



**RESEARCH ETHICS COMMITTEE
FACULTY OF EDUCATION
UNIVERSITY OF PRETORIA**

**POLICY GUIDELINES ON THE INCLUSION OF MINOR CHILDREN IN
RESEARCH INVESTIGATIONS¹**

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INTRODUCTION

In the Faculty of Education we acknowledge the central role that children play in our work. As educators, we value the opportunities to engage with children in our teaching, research and clinical practice and we see it as our responsibility not only to protect but to promote the best interests of the children with whom we engage in teaching, research and clinical practice.

RELEVANT LAWS, POLICIES AND GUIDELINES

As educators, researchers, and psychologists we subscribe to the laws, policies and guidelines as described below and we use these documents to make ethical and moral decisions about our engagement with children in our teaching, research and practice. We strive to meet the highest possible standards prescribed by the codes and documents that regulate our work with children.

1. The South African Constitution of 1996.
2. The Children's Act No. 38 of 2005.
3. The Health Professions Act No. 56 of 1974.
4. Ethics Code for Psychologists

¹ To be read together with the Guide for Ethical clearance applications in the Faculty of Education as well as relevant laws and other policies and guidelines of the University of Pretoria.

5. The South African Council for Educators: Code of Professional Ethics
6. UP Guidelines for Responsible research: Policy and Procedures
7. UP Code of Ethics for Research

Additional documents which the Faculty of Education Ethics committee consults in its decisions regarding the inclusion of children in research investigations include:

1. Schenk, K. & Williamson, J. 2005. Ethical Approaches to gathering information from children and adolescents in International Settings: Guidelines and Resources. IMPACT Family Health International: Horizons Population Council.
2. Medical Research Council of South Africa. Guidelines on Ethics for Medical Research: General Principles.

BASIC PRINCIPLES

The Faculty of Education Research Ethics committee subscribes to the following basic principles in general, but specifically with regard to the inclusion of children in research projects:

1. Best interests

Researchers in the Faculty of Education regard the principle of the best interest of the child as paramount when deciding on any matter that involves a child, but specifically whether to include children in research projects. Children's Act 38 of 2005 [par. 10] makes provision for the right of every child that is of such an age, maturity and stage of development to participate in a matter that involves that child, has the right to participate in an appropriate way and views expressed by the child must be given due consideration.

Children have the right to participate in research that involves them, but it remains incumbent upon the research investigator to demonstrate that their participation will be appropriate for their age, maturity and stage of development. Thus, children are only invited to participate when the information sought cannot be obtained from other sources. Children are never involved simply because they are available or because it is convenient for the researcher. It is incumbent upon the applicant to demonstrate that due attention has been given to protecting and advancing the best interests of the children who will be participating in their research.

2. Human rights

Researchers in the Faculty of Education protect and promote the human rights of the children in their research investigations. This includes but are not limited to, the rights to equality, human dignity, freedom and security (especially the right to bodily and psychological integrity), privacy, freedom of expression, to be protected.

As far as is possible within the constraints of the law, children should be treated as autonomous agents with the right to self-determination. They have the right to be consulted in matters affecting them and with due consideration to their age and development, have a right to be heard with respect to matters involving them. Also, as prescribed by the Children's Act (38 of 2005) Section 2, all actions or decisions involving a child must

- Respect, protect, promote and fulfil the child's rights
- Respect the child's inherent dignity
- Treat the child fairly and equitably
- Protect the child from unfair discrimination
- Recognise a child's need for development and to engage in play
- Recognise a child's disability and create an enabling environment

PRINCIPLES OF ETHICS

The five principles on which the Faculty of Education Ethics committee's functioning rests, are as follows:

1. Voluntary participation
2. Informed consent
3. Safety in participation
4. Privacy
5. Trust

When research involves children, it is especially important to pay close attention to these principles as children are always regarded as a vulnerable group by virtue of the unequal power relationships between them and the adult teacher, researcher or clinician.

