# ETHICAL RESEARCH INVOLVING CHILDREN

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## Finding the balance between protection and participation: What do you do when follow-up services are not readily available?

***Background context:***

A challenge for researchers is to find the right balance between protecting young people from risk while also providing them with an opportunity for meaningful participation. Researchers confront an ethical dilemma when appropriate follow-up services are not available to young people who disclose, for example, mental health needs. Such a dilemma emerged in a study conducted with child-headed households in three regions highly affected by HIV/AIDS in Northern Namibia. Despite anecdotal information on the psychosocial needs of children in this context, the absence of scientific evidence set limits to programme planning and policy-making/ programmes and policies aimed at improving the lives of young people. To respond to this, a study was developed to map the social networks of children heads of household and to measure depression among young people. The Children's Depression Inventory (CDI; Kovacs, 1985), a 17 item self-report depression questionnaire widely used cross-culturally for children aged 7 to 17 years, was adapted to the local context, pilot tested, translated, and back-translated (into Oshindonga, Rukwangali, and Silozi) in collaboration with local professionals.

***The ethical challenge:***

In the study regions, access to adequate services and supports was limited due to poverty, large distances, limited means of transportation, seasonal floods, domestic and international migration that separated families, and limited health and social infrastructure and human resources. Most notably, there was not a single psychiatrist or psychologist available and the very few social workers employed by the government were located in the regional capitals only. At the time of the study, there was no registry of orphans or child-headed households in the country. Taking into account the best available research evidence and consultation locally, it was believed that the study was not likely to cause serious harm to participants yet there was substantial confidence in the positive impact of the research for the community and young people in similar circumstances. In contrast with clinical screening, which should not proceed if certain treatment services cannot be provided to participants, other assessments such as the one proposed may create a healing space for disclosure and help young people access social supports. In fact, young people reported feeling appreciative of the opportunity to share personal feelings, resources, and support networks in a safe space.

***Choices made:***

Given this situation, the researcher identified and built collaborative partnerships with local stakeholders and experienced youth-serving agencies prior to starting data collection. Partners helped identify child-headed households and assisted in cases of disclosure of harm, with the permission of participants. Among those, there were several ministries, traditional authorities, community-based agencies, faith-based organizations, schools, and home-based care volunteers. This process of determining whether there were appropriate services available and accessible to young people was time consuming. Nonetheless, it provided legitimacy and visibility to the study, helped determine the type of follow-up that was appropriate for children according to age, gender, ethnicity, etc., and built networks of information and support so that assistance could later be offered to participants in need.

In many cases, individual resources (e.g., existing personal networks), local community-based or faith-based organizations (e.g., Catholic AIDS Action's home-based care volunteers in Namibia), and even informal community supports were potential sources of necessary assistance. For example, a child who had suicidal thoughts—although she had never acted upon them was, with her agreement, referred to a local organization working with orphans and vulnerable children for follow-up. In many other cases, the research team shared information about suitable local sources of help—from how to obtain a birth or death certificate to apply for government assistance to who they might discuss their fears with. The choices made show that risk may be significantly reduced by careful consideration and adoption of alternative procedures.

***Reflexive questions/considerations:***

- How is the context where your research will take place similar or different from the one described here?
- How likely are young people to need support as a result of their participation in the study?
- What could be done differently in the study to minimize young people's risk of harm and, therefore, their need for support?
- What type of support will they require?
- If professional services and programmes for young people do not exist in the community, can they be created in the context of the study?
- Otherwise, how can you ensure that adequate follow-up will be made with young people in need?

***References***

Kovacs, M. (1985) The Children's Depression Inventory (CDI). *Psychopharmacology Bulletin, 21*, 995-998.

Reference for this case study
Ruiz-Casares, M. (2013). Knowledge without harm? When follow-up services are not readily available. In K. te Riele and R. Brooks (Eds) *Negotiating ethical challenges in youth research* (pp. 84-95). New York: Routledge.

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