regards to barriers with mental health when performing an occupation in a social setting.

**The Experience of Aspiring First Generation College Students**

The third theme is preparing to become a first generation college student. This was discussed when one participant showed a picture of their summer 2021 plan. The picture of the plan the participant provided was a detailed to-do list and schedule that showed what the participant needed to complete in order to prepare for college over the summer break (Figure 4). Some quotes that were mentioned were that there was:
Over planning and stressing too much about the future….No time to rest now and live now….That sometimes gets in the way of enjoying something. (Lily)

This is a barrier because sometimes when you are too future oriented, it can create high expectations and let you down if your reality doesn't match with your plans.

Figure 4 College checklist

The participant shared that they were a first generation aspiring college student, so these quotes could be interpreted as a self created expectation and pressure to succeed as a first generation college student. Moreover, a significant amount of planning and preparation appears to depend on the participant, indicating that they may not have support within the family, as the family may not be aware of the intricacies that go into applying for college and meeting requirements. The group's discussion of being a first generation college student and how having
no time to rest and live now is indicative that they may have reduced occupational engagement due to time restraints and lack of occupational balance in their daily lives.

Moreover, the second quote indicates that a sense of self-doubt or lack of belief in one’s ability to achieve is apparent within participants. This may be due to the individual’s experience of not being successful in the past with regards to pursuing occupations of choice or from lack of opportunity and support to allow for success in occupational engagement. This quote is indicative of a sense of imposter syndrome, as participants believe that despite all they are doing to help themselves to succeed, if they try to set goals for themselves they will not achieve them and end up disappointing themselves. This is a common experience in individuals who are first gen-aspiring college students or are high achieving.
Discussion

The findings have contributed to answering our research question: “What are the contexts and barriers that impact the occupations of youth”? The barriers to occupational participation are anxiety, imposter syndrome, being an aspiring FGCS, sexism and racism. Using occupational justice the researchers can put into perspective what injustices “at-promise” youth face in their daily occupations. Occupational injustices that we found included occupation deprivation and occupation imbalance.

Anxiety prevented one participant from engaging in their occupation of hiking as seen in Figure 3. However, once she finished the hike, she felt accomplished, comparing it to climbing Mount Everest. This emphasizes a sense of meaning through participation in occupation, despite this barrier of anxiety. Being an aspiring FGCS was seen as anxiety provoking, with the presence of pressure to succeed, and high expectations; indicating that there likely is a presence of imposter syndrome in academia. Looking at these two themes from an occupational justice lens, our participants are experiencing occupational deprivation due to the stereotypes of FGCS and “at-promise” labels previously discussed in the literature (Nilsson & Townsend, 2014). Being a first generation student can also be viewed as an occupational imbalance. The participant’s quote in Figure 4. highlights occupational imbalance because she feels that she always has to plan ahead and be prepared for the future, instead of enjoying herself in the present moment. The participant, Lily, is so focused on being a first generation aspiring college student that she has given up leisure time and other occupations of choice so that she may work on college related tasks that may increase her chances of getting into a good college in the future, creating an occupational imbalance in her current day to day life. Lily recognized that this experience resulted in heightened levels of anxiety and worry surrounding academic success in the future.
Moreover, it is important to highlight the significance of the experience of imposter syndrome and how it can have a huge impact on overall senses of well-being and belief in one’s ability to perform well during occupational engagement (Beagan & Etowa, 2009). These participants are minority, high-achieving, and first generation college students, indicating that they are at an increased risk for feelings of imposter syndrome in the future, or may currently be experiencing these feelings due to precursors such as anxiety in academia. It can be argued that long-term experience of imposter syndrome can result in an individual withdrawing from important occupations due to feelings of inadequacy and lack of belonging, resulting in occupational deprivation. Research shows that when these populations are provided a supportive environment, whether it be with peers, at home, teachers, or employers, individuals report lower levels of stress than those who do not have these supports (Le, 2019).

The researchers also found that racism and sexism were topics that came up when discussing photos that participants presented. For example, in Figure 1, demonstrates the participants current perception of systemic racism and sexism and how it can impede an individual’s ability to participate in desired occupations, such as pursuing a career. Although the participants did not comment on actually experiencing sexism or racism in the present, they made it clear that based on their understanding of societal norms they are aware that this discrimination does exist and may impact their future pursuit of occupational engagement. They expressed worry that this discrimination is something they need to be prepared for when looking toward their futures. This anticipation for barriers based on the influence of social discrimination may be acting as a current barrier itself if it is effecting how the participants are currently planning for college and their career aspirations. In Figure 2, the participants related the ladders to life and career opportunities; the woman’s ladder having less opportunities that are more
difficult to reach. Sexism could be a contributor in this example due to microaggressions holding women back from moving up the ladder (McCurdy, 2020) or stereotypical expectations specific to homemaking and/or motherhood keeping their job opportunities limited to a specific amount of work hours so they can “do it all” (Cha, 2013). Discrimination in the areas of sexism and racism are already known to this youth population as a barrier that exists in the world and one they should prepare for if not one they have already experienced from something learned in school or at home. Although the barrier is known, the participants did not express any knowledge of how they can prepare for these discriminations which ultimately led to their ideas of wanting a safe place to further these types of discussions.
Implications

