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The Ethics of Research on "Babies Born of Wartime Rape" and other "Hard Cases": Challenges and Limitations of Participatory Approaches

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> *"They come here with narrow goals and time limits; they want to find the material for a specific subject in order to publish an article on it. They are not at all interested in receiving all the information on a subject. They do not want to get involved. They only want enough for their story."*[1]

Researchers may like to cast themselves as neutral observers of human phenomena using the simple, straightforward pursuit of the scientific method. Their "job" is to take theories and skills into the field, conduct research, write up the information, and move on to the next project. This style of research is, in Ratnesh Parthak's terminology, "tour bus scholarship."[2] The research is "unidirectional," as the researcher takes information from a subject and gives back little or nothing in return. This unidirectional research pattern is even more pronounced in the field of human rights where – in the words of one human rights researcher – "the whole point is to go in and get the facts about what happened and to get out quickly and publicize them." (citation?) Human rights researchers at international nongovernmental organizations like Human Rights Watch (HRW) and Amnesty International (AI) are taught to be neutral observers, to interview subjects one-by-one, in a kind manner, but without taking on the role of social worker or promising anything in return for testimony. By collecting information for purposes other than advocacy goals, academic researchers in the human rights field differ from their NGO counterparts in some respects, yet they tend also to be unidirectional in approach.

Unidirectional fieldwork suffers from two main ethical dilemmas. First, researchers acting under this paradigm do not see themselves as *intervening* in local affairs and, thus, fail to appreciate how their actions may spark existing tensions and ignite new conflicts. The process of outsiders interacting with local individuals and groups can affect power difference among conflicting groups, legitimize one group over another, or provide more information to the parties of the conflict about the past situation or the present. Recognizing research as intervention invites researchers to consider themselves not as doing researche *upon* a society, but rather *with* or *within* a society. This leads to the second (and very much interrelated) ethical dilemma. The uni-directional? research approach denies agency to actors in the local community and renders witnesses mere objects under study. What is missing is a compassionate engagement with the

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[1] Ratnesh Pathak, "Commercial Ventures and Tour Bus Scholarship in Banaras." *South Asia Graduate Research Journal* 3, No. 2 (Fall 1996): 38.
[2] Ibid.

subjects of the research and flexibility in pursuing the research agenda, while the researcher remains open to the possibilities of learning not just about, but *from* the local community.

The failure to engage fully at a local level may be explained in part by a desire to safeguard the privacy of the research subjects and to avoid retraumatizing "vulnerable" populations. In the human rights field, where protection of the identity of witnesses is a top priority, researchers find it difficult to imagine how they can possibly honor their witnesses' protection needs while engaging in larger community-level issues. For academic researchers, however, additional pragmatic considerations come into play. With often limited funding and time, researchers find it difficult to step outside of their agendas to contemplate how their research can or should avoid harm and add value to the community. Getting a paper published in a good academic journal requires an interesting and original topic, verifiable data, and good writing skills. Publishing requirements, however, do not necessitate any demonstration that the research process built capacity in the local community or that the research will be translated back to the community in a means that is clear, understandable, and useful for actors pursuing a social change agenda.

In contrast to traditional approaches, participatory research methods do not assume a great distance between the researcher and the researched.[3] On the contrary, this approach to fieldwork envisions a collaborative and mutually beneficial research *process* that "aims to develop theory which is not simply abstract but is a guide to inquiry and action at the present time."[4] This chapter explores how researchers could draw from the participatory research approach in addressing ethical issues that arise when conducting research on "hard cases," such as babies born of wartime rape in violently divided societies.[5]

Research on children anywhere – and, particularly on the population of children born of wartime - is "hard" in that it raises many ethical dilemmas without clear-cut solutions. While researchers may be motivated by a desire to help an exploited and extremely marginalized population, their work may result in the labeling of the population and foster their further exploitation. In other words, by studying the children researchers undermine their protection by drawing attention to them. Yet at the same time, the abandonment of research projects on children born of wartime rape will almost certainly ensure their further marginalization. Research on "hard" cases cannot be abandoned because researching in an ethically responsible manner is hard going. The research design, however, can be crafted to better safeguard the dignity of all involved. This chapter outlines the argument for a more participatory approach.

