The Institutionalization of Ethics
Challenges for Community-Based Research with Young People in the 21st Century

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Introduction

Engaging young people in critical social, political, and environmental issues via community-based research (CBR) benefits young people and the communities in which they live in many ways. At the program level, inviting young to participate in decision making within their schools and other youth-related programs improves academic performance (Vieno, et al. 2007), general participation (Ellis and Caldwell 2005) and overall well-being (Evans and Prilleltensky 2007). Opportunities for meaningful decision making are among the key qualities of youth development programs (Gambone et al. 2004). More broadly, communities that include young people in projects targeting local issues benefit through strong citizenry and a vibrant youth population (Flanagan, Syvertsen and Stout 2007; Libby, Sedonaen and Bliss 2006; Schusler et al. 2009). It is not surprising, given the evidence that youth engagement benefits young people and their communities, that many scholars now look for opportunities to engage young people in the research process. CBR is an approach to addressing critical social, political, economic, environmental or other community issues and places participants at the center of the research process. For young people, this means researchers engaging directly with those affected by such issues and inviting young people to be at the forefront of identifying problems, gathering information, and crafting and implementing solutions. As researchers seek to address community based problems in their research, engaging with young people in their communities is an important consideration for creating lasting change. However, as we will explore in this chapter, conducting research with young people can lead to a unique set of ethical problems for adult researchers.

An increasing number of studies employing a CBR approach suggest this is a growing trend among youth studies scholars. For example, researchers have worked with young people to consider potential programs that could address physical activity levels among tribal young people (Perry and Hoffman 2010). In a similar study, young participants were asked to identify community-preferred health interventions to address obesity (Goh et al. 2009). Photovoice,
a program that gives young people video cameras to document social problems, has been used to build curriculum, engage young people to address policy issues (Strack, Magill and McDonagh 2004), and to develop a youth violence prevention intervention (Snider et al. 2010). Trussell (2008, 164) suggests trends toward CBR with young people are a “paradigm shift [that] conceptualizes young people as active competent participants in the research process.” According to Trussel (2008), potential methods include those noted above, such as program design and implementation, in-depth interviews, and more unique methods, such as creating rap music, drawings, or writing an ethnography.

Based on this trend, CBR appears to be a promising way to enhance our understanding of how young people interact with critical social issues and an effective way to promote overall youth development. Placing a young person in the researcher role, which is a position of power, clearly has many benefits, yet our experience with CBR suggests there are many ethical questions that can arise from research that challenges the power differential characteristic of traditional research methods.

CBR is a different type of research, from the process of developing research questions with community members to sharing results immediately with those affected; there is much to CBR that does not look like ‘traditional’ research. However, most universities still evaluate and approve CBR by the same standards applied to all research; an ethic of justice; a focus on non-malfeasance and beneficence. Of course, community-based researchers desire those same outcomes, but the process by which they go about preventing harm and doing the most good is very different. This issue can become especially pronounced when researchers want to work with young people to address community problems. Young people, who hold significant knowledge about their world, not to mention the potential to change it, are considered legal minors and thus subject to additional protections in research. In this chapter, we will argue that Institutional Review Board (IRB) (Ethics Review Board in some countries) justice-based criteria used to evaluate research are not appropriate for CBR, and can in fact often undermine the very good CBR tries to accomplish, especially with young people. We will then suggest that an ethic of care (EOC) better aligns with the goals of CBR, and is a more relevant standard by which an IRB should evaluate the appropriateness of research involving young people. This examination, which builds on our experience navigating the IRB process, as well as ideas from related literature, asks scholars to consider and advocate for a new approach to the IRB—one that replaces limiting ideas about right and wrong with views about shared power among scholars and young people in the entire research process.