With regards to future community involvement and advocacy opportunities, the use of the PAR and photovoice methodology contributed to the occupational justice theory and how it can be utilized within the population. By first identifying the barriers these students were experiencing, this gave participants a direction in which they wanted to focus and allowed for the participants to work together to create a call to action piece that would be completed within the Huckleberry ACE Academy in which they attend. Our study demonstrates the positive impact that creating a sense of community can have on a population via the collaboration of occupational therapy students, a community partner, and the common goal of occupational justice by dismantling occupational barriers to increase occupational engagement within the “at-promise” youth population. With this in mind, it is crucial that these populations be provided with a supportive environment where they can feel a sense of belonging and community that fosters exploration of occupation and provides a positive experience that nourishes mental health and works to normalize the experience of imposter syndrome. If these populations are given further education on what imposter syndrome is and how it can affect their functioning, they may be able to change their relationship with their experiences with occupation and take steps to build resilience during times of high stress, so that they may be able to improve their overall satisfaction with their occupational performance.
Limitations

The presence of the COVID-19 virus was a significant impact on occupational engagement and a barrier to occupational participation in itself. This led to participants being unable to provide an accurate description of what their day to day occupations look like under normal circumstances. COVID-19 was also an impact on the abilities of researchers to create rapport with the participants and build a relationship that is conducive to gathering sensitive information, as all interaction during this time period will honor social distancing guidelines and will be online based. Another limitation of this study was that there was a disproportionate amount of women compared to men who participated in the focus groups, in addition to the facilitators being both females. This could have affected the comfort of the one male participant. For a future study, it should try to include a male and a female to be more representative of the group. Furthermore, the sample size of the population in general was also a limitation, as it is relatively small. This smaller sample size means that findings cannot be generalized to a larger population without further groups and research. While our study was meant to use images taken by the participants, it extended beyond to images found online. This occurred as a result of a participant being unable to express her barrier by taking a photograph. Therefore for the next time this study is done, the option of having images online can lead to more discussion for the PAR study.

Another limitation during the study was the time limit. Due to conducting the discussion on Zoom, the researchers could not anticipate the length of each section in order to fully discuss the photos and themes. It is necessary to adjust expectations and plan to meet the needs of the participant researchers to ensure they are able to share and say everything they want to say without feeling rushed in any way. Having more sessions could have allowed us to bring better
rapport with the students. The students were from different grade levels and did not know each other before the study which could have also added to the difficulty opening up on sensitive topics. Additionally, the use of a Google jamboard does not ensure all participants contributed equally to the research. There is no way to track on the jamboard who wrote each comment, so this may result in one participant dominating the conversation and could potentially hinder further conversation of topics among participants. The researchers facilitated the group and did not want to force participation as this is a sensitive topic that can cause distress. Further research on this should include longer sessions and a more flexible schedule to adhere to the participants’ needs. The last potential limitation was leaving the call to action piece to Huckleberry. The inability to complete the action piece with the research group is a limitation because the focus group will only plan an action. The actual plan is given to Huckleberry to implement at a later time.
Conclusion

The aim of this study is to allow for participants to represent themselves and their occupations of choice through the use of photos, while also allowing for them to identify and voice barriers in everyday occupations and the social/emotional impacts. Through this study, the following themes were found: racism and sexism, anxiety in occupation, and being an aspiring FGCS. Based on the discussion and literature, the themes of anxiety and being a first generation college student results in occupational deprivation and occupational imbalance of the youth, which may further lead to feelings of imposter syndrome in the future. The themes of sexism and racism resulted in difficulty with future occupational engagement for the participants as well.

This research study is vital to the field of occupational therapy because it is imperative to understand the inequality in the access of occupations. Furthermore, it enhances understanding of the importance of the context and barriers for individuals. With PAR and photovoice, the researchers contributed to the occupational justice framework by having the participants voice what they want as the solutions. PAR creates a dynamic in which both the researcher and the participant have an equal say in the research. Through having the participants guide all aspects of the research, the researchers add additional knowledge to what it means to have occupational injustice with the hopes of future justice. The journey towards occupational justice is a process, but by discussing these themes openly, “at-promise” youth are facilitating the removal of stigma from this population and are bringing to light the importance of occupational engagement and the impacts that barriers to occupational engagement can have on quality of life.

Within the field of occupational therapy, the researchers are advocates alongside the communities. The contribution of further research in the occupational injustices will allow us to understand the impact of these barriers to occupation on “at-promise” youth and the long-term
implications for overall well-being and quality of life. The PAR methodology with photovoice will aid in capturing the experience of “at-promise” youth to further communicate their stories, provide an opportunity for advocacy, and may be the precursor to facilitate the creation of a supportive community that strives towards occupational justice.
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INFORMATION LETTER LETTER OF INTRODUCTION TO POTENTIAL PARTICIPANTS IN OCCUPATIONAL BARRIERS STUDY
Dear Potential Study Participant,

We are five graduate students at Dominican University of California collaborating with Huckleberry Youth Programs, ACE Academy. We are conducting a research study as part of our Occupational Therapy masters program. The research study is being supervised by Karen McCarthy, OTD, OTR/L Professor of Occupational Therapy at Dominican University of California.

We are inviting you to participate in our study which is about using photography to explore racism in everyday activities. Participation in this study involves looking at and discussing photographs taken and selected by you by either Zoom or in person if allowable through current safety protocols of COVID.

If study is done through zoom it will involve:
- 3 online sessions
- 8 participants sharing their photographs
- 5 researchers and 1 ACE Academy Staff member (college advisor)
- You will receive a $25 dollar gift card for each session attended

To be eligible you must:
- Be between the ages of 16-18 years old
- Receive services at ACE Academy
- Proficient in English (group discussions will be in English)

If you have further questions, do not hesitate to contact Kerry Krohn at 510-461-6054 or ace@huckleberryyouth.org. Thank you for your interest.