Our discussion is divided into three parts. First, we begin with outlining the ethical concerns that arise whenever researchers work on difficult human rights issues in violently divided societies. Second, we turn to an explanation of participatory research, identifying its key attributes and outlining the ways in which it could address some of the ethical concerns of researchers working in violently divided societies on all issues, but especially babies born of wartime rape. Finally, we conclude with a list of ethical considerations that may help guide research on "hard topics" such as babies born of wartime rape.

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[3] Marlene de Laine, *Fieldwork, Participation and Practice* (London: Sage, 2000): 17, 27.

[4] Peter Reason, "Learning and Change Through Action Research," in J. Henry, eds, *Creative Management* (London: Sage, 2001).

[5] We use the term "violently divided societies" as more inclusive and more accurate than post-conflict societies. As our colleague and teacher Mohammed Abu-Nimer points out, all societies are always in some relationship to conflict and, thus, never truly "post-conflict."

CONTEXT MATTERS: RESEARCH IN A TRANSITIONAL SOCIETY

> *"Hi, have you seen any raped women?"* – Foreign journalist to human rights researcher, Zagreb, January 2003.
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> *"Once you find all those babies [born of wartime rape], we can start adopting them."* – Philanthropist to human rights researcher, New York, January 2003.

Research on deeply personal and socially taboo topics in violently divided societies poses special considerations. These societies are dealing with a legacy, sometimes stretching over a period of several years, of abuses of power that result in massive violence, large-scale violations of human rights, and institutional injustice. These are traumatized societies recovering from a period of terror and widespread violence. At the same time, they are societies that are trying to shape their own future, often in the face of heavy outside pressure. Dependency on foreign donors skews all aspects of civil society, and academic research is no exception. Power dynamics within and outside the area under study influence, for better or for worse, research agendas. The issue of "babies born of wartime rape" has garnered attention of researchers, not necessarily because it is a priority to people in the Balkans,[6] but because it is of great interest to people outside the Balkans. What ethical guideposts should guide researchers under these circumstances?

One guiding principle is based on the Hippocratic Oath of "do no harm" to the communities involved in the study.[7] This approach recognizes that even good intentions can have negative impacts. It allows for research interventions, but demands that the researcher take responsibility for the process, monitoring its impact and readjusting as needed. With a "do no harm" approach, the intervening parties learn from mistakes and successes and monitor their actions to ensure that no damage is done to the community. In violently divided societies, "do no harm" would require researchers to acknowledge the impact of outside pressures and be aware of their own role in perpetuating or challenging existing local power dynamics, as well as their role in shaping local public policy agendas.

Public debate at the local level often is predetermined by the international agenda, not by local concerns. One illustration of the kind of distortion that results from imposition of international agendas pertains to women's groups. In her study of the impact of international assistance on local NGOs, Aida Bagic found that women's groups that were established under the guidance of international agencies tended to reinforce women's traditional roles as caretakers

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[6] In Bosnia women today are concerned about such issues as recovering the remains of missing persons, obtaining better health care for themselves and their families, and improving the long-term economic prospects for their family and their state. In interviews conducted by the author and her research assistant with nearly a dozen women's groups in the summer and fall of 2003, not a single woman mentioned "babies born of wartime rape" as a priority issue. This does not mean that no one in the Balkans is concerned with this issue and indeed other organizations focusing either more specifically on children or more generally on humanitarian issues are addressing this issue.

[7] Mary B. Anderson,"Humanitarian NGOs in Conflict Intervention." In Chester Crocker et. al, eds, *Managing Global Chaos: Sources and Responses to International Conflict* (Washington, DC United States Institute of Peace, 1996): 349.

and supporters of men in local communities. Support was "oriented primarily to vulnerable groups, and not necessarily towards women themselves." [8] In contrast, women's groups which were more free to choose their own agenda, such as Zena Zenema or Medica Zenica, focused more on women's empowerment and in so doing often advanced broader rights than commonly found in Western countries. For example, local women's organizations, over the objection of the World Bank and other international organizations, supported the right to a one-year maternity leave, a right found in the old socialist system and far greater than the one to three months granted in most Western countries.[9]