Voluntary participation

When researchers consider involving children in their research, they should pay particular attention to the following:

1. Grounds for inclusion

- a. Children should only be involved when the information sought cannot be obtained elsewhere. Special attention should be paid to the content of questions in questionnaires and interviews. If questions can be equally well answered by adults or other roleplayers, the child should not be involved.
- b. Children have two roles to play in a research activity. They can be respondents or participants. Involving children as respondents should be kept to a minimum especially when information is sensitive. Involving children as participants where their input is maximized should be promoted.
- c. Researchers have a responsibility to identify appropriate opportunities for children to express their views about the research activities by taking into account their age and developmental status.

2. Beneficence

- a. Where children are involved in a research project, the researcher has the responsibility not only to minimize the possible risks of harm for them, but to maximize the benefits of participation.
- b. If there is any doubt whether the researcher will be able to protect the children's safety and integrity in a research project, children should not be included.
- c. The researcher is responsible for the wellbeing of the children participating in a project for the duration of the project.

3. Justice

- a. The benefits and burdens of the research activity should be equally distributed.
- b. Information-gathering should not involve children who are unlikely to benefit from the findings.
- c. Child participants should not be selected based only on their availability, compromised situation or their vulnerability.

Informed consent

Until a child reaches the age of majority [18 years] they have to be assisted by a parent/guardian/caregiver when approached for participation in a research project. According to the Children's Act 38 of 2005, a caregiver is defined as

“any person other than a parent or guardian, who factually cares for a child and includes

- A foster parent
- A person who cares for a child with the implied or express consent of a parent or guardian
- A person who cares for a child whilst the child is in temporary safe care
- A person at the head of a child and youth care centre where the child was placed
- The person at the head of a shelter
- A child and youth care worker who cares for a child who is without proper family care
- The child at the head of a child-headed household”

In addition, Section 32 of the Children’s Act (38 of 2005) provides that a person who holds no parental responsibilities and rights in respect of that child, but who voluntarily cares for the child indefinitely, temporarily or partially, including a caregiver who otherwise has no parental responsibilities and rights in respect of a child, must whilst the child is in their care

- Safeguard the child’s health, wellbeing and development, and
- Protect the child from maltreatment, neglect, abuse, degradation, discrimination, exploitation and any other physical, emotional or mental harm or hazards.

Par. 2 further provides that the person referred to above, subject to Section 129, may exercise any parental responsibilities and rights reasonably necessary to comply with the above, including the right to consent to any medical examination or treatment of a child if such consent cannot be reasonably obtained from a parent or guardian.

Section 129, par. 2 prescribes that a child may consent to his/her own medical treatment or to that of his/her child if

- a) the child is over the age of 12 years
- b) the child is of sufficient maturity and has the mental capacity to understand the benefits, risks, social and other implications of the treatment.

Par.3 prescribes that a child may consent to the performance of a surgical operation on him or herself or his/her children if

- a) the child is over the age of 12 years
- b) the child is of sufficient maturity and has the mental capacity to understand the benefits, risks, social and other implications of the treatment.
- c) The child is duly assisted by his/her parent or guardian

The Children's Act 38 of 2005 or the Health Professions Act 56 of 1974 do not make specific provision for the provision of psychological services to children and the requirements for informed consent in these cases. It is thus difficult to determine if, and under which circumstances a child can consent to the provision of psychological services unassisted by a parent, guardian or caregiver.

The Faculty of Education Ethics committee applies the following reasoning in such cases. Following the cue of the Medical Research Council, a distinction is made between therapeutic and non-therapeutic interventions.