Sincerely,

Kerry Krohn, OTS
Dominican University of California
50 Acacia Avenue
San Rafael, CA 94901
#Tellyourstory
Empowering Youth Through Photography
Youth will guide the research on the exploration of racism in everyday activities

Research will be facilitated by Dominican University of CA
Occupational Therapy students

You will Receive $25 per session (total 3 sessions)
DOMINICAN UNIVERSITY OF CALIFORNIA

I. I understand that I am being asked to participate in a research study designed to explore the barriers and supports of youth that may not have equal opportunity to activities, due to socioeconomic status, race, ethnicity, etc. This research is the main focus for an Occupational Therapy Program capstone called Exploration of Occupational Barriers of At-Promise Youth Using Photovoice. This research project is being supervised by Karen McCarthy, OTR/L, OTD of Occupational Therapy Department at Dominican University of California and ACE Academy. The youth who participate in the study will take pictures of their daily activities that are meaningful to them and then discuss as a group with the other youth participants. The participants are also “researchers”, who will participate in determining the questions that are relevant to the participants and analyzing the pictures taken by the youth.

II. I understand that participation in this research will involve independently taking pictures of my daily activities that are meaningful to me, and then discussing these pictures with other participants in a group. I understand that this will also involve participating in three 90 minute in person or online group sessions in the span of two months. I understand that topics discussed in these discussion groups will be about my daily life, thoughts and feelings relating to meaningful activities and potentially sensitive topics.

III. I understand that my participation in this study is completely voluntary and I am free to withdraw my participation at any time and for any reason.

IV. I understand that whether I agree to participate or not or if I decide to withdraw at any time of the study, I will not be penalized. My participation or refusal to participate or withdrawal from the study at any time will not affect the status of my participation in ACE Academy or my relationship with ACE Academy therapists.

V. I have been made aware that the group discussions will be recorded via audio, which will be transcribed into written texts. All identifying information and personal references in the recordings will be erased when these recordings are transcribed. All participants will be encoded as pseudonyms to keep confidentiality. This will be kept on a master doc, which will be kept in a password protected digital drive. The master doc will be separated from the recordings and other research files. One year after the completion of the research, all written and recorded materials will be destroyed.

VI. I agree to using photos in research
I am aware that my photos and verbal discussion will only be used in Dominican University of California’s Occupational Therapy program graduate capstone project poster presentations, workshops, and/or peer-reviewed journals with my consent, and I can refuse to include my photos or quotes at any point during or after the study. If I decide to not have my photos or discussion in the study, I can contact one of the student researchers or ACE Academy staff members. I will also not be able to view any publications related to this study until December 1, 2022.
VII. I understand that in order to take or present any pictures of any person(s), I must ask them for verbal consent. If verbal consent is not given, I understand that I can not take the photo and/or share it at photovoice meetings.

VIII. **I agree to release of liability for anonymity**

I understand that the content of this study, including the pictures, discussion points, or personal stories are confidential, and any unauthorized use of pictures (ex. posting on social media, discussing with family or friends outside the discussion group) is strictly prohibited, and if I violate any of the confidentiality stated above I will be eliminated from the study without compensation.

IX. I agree to release of liability for anonymity

I understand that the content of this study, including the pictures, discussion points, or personal stories are confidential, and any unauthorized use of pictures (ex. posting on social media, discussing with family or friends outside the discussion group) is strictly prohibited, and if I violate any of the confidentiality stated above I will be eliminated from the study without compensation.

X. I agree to release of liability for anonymity

I understand that the content of this study, including the pictures, discussion points, or personal stories are confidential, and any unauthorized use of pictures (ex. posting on social media, discussing with family or friends outside the discussion group) is strictly prohibited, and if I violate any of the confidentiality stated above I will be eliminated from the study without compensation.

XI. All procedures related to this research project have been satisfactorily explained to me prior to my voluntary election to participate.

If you decide you want to be in this study, please sign your name.

I. ________________________________, want to be in this research study.

________________________________________________________________________

(Sign your name here) (Date)
General Information about Research
This is a research study using photography to explore socioeconomic status, race, ethnicity, racism in everyday occupations, etc. in everyday meaningful activities, referred to as occupations by occupational therapists. You (or if you are signing on behalf of a minor, your child) will be taking pictures and discussing them on a zoom online group discussion or in person if allowable through current safety protocols of COVID. There will be eight participants including yourself, five researchers, and one Huckleberry staff member.

Procedures
Bi-weekly sessions and day and time of sessions will be decided with participants
Prior to First Meeting: All consented participants will confirm access to a phone, a camera or other means to take photos. If public health and safety permits, all sessions will be in person at the ACE Academy office at 361 3rd St, San Rafael, CA 94901, but if there are still regulations in place due to COVID-19, all sessions in this study will be online via zoom.

2 weeks after recruitment closes, there will be an Orientation Session (approx. 90 minutes): Researchers will introduce the study, discuss group norms and expectations when creating a safe space for the participants to speak and feel heard. Participants will fill out the demographic form at the beginning of this session where they will pick an alias name to be used in the final product of the paper so that their information remains confidential from the public (Appendix E). Forms will be kept on a secured drive assessed only by ACE Academy staff and researchers. During this session photovoice and PAR will be explained through examples from previous research (Goodman, 2018, Lam et al., 2020, Stack and Fei, 2018). Researchers will explain that phones and cameras will be used to capture participants’ occupations and barriers through taking photos of anything that the participant relates to their occupations and/or barriers in a way they can describe to the group. Then researchers will explain what occupations are and what potential barriers to occupations may look like. Participants will then take random photos in their environment during an activity on occupations to get experience on describing occupations and photos. Researchers will use SHOWed questions (Appendix E) to probe participants into discussion on photos and possible barriers to occupations (social, physical, emotional, financial). Then the researchers will present possible themes for the research question (i.e. impact of racism, socioeconomic status, gender, safety, discrimination, etc.) to the group. The overall research question and focus of the study will then be chosen by the participants as they discuss how the topics resonate with them. The participants will be given an explanation of their photo project to complete before the next session. This project will be taking photos based on the research question that either represents occupations and/or occupational barriers and bringing 3 of those photos to the next session where they will describe them to the group during the showcase.