It follows that another guiding principle for researches in this context is that of maximizing local participation in research projects. The notion of local participation "not only serves the instrumental needs of researchers, but also it is responsive to and expressive of human rights values."[10] Carole Pateman's seminal work, *Participation and Democratic Theory,* emphasizes the wider function of participation. In so doing, she moves beyond the view of participation advanced by Mill and Bentham which emphasized its "protective function" – defined in her words as "the protection of the individual from arbitrary decisions by elected leaders and the protection of private interests."[11] Pateman instead draws heavily from Rousseau for the insight that participation - whatever the nature of the process in question – is "very much more than a protective adjunct to a set of institutional arrangements; it also has a psychological effect on the participants, ensuring that there is a continuing interrelationship between the working of institutions and the psychological qualities and attitudes of individuals interacting within them."[12] The psychological function of participation is especially important to violently divided societies where it may increase the feelings of individuals and collectives of "belonging" in a community, enhance their understanding of previously unattainable freedoms, and educate individuals and collectives so that they are willing and able to cooperate civilly and justly in managing disagreements.[13]

Too often research interventions have an opposite effect. Instead of promoting belonging and cooperation, they enhance feelings of alienation and exacerbate communal tensions. By overlooking local capacities and, at best, tokenizing local input, researchers undermine local capacities. Research need not be delivered in a way that treats beneficiaries as passive victims, but instead welcomes them as partners in the endeavor.Research interventions that do not take into consideration the capacities and existing coping mechanisms of people in the locality will be less effective and even harmful.[14] Researchers can take steps to reduce the relative power imbalances between them and local parties by creating mutual obligations and giving beneficiaries control over some aspect of the process. They may also design research projects to

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[8] Aida Bagić and Paul Stubbs, "Civil Society Development Programme An Independent Evaluation, CARE International Bosnia and Herzegovina and Croatia," Zagreb, Croatia, 2000, http://www.carecro.org/care/dok/CSD_report.doc

[9] Sali-Terzic, supra at 146. This observation was also supported by my interviews in Sarajevo and Zenica in December 2003.

[10] Janet E. Lord, "The Challenges and Limitations of NGO Participation in International Legal Processes," ASIL Annual Meeting 2001 (manuscript on file with author).

[11] Carole Pateman, Participation and Democratic Theory (New York: Cambridge University Press, 1970), p. 14.

[12] Ibid., p. 22.

[13] Ibid, pp. 24-27 (drawing from Rousseau, The Social Contract).

[14] See Report of the Panel on United Nations Peace Operations (Brahimi Report) webhttp://www.un.org/peace/reports/peace_operations/

permit adaptation as internationals and locals learn from one another, and capacities and contexts change. Participatory research methodologies provide some guidelines for ensuring that those affected by research are fully and mutually engaged in the process of inquiry.[15] In the case of "babies born of wartime rape," participatory research wields considerable challenges and promises great benefits. It is to an overview of these strategies and their application to "babies born of wartime rape" that we now turn.

I. THE CONTRIBUTION OF PARTICIPATORY RESEARCH STRATEGIES

> *"Your study is great. We are so proud of you [academic referring to publications]. I just have one question: What does it have to do with us?"* – Serbian Women's Rights Activist to Foreign Academic[16]

Paulo Freire was a pioneer in developing the concept of engagement in critical analysis and organized actions to improve individuals' own situations. Oppressed people themselves must be fully engaged in the investigatory process.[17] Specifically, he asserted that research subjects become involved in all stages of the process, through participating in research question formation, designing instruments of the research, as well as playing an important role in the data collection and interpretation stages.[18] Various types of participatory research have derived from these origins,[19] but at their core participatory researchers may be characterized by a worldview shaped by a set of assumptions about human nature and the nature of research. This section begins be identifying in general terms the strengths and limitations of participatory research and then, through an exploration of the main assumptions of participatory research explains the implications for research on babies born of wartime rape.

Strengths and Limitations

The strengths of participatory research strengths include its potential to: (i) advance community and individual empowerment, (ii) build and nourish supportive relationships, (iii)

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[15] Nelson, et al., 2001: 834.

[16] Comment made to author, July 2000.

[17] cite Paulo Freire, *Pedagogy of the Oppressed*. (1972)

[18] Gregory Nelson, Joanna Ochacka Kara Griffin, John Lord, "Nothing About Me, Without Me: Participatory Action Research with Self-help/Mutual Aid Organizations for Psychiatric Consumer/Survivors." *American Journal of Community Psychology* 26, no.6 (December 1998): 881-912.

