

# MUSIC IS MY LIFE

A SHOW OF ART BY  
HOMELESS YOUNG PEOPLE

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# ENGAGING HOMELESS YOUNG PEOPLE IN HCI RESEARCH

## THEY ARE NOT JUST VULNERABLE, BUT ALSO SUSCEPTIBLE



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As HCI researchers, what do we mean when we describe a group of people as vulnerable? And, furthermore, how should we proceed? In an effort to make progress on these questions, here I discuss vulnerability, susceptibility, and more than six years of research with homeless young people.

Vulnerability has been used as a principle in human research subject protection at least since the Belmont Report was published in 1979. Yet some have questioned the usefulness of vulnerability on the grounds that it **has been** too broadly applied and that it is not a principle at all but rather a description of the human condition.

Taking up the first point, that vulnerability has been applied too broadly, we can consider the sheer number of groups that have been described as vulnerable. In U.S. government and international organization documents, vulnerability has been assigned to groups as diverse as pregnant women, children, prisoners, students, employees, members of the armed forces or police, nursing home residents, people receiving welfare benefits or social assistance, other poor people, the unemployed, patients, some ethnic and racial minority groups, homeless persons, nomads, refugees, politically powerless individuals, and

people unfamiliar with modern medical concepts. Identifying all these groups as vulnerable may help to frame research that is less likely to cause harm to participants. However, it also gives rise to the question: Is everyone vulnerable?

Answering this question, bioethics scholar Miguel Kottow argues that all human beings are vulnerable and that groups of people labeled as vulnerable may in fact be *susceptible*. This distinction is subtle but important. Vulnerability applies to everyone, since all human beings are “poorly equipped with instinct and their nature is incomplete, wherein lies their potential flourishing but also their

## SPECIAL TOPIC

vulnerability ... perils also lurk in the aggressive behavior of fellowmen and the violation of socially accepted rights" [1]. Thus, vulnerability describes a state—where harm is possible but has not already occurred—that applies to all. On the other hand, susceptible people are those who are no longer in a state of unharmed vulnerability, since they have already been harmed in a way that leaves them open to further harm. Thus, susceptibility arises for people who "having become the victims of harm and deficiencies ... are now in a vulnerable state of susceptibility that ... indicates ... increased liability to additional harm" [1].

To illustrate the difference between vulnerability and susceptibility, consider the case of homeless young people, ages 15 to 30. Following Kottow, we may say that all young people, whether living at home or homeless, are vulnerable. However, there do seem to be important differences between young people still living at home or supported by families and young people who are experiencing homelessness. How might we differentiate between these two groups? Again, following Kottow, we say that the young people experiencing homelessness have already been harmed and so are susceptible to further harm. This leads to two questions: From where did this previous harm arise? And how might homeless young people be further harmed?

Regarding previous harms, extensive research in psychology and sociology has reported that young people who become homeless have often experienced abuse or neglect in early childhood, leading to a higher likelihood of mental illness and substance abuse [2]. Additionally, young people who become homeless have often had negative experiences with institutions such as schools, foster care, and other social services. Due to these harms, young people experiencing homelessness do not

generally trust strangers, adults, and institutions. This, in turn, affects a homeless young person's ability to take part in formal education programs, find work, and participate in mainstream society, leading to a general lack of life skills that may lead to instability and homelessness.

Once homeless, a young person may be further harmed by persistent negative experiences with institutions such as police and the court system, by violence, or by the situational exacerbation of mental illness or substance abuse, and so on. Harm may also arise through societal factors such as stigmatization and stereotyping. Finally, and important for our purposes, the potential exists that further harm may come if homeless young people participate in research. For instance, since homelessness carries stigma in the U.S., young people may be harmed if their confidentiality is not maintained by researchers and their status as homeless becomes common knowledge. Or, in another example, since many young people who experience homelessness attend programs at service agencies especially designed to meet their needs, they may be further harmed if researchers intervene in the operation of these service agencies in ways that interfere with services and weaken systems of support.

Thus, previously harmed and at risk of further harm, homeless young people, unlike their homed peers, are susceptible—even to harm arising from the actions of well-meaning researchers. However, this is by no means a monolithic group but rather a heterogeneous mix of youths and young adults with a wide variety of experiences. Thus, susceptibility is not fixed and invariable but may range over a wide spectrum, differing substantially from one young person to the next. Additionally, like anyone their age, homeless young people are navigating the terrain between

youth and young adulthood and have ordinary developmental desires for autonomy and independence. Accordingly, researchers who engage with homeless young people need to respect their dignity while also paying close attention to the particular needs brought on by their extraordinary circumstances.