2 weeks after Orientation session: Photo Project Showcase Session (approx. 90 minutes): The first part of the session will be that the participants share and describe photos taken. The researchers will use SHOWed questions (see Appendix E) to formulate a discussion with the participants. Social injustice and barriers to occupations (social, physical, emotional, financial) will be uncovered and explored. If this session is in-person, youth will share in a group peer setting with the research team in person. If the session is online through zoom, participants will be put in small peer groups and/or peer mentors to help analyze the photos (barriers, facilitators,
link to identity, problems) to discover possible solutions or calls to action. Then the participants and researchers will come together to mind map all the calls to action/problem ideas to decide on one to move forward with as a group. Lastly, participants will decide whether or not to formulate the call to action, which could be a letter to school, parents, community partner, and/or town hall; or a flyer to post in the community for awareness, or even a showcase of their photos to their parents or the community. During this stage, they will collectively work on this subject of action and decide how to distribute/present it as a group. This distribution or presentation will only be in person if there are no public health regulations in place against it due to COVID-19, otherwise it will be online via zoom.

Call to Action/Debrief Session (approx. 90 minutes): Participants will distribute and/or present their chosen course of action directly correlated to what they decided in the previous session or continue to discuss the topic if no call to action was determined.

End of every session (approx. the last 15 minutes): At the end of every session, participants and researchers will debrief to check in and discuss any difficult feelings or thoughts that have arisen during the duration of the sessions. It is important that during the debrief all participants are aware of their barriers to occupation and that identifying them can be sensitive and/or difficult to discuss. If any of the participants are distressed by this they can stay after the session to debrief further with the researchers where they may further request services to support their mental health. In cases where individuals are in need of further support, ACE Academy staff will follow their safety protocol to ensure proper support is in place for participants. Another key component of closing the sessions will be discussing any changes or talking about any new information that will be introduced in the next session. During this time, participants may also discuss any concerns or questions that they may have. Participants will receive their gift card compensation by the end of the day of each session they attended with a possibility of receiving 3 gift cards by the end of the research since there are 3 sessions.

Potential Risks

Participants may become more aware of the barriers in their lives, which could be emotionally tasking and discomforting. Participants’ conflicts with family, lack of family support, or trauma may cause emotional distress. Conflicts and disagreements could arise among participants during discussions of sensitive topics. The extensive length of the meetings may cause fatigue, and language barriers may lead to frustration.

Potential Benefits

A potential benefit to the participants is that they may get to strategize what actions to take about potential barriers to occupational participation that they may become aware of during the duration of the study. Moreover, because this research will be conducted in a group setting, participants may get the opportunity to develop a sense of community and create new connections among individuals that they may have not otherwise have had the opportunity to meet. This new community could further serve as a support system for individuals post-study and may allow for them to further explore their occupations and barriers in their day to day lives. Another potential benefit of the research is that participants will be provided with a means of
advocating for themselves or expressing their needs through the use of photography; this could further spark interest in art and introduce a new occupation to individuals in their day to day lives.

Confidentiality

Confidentiality cannot be guaranteed during the research study. However, data will be kept confidential by limiting access to research data, and limiting any potential bias or coercion from the researchers and ACE Academy staff. Group discussions and data analysis portions of the study will be held on a HIPAA compliant telehealth platform. You will pick a pseudonym to use during group discussions and for the published research to protect your identity from the public. Data from the group discussions will be stored on a password protected drive accessed only by the researchers and ACE Academy staff. ACE Academy staff will only discuss youth (using their preferred pseudonyms) with researchers after completion of data collection, during the data analysis portion of the study. The ACE Academy staff involved will only be there as a mental health support and will not facilitate group discussions in any way. If needed, the staff member can refer the client to in house mental health services within Huckleberry.

Compensation

You will receive a 25 dollar visa gift card for your diligent participation and self-exploration throughout the study after each session; each participant has an opportunity to earn a maximum of 75 dollars by the end of the study.

Additional Costs

To be compliant with current COVID-19 guidelines, all meetings will be conducted online through Zoom, so there will be no cost to the participants regarding transportation. However, if COVID-19 protocol were to be lifted, then participants would be required to find means of transportation for themselves to get to 361 3rd St, San Rafael, CA 94901 of the ACE Academy site for in-person sessions. In this scenario, participants will have to arrange for and fund their own transportation. The participants will be required to set aside time for Zoom meetings, but researchers will be flexible with scheduling and will strive to accommodate participants by scheduling at times when participants are available. Participants will also be required to actively participate in conversations regarding their photos and will need to provide effort in explanations or descriptions so that data may be collected accurately. In the extreme instance that a participant lost access to technology mid study, the participant may have to purchase new devices such as a cell phone, camera, or laptop if they desired to further participate in study.

Voluntary Participation and Right to Leave the Research
I understand that my participation in this study is completely voluntary and I am free to withdraw my participation at any time and for any reason. I understand that whether I agree to participate or not or if I decide to withdraw at any time of the study, I will not be penalized, and my participation or refusal to participate or withdrawal from the study at any time will not affect the status of my participation in ACE Academy or my relationship with my ACE Academy staff members.