[19] Many scholars in this area draw sharper distinction between the terms "action research," "participatory research," and "participatory action research." For example, Nelson's literature review of participatory action research states that action research is about involving all stakeholders in a consensus building process of organizing research in order to solve specific problems. Participatory research is more challenging, and researchers are traditionally more focused on the power dynamics of the context and specifically aligned with the disadvantaged. (*see* Nelson, Geoffrey, Joanna Ochocka, Kara Griffin, John Lord. "Nothing About Me, Without Me: Participatory Action Research with Self-Help/Mutual Aid Organizations for Psychiatric Consumers/Survivors." *American Journal of Community Psychology* 26:6 (1998): 884-885.) However, for the purposes of this paper, it is more useful to use Reason and Bradbury's conception of action research as an approach rather than a particular methodology. Seeing this as an approach allows a variety of particular methodologies that would not strictly be considered "action research" or "participatory action research" to be discussed in the context of the assumptions underlying the approach, not in the methodology's adherence to certain rules or formats.

spark positive social change, and (iv) foster learning as an ongoing process.[20] By adding new perspectives to the design, implementation and evaluation of projects, participatory research may lead to more creative outcomes and for more interdisciplinary work with practitioners of all sorts. Through this method, major organizational changes may be possible which otherwise may not have entered the realm of possibility.[21]

The focus on using research to inform action also has the effect of changing the perspective of the local community to empower them to conduct their own research as a means of informing future action. [22] Participatory approaches grew out of progressive approaches of raising consciousness among historical disadvantaged or socio-economically depressed groups that their deprivations result from social forces, rather than inherent deficiencies or some accident of fate.[23] If only oppressed groups were provided with the tools to critically analyze their situation, they would be in a better position to take actions to promote social change, both within their own communities and the larger social structures. The assumption is that greater awareness and education are the basis for effective organization and action. In this sense, participatory research strategies function as a capacity building effort that focuses on transferring research and evaluation skills to the local community for future use. The capacity building nature of this approach provides the basis for participants to conduct regular self-reviews of action strategies, rather than relying on outsiders to conduct evaluations or monitoring.[24]

In some cases, the strengths of participatory approaches can present limitations. In breaking down traditional roles between the researcher and his/her research subjects, the subjects and objects of knowledge production lose many of their distinctive traits. As the positivist paradigm is often deeply rooted in both communication and relationships, it is often difficult to break away from the role that may be embedded, and to re-engage in a reflexive and equal way in participatory research. The participants and researchers may struggle over the control and ownership of the research process, such that researchers give greater control to the stakeholders, and the stakeholders become actively engaged in the work itself.[25]

One significant challenge facing researchers using participatory action is the constant issue of learning to live the values that help guide actions and to shape coherent thoughts.[26] Incorporating this reflection and into everyday interaction, and the self that is both public and private is a challenge for researchers, as they aspire to live up to the goal of practicing what they preach.[27]

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[20] Gregory Nelson, Joanna Ochacka Kara Griffin, John Lord, "Nothing About Me, Without Me: Participatory Action Research with Self-help/Mutual Aid Organizations for Psychiatric Consumer/Survivors." *American Journal of Community Psychology* 26, no.6 (December 1998): 881.

[21] William F. Whyte, "Advancing Scientific Knowledge Through Participatory Action Research." *Sociological Forum* 4, no. 3 (1989): 367-85.

[22] Ernest T. Action Research: A Handbook for Practitioners. Thousand Oaks: London, 1996: 9-11.

[23] Tilakaratna, S. Stringer, "Stimulation of Self-Reliant Initiatives by Sensitized Agents: Some Lessons from Practice." In Orlando Fals-Borda and Mohammad Anisur Rahman. (Eds.) *Action and Knowledge: Breaking the Monopoly with Participatory Action Research* (New York, The Apex Press, 1991): 136.

[24] Ibid, 137.

[25] Gregory Nelson, Joanna Ochacka Kara Griffin, John Lord, "Nothing About Me, Without Me: Participatory Action Research with Self-help/Mutual Aid Organizations for Psychiatric Consumer/Survivors." *American Journal of Community Psychology* 26, no.6 (December 1998): 881.

[26] Ibid..

[27] Reason, "Learning and Change Through Action Research."