- **Therapeutic psychological interventions** are classified as those psychological acts that are designed to bring about a direct improvement in psychological and social functioning and are likely to provide an immediate or direct benefit to the child and includes career counseling, trauma counseling and other forms of personal counseling. The Ethics committee views therapeutic interventions as similar to medical treatment according to the Children's Act 38 of 2005 for which a child over the age of 12 can consent to without being assisted by a parent/guardian/caregiver.
- **Non-therapeutic psychological interventions** are classified as those psychological acts that do not bring about a direct improvement in psychological and social functioning and do not bring any immediate or direct benefits to the child. This includes all forms of psychological assessments, mental status examinations and psychological analysis that do not have as its immediate goal an improvement in psychological or social functioning. The Faculty of Education Ethics Committee views these interventions as similar to medical operations (in terms of intrusiveness) according to the Children's Act 38 of 2005 for which a child over the age of 12 can consent to with the assistance of a parent/guardian/caregiver.

Thus, the research worker bears the responsibility of demonstrating what kind of research will be conducted and has to demonstrate that the child between 12 – 18 is capable of giving informed consent without the assistance of a parent/guardian/caregiver. The researcher must also be able to demonstrate that the risk of participation for the child is negligible, in other words not greater than that encountered in everyday life and that the benefits of participation exceeds the risks involved.

Taking a cue from the Children's Act 38 of 2005 Section 31 which states that before a person holding parental responsibilities and rights in respect of a child takes any major decision that will affect the child's circumstances and

wellbeing, that person must give due consideration to any views and wishes expressed by the child, bearing in mind the child's age, maturity and stage of development, the Faculty of Education Ethics Committee believe that all children to be considered for inclusion in a research project have a right to full information about a research project, presented in an appropriate way that takes into account the child's age, maturity and stage of development, that will allow them to make an informed decision about their participation even though a parent/guardian/caregiver may have consented to their participation.

1. Autonomy

- a. Children should be respected and treated with honesty and integrity. They have a right to be heard in matters that involve them.
- b. Children must have the opportunity to express their views and to make choices in a way that is appropriate to their understanding. This implies that informed consent from a parent/guardian/caregiver² is a necessary but not sufficient prerequisite for a child's participation.
- c. Notwithstanding consent from the parent/guardian/caregiver, the child must have an opportunity to actively agree to participation and their refusal to participate should be honoured by the investigator.
- d. A child who wishes to be assisted by a trusted adult during a research investigation should be permitted to do so.

2. Exceptions

- a. In exceptional cases, the nature of the research may merit the participation of children without their parents' knowledge and/or consent. Such research should be avoided as far as possible and only be conducted
 - i. with children 12 years and older,
 - ii. when risks of participation are minimal,
 - iii. in the context of programme evaluations,
 - iv. when no information will be collected from children,
 - v. with children who are not classified as orphaned, separated or unaccompanied, or in need of care as defined by the Children's Act 38 of 2005.
 - vi. Only in the context of therapeutic interventions.

² Caregiver means any person other than a parent or a guardian who factually cares for a child and includes a foster parent, or guardian of the child; a person who cares for a child whilst the child is in temporary safe care; the person at the head of a child and youth care centre where a child has been placed; the person at the head of a shelter; a child and youth care worker who cares for a child who is without appropriate family care in the community; the child at the head of a child-headed household (Child Care Act, 2005).

- b. The research investigator must pay meticulous attention to justification for research where children are involved without the knowledge and consent of their parents.
- c. The use of psychological tests and/or procedures focused on assessment and analysis are regarded as highly intrusive and must always be accompanied by informed consent from a parent/guardian/caregiver as prescribed by the Health Professions Act (Act 56 of 1974).
- d. Notwithstanding the above requirements, the research investigator shall endeavour to obtain the informed consent of a parent/guardian/caregiver where this is possible.