Since homeless young people are susceptible, if we seek to investigate the experiences they have with information systems and technologies, how should we engage them in HCI research? I have explored this question for more than six years. To provide examples of how I employed susceptibility as a working concept, I will discuss here my research and summarize four ways in which I accounted for susceptibility: long-term commitment, participation, precaution, and methods and dissemination.

**Long-term commitment.** We now know that homeless young people engage regularly with a variety of computational devices [3]. Yet, when I began in 2007, little was known about their experiences with information systems and technologies. Given their susceptibility and the potential for further harm, it was important to proceed in a way that allowed me to gain skills and knowledge for working with homeless young people. One way to build skills and knowledge is to proceed slowly, allowing time to reflect on prior experiences, refine approaches, and re-examine purposes. Subsequently, I employed value-sensitive design theory and methods [4] and made a long-term commitment to HCI research with homeless young people, working with hundreds of young people over the past six years.

**Participation.** Another way to proceed in research with homeless young people while remaining mindful of their susceptibility, heterogeneity, and autonomy is to engage actively with their community. Therefore, I co-created a community technology center for homeless young people, where I was a volunteer instructor and taught classes to more than 100 young people in 18 months. Students at the community technology center were, on average, the same age as undergraduate students, but their circumstances and past experiences left them largely unprepared for finding work. Thus, classes focused on practical computer-mediated activities related to finding

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a job, such as applying for work online. However, unlike other courses, the classes in the community technology center used techniques employed in design studios. Thus, students were invited into learning activities oriented toward acquiring life skills while also enhancing their capacity for self-reflection [5]. Young people responded very positively to the classes, and staff at the service agency that houses the center have built on the curriculum, continuing to use it to engage homeless young people.

**Precaution.** Information systems necessarily intervene in people's lives, changing conditions and bringing both benefits and risks. Accordingly, I consider the question of benefit versus risk by asking, "Am I doing more harm or more good?" This question is vitally important when working with homeless young people, who are susceptible yet autonomous and deserve respect rather than paternalism.

In order to engage precaution, I wrote value scenarios, which take the long-term effects of information systems and technologies into account. In writing these scenarios, I reflected on my values as a designer, specifically how I might adopt a stance of precaution for working with homeless young people while also finding a way forward in designing new systems or making changes to those that already exist [6]. Additionally, I reflected on the community technology center along with service agency staff and a young person transitioning out of homelessness. We considered how digital media had been introduced into a service agency setting without negatively impacting vital relationships between young people and service agency staff [5].

**Methods and dissemination.** In order to take susceptibility into account while remaining attentive to the wide range of experiences and skills among homeless young people, I purposefully employed a broad range of methods in my research. For example, building on the keen interest that homeless young people have in music [3,4] and aided by my formal musical training and years of performing and teaching, my dissertation explored the role of music in the lives of homeless young people. In order to remove barriers to participation, I incorporated activities tailored for people with different



**Figure 1.** Shelly was feeling depressed one day, so she took her Music Emote with her on a walk. She put in her ear buds and used the keyboard to type "Sad/Lonely." The Music Emote pulled up a list of songs that fit the description, and Shelly listened to those songs as she took her walk. Afterward, Shelly felt happier because she was able to listen to songs that she could genuinely relate to. Shelly uses her Music Emote almost every day to help herself be in better control of her emotions.

levels of comfort or ability, including interviews, which emphasized verbal expression, and design activities, which emphasized drawing and writing [4].

Additionally, the design activity was carefully planned so that participant contributions could be shared in community settings. In the design activity, young people envisioned music devices that could help someone who was homeless, drew pictures of the devices, and wrote stories about situations where the devices would be used (see example in Figure 1). All of the drawings and stories are anonymous, and participants chose whether to give permission for their drawings and stories to be included in a public art exhibit. This resulted in a set of 129 drawings and stories that make up an exhibit called "Music Is My Life." Funded in part by a grant from the City of Seattle Neighborhood Matching Fund, the "Music Is My Life" exhibit recently completed a three-month run at a contemporary art museum, where it was seen by more than 4,000 people, and is currently on display at a small gallery downtown.

In order to increase the likelihood that the exhibit would meet the goals and needs of homeless young people and the larger community, young people were part of the planning team and worked alongside staff, faculty, and students at the University of Washington, businesspeople, service agency staff, and other neighbors. (Find out more about "Music Is My Life" at <http://www.facebook.com/MusicIsMyLifeProject>)

**Conclusion.** This article distinguished between vulnerability and susceptibility, providing examples of the application of susceptibility as a working concept in HCI research with homeless young people. Looking forward, the possibility exists that considerations of long-term commitment, participation, precaution, and methods and dissemination may be useful to HCI researchers who wish to engage with groups typically described as being vulnerable.

#### ENDNOTES

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