Another issue in the field is the question of information dissemination. Here, the challenges go beyond researcher and participants and into the larger community of knowledge shapers and distributors. Journals have some responsibility to use informed consent before publishing information about human subjects. The role for ethical integrity in scholarly journals is no exception – informed consent in information dissemination may serve to protect the weak from the powerful, and is a mechanism of trust.[28] The financing of projects must also be considered as an ethical issue in shaping the knowledge creation and process of research. Several prominent cases indicating the importance of independent social science work from the vested interests of government and industry led scholars to emphasize the involvement of autonomous research with outside oversight and government protections for research subjects.[29]

Critics of participatory research also decry that the role that theory plays in shaping research is minimal, or often an afterthought. "Participatory research methodologies provide very little space to integrate theory in the early stages of research, emphasizing theory that emerges from the particular practices that are part of the research project. This is problematic: as theory and practice are intertwined, theory is not something that just emerges from a particular research activity or practice."[30]

Participatory research must also address the criticisms of having inadequate empirical data collection and openness about research process.[31] A common response of participatory research proponents and practitioners is that they are conceptualizing knowledge formulation and accumulation in new ways. The concept of "rigor" under conventional thinking is unmatched when the researcher has full autonomy over the research process, whereas it needs re-definition in the context of participatory research. In participatory research, factual considerations may be checked and rechecked by others with firsthand knowledge. This serves to safeguard against researcher self-delusion and unintentional manipulation of data analysis.[32]

Assumptions of Participatory Research

The first assumption of participatory research is that process of researching is not a value neutral, rational, or objective process, especially in social science research. Participatory research acknowledges that researchers are intervening within or upon a society and this intervention carries with it power dynamics and consequences. This raises ethical and practical concerns about appropriate roles for outsiders and insiders in creating research agendas and conducting research. It also provides an understanding that researchers have responsibilities to

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[28] Rachelle D. Hollander, "Journals Have Obligations, Too: Commentary on 'Confirmational Response Bias.'" *Science, Technology, and Human Values* 15, no. I, (Winter 1990), 46-49.

[29] See, e.g., Herbert C. Kelman, "The Use of University Resources in Foreign Policy Research." *International Studies Quarterly* 12 no.1 (March 1968): 16-37 (discussing the Project Camelot case). See also Erve Chambers and M.G. Trend, "Fieldwork Ethics in Policy-Oriented Research" *American Anthropologist* 83 (1981): 626-628.

[30] Ruth Beilin and Lucia Boxelaar, "Rethinking Action Research: Theory and Extension Practice" paper presented at the APEN 2003 National Forum, cited from: http://www.regional.org.au/au/apen/2001/p/BeilinR.htm November 5, 2003.

[31] Judy McKay and Peter Marshall, "The Dual Imperatives of Action Research." *Information Technology & People* 14, no.1 (2001): 46.

[32] William F. Whyte, "Advancing Scientific Knowledge Through Participatory Action Research." *Sociological Forum* 4, no.3 (1989) 367-85, 381. See also John R. Schuerman, "Improving the quality of Social Welfare Scholarship; response to 'Confirmational Response Bias." *Science, Technology, and Human Values* 15, no.1 (winter 1990): 56-61.

the communities with which they have conducted their research, both in the production of knowledge and the design and process of research process itself.

The issue of "babies born of wartime rape" is a complicated one with multiple layer of power hierarchies that may be disturbed by a research intervention. To some extent, the hierarchies in question are between a rape victim and society, and participatory research would seek to enhance the victim's power in society. But to a large extent the power hierarchy is between a rape victim and her child, both of whom are marginalized by society, but where the mother also has power over the child. The ethical researcher seeks to find a way to speak about infanticide, abuse or neglect (with mothers or grandmothers as perpetrators) without enabling or legitimating those outcomes and without reinforcing power hierarchies between traumatized women and their societies.[33]

The second assumption of participatory research is that all research is value-laden. Research designs can attempt to minimize or control for bias, but essentially research is a human endeavor, not a sterile laboratory design where factors can be precisely manipulated or controlled to achieve a desired effect.[34] Researchers have agendas. Researchers filter and make choices, and this affects the research. In the case of "babies born of wartime rape," constructing labels and framework for thinking about the "subject" is a value-laden enterprise, designed with a particular agenda (i.e., a humanitarian agenda). Participatory research approaches do not deny values and agendas, but demand reflection about what they are and what they mean in the particular contexts.