Signature of parent or guardian (If participant is under the age of 18) or participant aged 18:

__________________________

Date: __________
APPENDIX E

SHOWed QUESTIONS (For discussion purposes)
● What do you see here?

● Why is this really happening here?

● How does this relate to our lives?

● Why does this situation, concern, or strength exist?

● Why do we care about it?

APPENDIX F

DEMOGRAPHIC FORM
PHOTOVOICE DEMOGRAPHIC FORM

Today’s date:

__________________________________________Gender:

____ Full Name ___________________________ Date of Birth (MM/DD/YY)

Parent/ Guardian Name (only needed if you are under 18 years of age)

Please provide an appropriate fake name of your choice that will act as your name for the process of data collection and published research *. : ______________________________

*If the same name is chosen by two participants, researchers will collaborate with participants to differentiate between them.

Access to a smartphone or camera to take photos during research: Y/N

Receive services at Huckleberry (if NO you cannot participate in this study): Y/N

Indicate which days you are available to participate (example: Monday 2-6pm):
Monday______ Tuesday _________ Wednesday_______ Thursday _________ Friday _________

Guardian Phone Number (only if you are under 18 years of age): (__________)

Participant Phone Number: (____) __________________________

Participant Email address: __________________________________

THANK YOU FOR YOUR PARTICIPATION!
APPENDIX G

PHOTO RELEASE FORM
DOMINICAN UNIVERSITY of CALIFORNIA

OCCUPATIONAL THERAPY DEPARTMENT

PHOTO RELEASE FORM

By signing my name below, I understand and agree that I will not take photographs of anyone other than myself and will use these photos to share the occupational barriers I experience every day. I will not share these photos with anyone or on social media platforms or public domains (i.e. Youtube, Wikipedia, or Reddit). I understand that the photos are used for the research only and acknowledge that I have been advised to delete photos taken during the duration of the study once the research has been completed, so as to protect my identity. The photos must be appropriate for youth and young adults, as they will be discussed openly with a group. Although your content is confidential, Huckleberry staff are mandated reporters and any personal explicit content (nudity, drug and/or alcohol usage) that is unsafe to yourself or others will be reported. I consent to have my photos be featured in the published research article and/or poster unless otherwise stated.

Signature: ________________________________

Date: ________________________________

Parent/ Guardian Name (only needed if you are under 18 years of age):

________________________

Signature: ________________________________

Date: ________________________________
APPENDIX H PHOTO RELEASE (SPANISH)

FORMULARIO DE LIBERACIÓN DE FOTOS
Formulario de liberación de fotos

Al firmar mi nombre a continuación, entiendo y acepto que no tomaré fotografías de nadie más que yo mismo y usaré estas fotos para compartir las barreras ocupacionales que experimento todos los días. No compartiré estas fotos con nadie ni en plataformas de redes sociales o dominios públicos (es decir, Youtube, Wikipedia o Reddit). Entiendo que las fotos se utilizan sólo para la investigación y reconozco que se me ha aconsejado eliminar las fotos tomadas durante la duración del estudio una vez que la investigación se ha completado, con el fin de proteger mi identidad. Las fotos deben ser apropiadas para los jóvenes y los adultos jóvenes, ya que se discutirán abiertamente con un grupo. Aunque su contenido es confidencial, el personal de Huckleberry son reporteros obligatorios y cualquier contenido explícito personal (desnudez, consumo de drogas y/o alcohol) que no sea seguro para usted o para otros será reportado. Doy mi consentimiento para que mis fotos aparezcan en el artículo de investigación publicado y / o póster a menos que se indique lo contrario.

Firma: __________________________________________________________
Fecha: __________________________________________________________

Nombre del Padre/Guardián (solo es necesario si es menor de 18 años):
________________________________________
Firma: __________________________________________________________
Fecha: __________________________________________________________
APPENDIX I

CONSENT (SPANISH)

FORMULARIO DE CONSENTIMIENTO
Información general sobre la investigación
Este es un estudio de investigación utilizando la fotografía para explorar el estatus socioeconómico, raza, etnia, etc., o el racismo en las ocupaciones cotidianas. Usted (o si está firmando en nombre de un menor de edad, su hijo) tomará fotos y las discutirá en una discusión de grupo en línea de zoom o en persona si se permite a través de los protocolos de seguridad actuales de COVID. Habrá ocho participantes, incluyendo a usted, cinco investigadores, un empleado de Huckleberry

Procedimientos
Las sesiones quincenales y el día y la hora de las sesiones se decidirán con los participantes

Antes de la Primera Reunión: Todos los participantes confirmarán el acceso a un teléfono, una cámara u otros medios para tomar fotos. Si la salud pública y la seguridad lo permiten, todas las sesiones serán en persona en la oficina de la Academia ACE en 361 3rd St, San Rafael, CA 94901, pero si todavía hay regulaciones debido a COVID-19, todas las sesiones en este estudio estarán en línea a través del zoom.