A re-conceptualization of research as an intervention where the researcher is supposed to have greater interaction with the community demands a different set of ethical consideration for the researcher than that presented by the neutrality model. The ethical model for this engagement is not a neutral expert model, but a more "feminist communitarian ethical model" of research.[35] In this model, the researcher is a "morally involved, self-aware, self-reflexive and interacting individual who holds the self personally responsible for the political and ethical consequences of their actions."[36] The ethical considerations ultimately should be made on both intellectual and emotional considerations. Researchers should make decisions based on "values, ethical codes, moral and professional standards, intuition and feelings."[37] In the case of "babies born of wartime rape," researchers' bases for initiating and conducting the research may be intimately tied to their own ethical codes on respect for the dignity of women and children, tied to their own experiences as mothers. While traditional research methodologies may disqualify such value-oriented motivations for research, participatory research encourages them.

The third assumption of a participatory research approach concerns a particular understanding about power that is focused on structural relationships. In one view (often deemed the "traditional" view), power is a zero-sum contest where the goal is getting someone to do something that they would not normally do.[38] Research is conceived as "resources to be

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[33] We are indebted to Charli Carpenter for this insight.
[34] Thomasina J Borkman,. and Marsha A. Schubert. "An Organizational Typology for Self-Help Groups." *American Journal of Community Psychology* 19: 5 (October, 1991): 52.
[35] De Laine, Marlene, 2001: 27-29.
[36] De Laine, Marlene, 2001: 28.
[37] Ibid.
[38] John Gaventa and Andrea Cornwall. "Power and Knowledge." in Peter Reason and Hilary Bradbury, Eds,. *Handbook of Action Research* (London: Sage Publications, 2001): 70-72.

mobilized to influence public debates."[39] The "better" research is the one that is more objective, rational or credible because it will have more influence. The goal is to counter expertise with expertise. According to this conception of power, the lack of participation of some voices or segments of society signals that group's apathy or inability. The matter of explicit and implicit policies of exclusion simply does not come up. In other words, research is seen as a process in which an "objective" outsider sets the agenda, defines the terms, and draws the conclusions and those who do not participate accept the process and its outcomes.

Participatory research does not see power as zero-sum, but rather as relational. A relational conception of power does not attempt to eliminate power from human relations, but rather seeks understand the ways in which power shapes the boundaries of what is possible. Traditional research distorts reality because it is filtered through "experts." Moreover, the expert-dependent approach reinforces passivity in the research "subjects" because as professionals acquire information from subjects, research reinforces dominant forms of knowledge.[40] Power in the research setting rests in defining how the "problems" under study are conceptualized in the first place. Participatory research approaches seek to counter this hidden power bias by allowing more voices into the process of producing knowledge.

One central dilemma of research on children born of wartime rape involves whether and how to allow children's voices into the research process. Most participatory research schemes only requires the participation of adults in the society where the children are being raised, not the children themselves. In some cases children are banned from the research altogether, based on the reasoning that research involving children as participants would raise a plethora of ethical concerns, including the ability of younger children to consent and their general susceptibility to exploitation. Yet reliance on adults to represent children raises its own ethical red flags. Different adults in different sectors of that society may have very different ideas about the proper focus of the project (so it may be contested, and impossible to gain "society-wide" agreement); and many of them may not indeed have the children's best interests in mind, or if they think they do, may define them differently.[41] Empowering adults to set the research design for a project on children is analogous to allowing the men in a refugee camp to design a research project on 'their' women. In both cases, the target of the research design must be included for the research to be participatory. Yet both cases also raise genuine privacy concerns, and in both cases the need to avoid exploitation and to respect the decision to opt-out is great.[42]

A fourth and related assumption of participatory research is that its initiation should be fully participatory. Control and ownership of the research process (or the creation of knowledge) should be shared among all participants rather than having a research process imposed.[43] Outsider-conceived projects require, in the very least, endorsement and agreement.[44] In this reciprocal research relationship, the researcher and participant are dependent on each other and each brings a particular set of skills and competencies to the endeavor. The researcher's skill and contribution is the intellectual framework and knowledge of process, while the "problem

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[39] Ibid: 70.
[40] Ibid: 74.
[41] We are grateful to Charli Carpenter for this point.
[42] Nancy Scheper-Hughes discusses this problem in *Small Wars: The Cultural Politics of Childhood* (University of California Press, 1998).
[43] Nelson, et al, 1998: 885.
[44] Reason and Bradbury, 2001: 10.

owner" brings their knowledge of the context. The contributions of each are valued and considered essential to conducting research. Especially as research involves an element of problem solving, participatory research recognizes the value of engaging stakeholders, especially oppressed people, in informing research interventions.[45]

The participatory nature of participatory research implies a shift from the traditional or conventional roles of all involved in the research process.[46] The various names used to describe the different actors, such as "co-researchers," "research participants," or "problem owner"[47] demonstrates this commitment to moving away from the expert/subject model. The shift in the roles is reflected in more than just the changed names of those involved, but also in how the research relationship is formed. It requires a shift in the roles of each party, particularly around the issues of control and ownership. Research is about entering into authentic relationship building.[48] Nelson *et al* describe this as a two-sided deal, where researchers need to "let go" of control and the consumer or the participants of the study need to "step up" and become more engaged.[49]

Trust defines the more collaborative relationship.[50] Trust is related to believing that the goals of the researcher and participants are the same or, at the very least, not in conflict. The participants trust that both the process and the outcome will be conducted in a sensitive manner and will involve fairness and input. There are many ways that the trust of participants can be earned. The trust can come from sustained interaction with the group over time, the involvement of a third party that can broker the relationship, or from prior involvement with the group where a trusting relationship was formed.

At the same time, however, trust is often hard to foster and the creation of research agendas does not occur in a vacuum. Each participant in the creation of a research agenda brings her own agenda to the table. Thus, even in the most participatory research design, the researcher chiefly responsible for the project rightly retains some autonomy over the project's focus, particularly when, as the case of babies born of wartime rape, there is a risk of it being co-opted by others with different agendas.

The fifth and final assumption of participatory research approaches is that research is intimately linked to action. First, action can be a discovered sense of empowerment or consciousness-raising among historically disadvantaged groups about the factors leading to their current social or economic condition. In this sense, research not only serves a purpose of working to test a hypothesis or further develop a theory, but also provides a potential process to build awareness among participants about their circumstances. Involving local groups in the research process allows them to engage with the content of the research in a more direct way than simply serving as the raw data for a study. Research, as a process of interacting with

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[45] Ibid, 885.
[46] Nelson, et al, 1998: 886.
[47] Judy McKay and Peter Marshall. "The Dual Imperatives of Action Research." *Information Technology & People* 14: 1 (2001): 47.
[48] Nelson, et al, 1998: 886.
[49] Ibid, 886.
[50] Helen Jenks Clarke, "Research for Empowerment in a Divided Cambodia." In Marie Smyth and Gillian Robinson. (Eds), *Researching Violently Divided Societies: Ethical and Methodological Issues.* (Tokyo: United Nations University Press, 2001): 101.
2001:

groups, can also be a capacity building opportunity where the skills and resources of inquiry are translated to local groups.

Second, action in this context can serve the purpose of informing future activities of the group. Research can be used to determine the needs of a group in order to plan more effective interventions or programs or to find news ways to engage with the constituent group. Research can also be used to inform or influence future policy decisions. In this sense, research can have a very explicit social justice agenda. In this sense, participatory research draws from feminist research methodologies, which places a strong social justice component on research and stands in direct opposition to traditional models of research, which demands a level of objectivity that positions the research away from making moral claims or having a goal of changing society.[51]

The case of babies born of wartime rape demonstrate one of the main ethical dilemmas with this approach of linking research to actions which in turn are linked to broader social justice agendas. The people under study may agree that children born of wartime rape should be treated better, but they may not see eye-to-eye on the desired direction of social change. Moreover, they may not feel like being involved to the extent required by genuinely participatory work aimed at social transformation.[52] Or perhaps only a small sector of the population will be willing and able to participate. If participation is time-consuming, for example, women with small children or with other caretaking duties may be unable to participate unless childcare is provided. While the research redesign may anticipate such obstacles, researchers can never foresee all of the potential roadblocks to participation.