2 semanas después del cierre del reclutamiento, habrá una Sesión de Orientación (aprox. 90 minutos): Los investigadores presentarán el estudio, discutirán las normas y expectativas del grupo al crear un espacio seguro para que los participantes hablen y se sientan escuchados. Los participantes completarán el formulario demográfico al comienzo de esta sesión, donde elegirán un sobrenombre que se utilizará en el producto final del documento para que su información permanezca confidencial del público (Apéndice E). Los formularios se mantendrán en una unidad segura evaluada sólo por el personal de ACE Academy y los investigadores. Durante esta sesión, el fotovoz y el PAR se explicarán a través de ejemplos de investigaciones anteriores (Goodman, 2018, Lam et al., 2020, Stack and Fei, 2018). Los investigadores explicarán que los teléfonos y las cámaras se utilizarán para capturar las ocupaciones y barreras de los participantes a través de la toma de fotos de cualquier cosa que el participante relacione con sus ocupaciones y/o barreras de una manera que puedan describir al grupo. A continuación, los investigadores explicarán cuáles son las ocupaciones y cómo pueden ser las posibles barreras a las ocupaciones. Los participantes tomarán fotos aleatorias en su entorno durante una actividad sobre ocupaciones para obtener experiencia en la descripción de ocupaciones y fotos. Los investigadores utilizarán las preguntas SHOWed (ver Apéndice D) para sondear a los participantes en la discusión sobre fotos y posibles barreras a las ocupaciones (sociales, físicas, emocionales, financieras). A continuación, los investigadores presentarán posibles temas para la cuestión de la investigación (es decir, el impacto del racismo, el estatus socioeconómico, el género, la seguridad, la discriminación, etc.) al grupo. La pregunta general de investigación y el enfoque del estudio serán elegidos por los participantes mientras discuten cómo los temas resuenan con ellos. A los participantes se les dará una explicación de su proyecto fotográfico para completar antes de la próxima sesión. Este proyecto tomará fotos basadas en la pregunta de investigación que representa ocupaciones y/o barreras ocupacionales y llevará 3 de esas fotos a la próxima sesión donde las describirán al grupo durante el escaparate.

2 semanas después de la sesión de Orientación: Sesión de Showcase del Proyecto Fotográfico (aprox. 90 minutos): La primera parte de la sesión será que los participantes compartan y describan las fotos tomadas. Los investigadores utilizarán las preguntas SHOWed (véase el Apéndice D) para formular una discusión con los participantes. Se descubrirán y explorarán las
injusticias sociales y las barreras a las ocupaciones (sociales, físicas, emocionales, financieras). Si esta sesión es en persona, los jóvenes compartirán un entorno de compañeros de grupo con el equipo de investigación en persona. Si la sesión está en línea a través del zoom, los participantes serán puestos en pequeños grupos de pares y/o mentores de pares para ayudar a analizar las fotos (barreras, facilitadores, enlace a la identidad, problemas) para descubrir posibles soluciones o llamadas a la acción. A continuación, los participantes e investigadores se unirán a planificar todas las llamadas a la acción/ideas de problemas para decidir sobre uno para seguir adelante como un grupo. Por último, los participantes decidirán si formulan o no la llamada a la acción, que podría ser una carta a la escuela, a los padres, a la comunidad y/o al ayuntamiento; o un folleto para publicar en la comunidad para la conciencia, o incluso un escaparate de sus fotos a sus padres o a la comunidad. Durante esta etapa, trabajarán colectivamente en este tema de acción y decidirán cómo distribuirlo/presentarlo como grupo. Esta distribución o presentación sólo será en persona si no hay regulaciones de salud pública en su contra debido a COVID-19, de lo contrario será en línea a través de zoom.

**Llamada a la Acción/Sesión de Debrief (aprox. 90 minutos):** Los participantes distribuirán y/o presentarán el curso de acción elegido directamente correlacionado con lo que decidieron en la sesión anterior o continuarán discutiendo el tema si no se determina ninguna llamada a la acción.

**Final de cada sesión (aprox. los últimos 15 minutos):** Al final de cada sesión, los participantes e investigadores interrogarán para discutir cualquier sentimiento o pensamiento difícil que haya surgido durante la duración de las sesiones. Es importante que durante el informe todos los participantes sean conscientes de sus barreras a la ocupación y que identificarlos pueda ser sensible y/o difícil de discutir. Si alguno de los participantes se angustia por esto puede quedarse después de la sesión para informar más adelante con los investigadores donde pueden solicitar más servicios para apoyar su salud mental. En los casos en que las personas necesiten más apoyo, el personal de Academia ACE seguirá su protocolo de seguridad para garantizar que se reciban un apoyo adecuado para los participantes. Para cerrar las sesiones los participantes discutirán cualquier cambio o hablar sobre cualquier nueva información que se introducirá en la próxima sesión. Durante este tiempo, los participantes también pueden discutir cualquier inquietud o pregunta que puedan tener. Los participantes recibirán su compensación con tarjeta de regalo al final del día de cada sesión a la que asistieron con la posibilidad de recibir 3 tarjetas regalo al final de la investigación ya que hay 3 sesiones.

**Riesgos potenciales**

Los participantes pueden ser más conscientes de las barreras en sus vidas, que podrían ser emocionalmente difícil. Los conflictos de los participantes con la familia, la falta de apoyo familiar o el trauma pueden causar angustia emocional. Podrían surgir conflictos y desacuerdos entre los participantes durante los debates sobre temas sensibles. La amplia duración de las reuniones puede causar fatiga, y las barreras del lenguaje pueden llevar a la frustración.

**Beneficios potenciales**

Un beneficio potencial para los participantes es que pueden llegar a la estrategia de qué acciones tomar sobre las posibles barreras a la participación ocupacional que pueden tener en cuenta durante la duración del estudio. Además, debido a que esta investigación se llevará a cabo en un entorno grupal, los participantes pueden tener la oportunidad de desarrollar un sentido de
comunidad y crear nuevas conexiones entre individuos que de otra manera no han tenido la oportunidad de conocer. Esta nueva comunidad podría servir aún más como un sistema de apoyo para las personas después del estudio y puede permitirles explorar más a fondo sus ocupaciones y barreras en su vida cotidiana. Otro beneficio potencial de la investigación es que se proporcionará a los participantes un medio de abogar por sí mismos o expresar sus necesidades a través del uso de la fotografía; esto podría despertar aún más el interés por el arte e introducir una nueva ocupación a las personas en su vida cotidiana.

Confidencialidad

La confidencialidad no se puede garantizar durante el estudio de investigación. Sin embargo, los datos se mantendrán confidenciales limitando el acceso a los datos de investigación y limitando cualquier posible sesgo o coacción por parte de los investigadores y el personal de Academia ACE. Las discusiones grupales y las partes de análisis de datos del estudio se llevarán a cabo en una plataforma de telesalud compatible con HIPAA. Elegirás un seudónimo para usar durante las discusiones grupales y para la investigación publicada para proteger tu identidad del público. Los datos de las discusiones de grupo se almacenarán en una unidad de Google protegida por contraseña a la que solo acceden los investigadores y el personal de Academia ACE. El personal de Academia ACE solo hablará sobre los jóvenes (utilizando sus seudónimos preferidos) con los investigadores después de completar la recopilación de datos, durante la parte de análisis de datos del estudio. El personal de Academia ACE involucrado solo estará allí como apoyo de salud mental y no facilitará discusiones grupales de ninguna manera. Si es necesario, el miembro del personal puede referir al cliente a los servicios de salud mental dentro de Huckleberry.

Usted recibirá una tarjeta de regalo de visa de 25 dólares para su participación diligente y autoexploración a lo largo del estudio después de cada sesión; cada participante tiene la oportunidad de ganar un máximo de 75 dólares al final del estudio.

Costos adicionales

Para cumplir con las pautas actuales de COVID-19, todas las reuniones se llevarán a cabo en línea a través de Zoom, por lo que no habrá ningún costo para los participantes con respecto al transporte. Sin embargo, si se levantara el protocolo COVID-19, entonces los participantes tendrían que encontrar medios de transporte para ellos mismos para llegar al 361 3o St, San Rafael, CA 94901 del sitio de la Academia ACE para sesiones en persona. En este escenario, los participantes tendrán que organizar y financiar su propio transporte. Los participantes tendrán que reservar tiempo para las reuniones de Zoom, pero los investigadores serán flexibles con la programación y se esforzarán por acomodar a los participantes programando en momentos en que los participantes estén disponibles. Los participantes también deberán participar activamente en las conversaciones con respecto a sus fotos y tendrán que proporcionar esfuerzo en explicaciones o descripciones para que los datos puedan ser recogidos con precisión. En el caso extremo de que un participante perdió el acceso a la tecnología a mitad del estudio, el participante puede tener que comprar nuevos dispositivos como un teléfono celular, cámara o computadora portátil si desea participar más en el estudio.

Participación Voluntaria y Derecho a Dejar la Investigación
Entiendo que mi participación en este estudio es completamente voluntaria y soy libre de retirar mi participación en cualquier momento y por cualquier motivo. Entiendo que si acepto participar o no o si decido retirarme en cualquier momento del estudio, no seré penalizado, y mi participación o negativa a participar o retirarme del estudio en cualquier momento no afectará el estado de mi participación en Academia ACE o mi relación con mis miembros del personal de Academia ACE.

**Firma del padre o Guardián (si el participante es menor de 18 años) o participante de 18 años:**

___________________________

**Fecha:** __________
APPENDIX J

HUCKLEBERRY CONSENT TO RELEASE INFORMATION
I, _____________________________________________ (Parent or Guardian Name), hereby authorize Huckleberry Youth Programs staff and ______________________________________ (Name of Student’s High School) to exchange the following information in regards to _________________________________ (Student’s Name), in order to coordinate and assist in my student’s academic, social, and emotional progress.

If you authorize Huckleberry Youth Programs staff to have access to the information detailed below, please initial next to each item.

__________ Username and password to access to all academic records including transcripts, class schedule, progress reports, quarter and semester grades, attendance, and record of missing assignments through the school’s Aeries SIS Portals (online system)

__________ Unrestricted communications with my student’s teachers and administrative staff regarding my child’s behavior and academic progress

I understand that this permission to exchange confidential information expires one year after the date of initial authorization. I understand that I may revoke this consent at any time and that any cancellation or modification of this authorization must be done in writing. I am aware that I have the right to receive a copy of this authorization.

_________________________________________ Date
Student Signature

_________________________________________ Date
Parent/Guardian Signature

Aeries Username (email):_________________________________

Password:_____________________________________________
APPENDIX K

HUCKLEBERRY CONSENT TO RELEASE INFORMATION (SPANISH)
HUCKLEBERRY YOUTH PROGRAMS
AUTHORIZED PARA COMPARTIR E INTERCAMBIAR INFORMACION

Yo ___________________________________ (Nombre de Padre/ Madre/ Guardián) le doy permiso al personal de Huckleberry Youth Programs y de _____________________________ (Nombre de High School) para que compartan adecuada información sobre mi hija/hijo/a _______________________________ (Nombre de hijo/hija) para así coordinar y asistir en su desarrollo emocional, social y académico.

**Favor de escribir sus iniciales** al lado de los puntos siguientes si es que desean compartir esta información con el personal de Huckleberry Youth Programs:

- _______ El nombre de usuario y la contraseña para el sistema de grados. Esto les daría al personal de Huckleberry Youth Programs acceso a todos los archivos académicos de mi hijo/hija, incluyendo todas sus notas, su horario de clases, su asistencia escolar, y todas las tareas que le faltan.