II. CONCLUSION

The broad ethical guidelines that emerge from this discussion that may be instructive to researchers considering the issues of babies born of wartime rape include the following considerations.

- *The nature of research as an intervention necessitates that the researcher engage with ethical concerns beyond not causing harm, but also to consider who benefits from the research process and output.* The researcher is clearly benefiting when the research fulfills a professional requirement. Professional benefit is perfectly legitimate, but the local participants in the research process must also benefit from the research process. The researcher should consider the ways in which the research can add value to the community rather than simply being a situation where knowledge is extracted. The researcher should discuss these issues with the partner community. Sensitive issues such as babies born of wartime rape should be approached cautiously and with due regard for cultural cues. When possible, however, involving the community into the decision-making process of what will be studied may be one way to add value to the community because this allows the research to be conducted—in part or in whole—on a topic of interest and use to the community.

- *Setting the research agenda should be a two-way process.* The involvement of the problem owners in setting the research agenda, defining the most important problems,

[51] Barrett, 1996: 164

[52] This issue is laid out in Gera Kirsch, *Ethical Dilemmas in Feminist Research: The Politics of Location, Interpretation, and Publication* (State University of New York Press, 1999).

and determining an action strategy has two major results. The first is to break up dominant ways of producing knowledge and contribute in an effective manner to the literature. The second is that by having the research process be conducted in an organic way, with significant input from local actors, the potential for participating individuals to be empowered in defining their role is greater. Both of these goals are present in the case of babies born of wartime rape.

- *Research with human rights organizations should be consistent with the values and ethics of the community in both process and output*. Whenever your research involves work with local human rights groups, additional considerations arise. Human rights organizations are, by definition, political groups that confront power structures. In this sense, process is as important as outcome. Inclusive, democratic, and participatory processes reinforce the core concept of human rights, human dignity. A key aspect of promoting social change is to embrace strategies that empower those aspects of communities that were previously marginalized to articulate their own needs and demands. As noted in this chapter, this is particularly challenging where the needs and demands of one marginalized group (children born of wartime rape) conflict with another marginalized group (the mothers of these children), and both contend in different ways with the competing demands of greater society.

- *Researchers should consider alternate frameworks for evaluating research.* Viewing research as an intervention into the society allows for the research projects to be evaluated beyond just the quality or the content of the final research project. How the individual interacts with the community can be one point in the evaluation. In hard cases such as babies born of wartime rape, one may ask: Was the individual self-aware of the choices he was making in designing the research agenda? Was the researcher sensitive to the needs of the local community? Was the local community able to participate in the research process?

Another point for evaluation should be on the outcome of the research findings. While the research process might have been designed to be more open and participatory, the way in which the final outcomes are handled should also be considered. Did the researcher send copies of the final product to the local community? How was the information translated back to the community? Did the researcher take the extra step to design a more accessible version of the research findings for the local community? Did the researcher allow the community access to the data? Did the local community find the final research output to be useful in their activities? How did the individuals studied felt about the experience and how they viewed the researcher?[53]

This chapter provided an overview of the ethical considerations of researching "hard cases" and discussed some of the challenges of using participatory approaches. The process of thinking through the ethical obligations and potential challenges of a research project can be difficult, especially if one has not been immersed in the reality of the field. However, many

[53] Marlene De Laine, 2001: 57

difficulties may be anticipated and prevented if the potential for negative impacts of research-interventions are considered. Furthermore, increased attention to the researcher/community relationship will also allow more research to be framed in such a way that is not only academically appropriate and rigorous, but serves to foster capacity building and empowerment within the community.

The challenge of human rights-oriented research includes finding ways to discuss the process of research and to discuss how to evaluate the impact of research beyond traditional attention to where the study was published or the quality of the data. We all have a role to play in this. In a wide range of resources on ethics it can often be difficult to hear the voices of researchers emerge to provide the practical, on-the-ground kind of advice that can help future researchers and local communities. Even rarer is the paper or article that discusses a "failure" of a research project even though there is much to be learned from "negative examples." Academics have an amazing ability to hide themselves in the formal language so often used in academic publishing. Yet, the story of real people confronting real ethical situations may help other researchers and they struggle with their own problems. Problems abound when conducting research in violently divided societies. No one denies this, but talking about those problems, thinking through solutions and addressing practical issues can go a long way to ensuring more ethical research in the field.