- _______ Comunicación sin restricción entre el personal de Huckleberry Youth Programs y maestros de su hijo/hija acerca el comportamiento y el desarrollo académico de mi hija/hijo

Yo entiendo que este permiso para intercambiar información confidencial se vence en un año y de que yo puedo cancelar esta autorización en cualquier momento y si así lo decidiera necesito hacerlo por escrito. También he sido informada/o de que tengo derecho a obtener una copia de esta forma si así lo deseo.

Firma de la estudiante ________________________________ Fecha de hoy ____________

Firma del Padre/Madre/Guardián ______________________________ Fecha de hoy ____________

Aeries Username (email):

Password: ______________________________
APPENDIX L

HUCKLEBERRY PERMISSION FORM
PERMISSION FORM

Your son/daughter has been invited to participate in Huckleberry Youth Programs’ Wellness Academy. This year of Huckleberry Wellness Academy will run from January 2020 - December 2020.

I, _______________ , do hereby give my son/daughter, ________________
(Parent/guardian name)
(Son/daughter name)

permission to participate in the Huckleberry Wellness Academy, a program of Huckleberry Youth Programs, a non-profit organization that provides access to health services for Marin County residents. I understand that participation in this program means that my child will receive snacks/food and that I will let program staff know of any food allergies my child might have. I also understand that participation in Wellness Academy includes participation in recreational activities.

I, The undersigned:

1. In the event of an accident or other emergency, when a parent/guardian is not available, authorize any Huckleberry Youth Programs staff member or volunteer to make arrangements considered necessary for my child to receive hospital or medical care, including transportation. Under such circumstances, I authorize the physician named on this form, or should that physician not be available, a licensed physician or surgeon, to undertake the care and treatment deemed necessary for my child.

2. In addition, I also give permission to Huckleberry Youth Program staff to provide transportation for any activities associated with the Huckleberry Wellness Academy.

3. Agree to release, indemnify, and hold harmless Huckleberry Youth Programs, its employees and volunteers from damages, injury or death arising out of the above named student’s participation in the risks of such program.

4. Certify that the student is physically fit and able to engage in this activity.

5. Agree that the student shall act in a responsible manner and follow all rules and understand that violation of the rules may result in student(s) being sent home at the parent/guardian’s expense.

6. Agree to allow Huckleberry Youth Programs the use of video, photographs, pictures and statements taken during the event for promotion and information regarding the above-mentioned activity.

7. Agree to allow Huckleberry to administer an evaluation survey at the beginning and end of each year to assess student’s thoughts on specific health issues such as:
communication, health and wellness, self esteem, academic motivation, teen pregnancy and drug and alcohol abuse prevention. We will use these results to assess the needs of our students and how we can better serve them. This survey may be published for research purposes, while protecting student’s individual privacy.

Parent/Guardian signature: _________________________________ Date: ____________________________
APPENDIX M

HUCKLEBERRY PERMISSION FORM (SPANISH)
FORMA DE PERMISO

Huckleberry Youth Programs ha invitado a su hijo/hija a participar en Huckleberry Wellness Academy. **Huckleberry Wellness Academy se llevará a cabo desde enero 2020 - diciembre 2020.**

Yo, __________________________, por este acto le doy permiso a mi hijo/hija, ____________________________________

Nombre de Padre/Guardián

_____ Nombre de hijo/hija

de participar en Huckleberry Wellness Academy, un programa patrocinado por Huckleberry Youth Programs, una organización no lucrativa, que provee acceso a servicios de salud a residentes del Condado de Marin. Yo entiendo que como parte de este programa, mi hijo/hija recibirá comida **y que yo le dejaré saber al personal de los programas de cualquier alergia que mi hijo/hija tenga.** También entiendo que como parte de este programa, mi hijo/a participará en actividades físicas.

También le doy permiso a Huckleberry Youth Programs de proporcionar el transporte para cualquier actividad asociada con Huckleberry Wellness Academy.

**Yo, el infrascrito:**

1. **En caso de un accidente u otra emergencia, cuando no haya un padre/guardián, le doy la autorización a cualquier personal de Huckleberry Youth Programs de hacer los arreglos necesarios para que mi hijo/hija reciba atención médica, incluyendo transportación. Debajo tales circunstancias, yo autorizo al médico nombrado en esta forma, o si no está disponible este médico, que un médico o cirujano licenciado cuide a mi hijo/hija si es necesario.**

2. **Le doy permiso a los empleados de Huckleberry Youth Programs para proveer transportación para que mi hijo/a participe en las actividades del programa.**

3. **Acepto que Huckleberry Youth Programs y su personal no son responsables ni culpables por daños, heridas o muerte del estudiante nombrado, causado por su participación en Huckleberry Wellness Academy.**

4. **Yo afirmo que mi hijo/hija está físicamente apto para participar en actividades asociadas con los programas**
5. Acepto que el estudiante debería de actuar responsablemente y seguir todas las reglas correspondientes a este programa y entiendo que violación de las reglas puede resultar en suspensión del programa al costo del los padres/guardián.

6. Acepto que Huckleberry Youth Programs use las fotografías, video, y opiniones tomadas durante Huckleberry Wellness Academy como promoción e información sobre el programa.

7. Acepto que mi hijo/hija participe en la evaluación de Huckleberry Wellness Academy al principio y al final del año académico. La evaluación consiste en un cuestionario en que se les preguntará a los estudiantes sus opiniones e ideas sobre temas relacionados a la salud como son: la comunicación, el auto estima, la prevención del embarazo entre jóvenes y la prevención del uso del alcohol y drogas. Esta evaluación será utilizada para mejorar los servicios que les ofrecemos a los jóvenes y para llevar a cabo investigaciones relacionadas con la salud y bienestar de los adolescentes.

Firma de Padre/Guardián: ___________________________ Fecha: ___________________________