Safety in participation

1. Safeguards

- a. Children who are in especially vulnerable situations, or in need of care require additional safeguards to protect their welfare.
 - i. Orphaned³, separated⁴ or unaccompanied⁵ children require special consideration..
 - ii. Children and adolescents separated from their parents may only be included in research if it relates specifically to their status as separated children or when conducted in schools, organizations or institutions where all children are included as participants.
 - iii. Even though unaccompanied children may exercise decisions about themselves and their children in their capacity as caregiver, it is ethically recommended that their best interests are independently protected by an adult from their immediate community who can promote and protect the child's best interests.
 - iv. Children in need of care as defined by the Children's Act 38 of 2005 may only be included if the research investigator has the training, experience and resources to respond appropriately to the child as prescribed by the Children's Act.

2. Beneficence

- a. Research projects that involve orphaned, separated or unaccompanied children or children in need of care must provide for some immediate benefits to the children as a result of participation.
- b. Research investigators must simultaneously recognize that their presence in the child's life may create expectations that they may

³ A child whose parents has died.

⁴ A child who may have one or both parents living but who is in the care of another adult or an institution

⁵ A child who is not being cared for by any adult.

not be able to meet. The investigator shall take all reasonable steps to ensure that child-participants do not develop unrealistic expectations as a result of their participation.

- c. Research investigators have the responsibility not only to ensure that their training, qualifications and experience equip them to respond appropriately to child-participants, but to promote and advance the best interests of child-participants.

Privacy

1. Confidentiality

- a. The research investigator who conducts research with child-participants realise that he/she has a responsibility to safeguard a child's privacy and avoid unnecessary intrusion.
- b. The researcher shall take all reasonable steps to ensure that the identity of child-participants are protected when gathering personal data from participants.
- c. It is the researcher's responsibility to explain to children the extent and the limits of confidentiality.
- d. If confidentiality cannot be guaranteed, then children should not be involved in the research.
- e. If a child-participant decides to forego the requirement of confidentiality, the burden falls on the researcher investigator to prove that such decision was informed.

2. Intrusion

- a. The research investigator who conducts research with children shall not collect any data from children that can be regarded as unnecessarily intrusive. The criteria for unnecessary intrusion involve
 - i. Asking questions that should be more appropriately answered by adults.
 - ii. Conducting psychological assessments and obtaining psychological data without the informed consent of a parent/guardian/caregiver and without the permission of a registered psychologist who may release the data.
 - iii. Gathering any data beyond that which can be justified by the research question.
 - iv. Utilising inappropriate data collection methods and instruments for which the researcher is not qualified or registered and which cannot be adequately justified.

Trust

The research investigator acknowledges that all research, but especially that involving child-participants implies an unequal relationship between researcher and participant that is built on trust. As such, the primary responsibility for maintaining that relationship of trust lies with the research investigator who undertakes to

1. keep child-participants fully informed about any changes, amendments to the research project,
2. to actively collaborate with all role-players⁶ to promote the best interests of children and to protect their wellbeing,
3. continually discuss with child-participants the conditions of their participation,
4. refrain from any action that could constitute improper pressure on the child-participant to participate and simultaneously to create opportunities for the child-participant to discuss their concerns freely.

INSTITUTIONAL STRUCTURES THAT ENSURE WELLBEING OF CHILD-PARTICIPANTS

Ethical supervision

All research⁷ conducted under the auspices of the Faculty of Education at the University of Pretoria must make provision for a process of ethical review and supervision. The Faculty of Education Ethics Committee is responsible for accepting, reviewing and deciding on applications for ethical clearance for all research. Research that involves human respondents, child-participants or any confidential research must be reviewed and approved by the Faculty of Education Ethics committee before the research can commence.

Faculty of Education Ethics Committee

Before granting approval, the responsibility of the Faculty of Education Ethics Committee is to ensure that children and adolescents are protected from harm and to withhold approval if protection cannot be assured. After approval has been granted, the Ethics Committee has the responsibility to review changes to the protocol, informed consent forms, study sites, and other relevant procedures.

⁶ Including, but not limited to, the child-participant, their parents/guardians/caregivers, community structures, organisations and institutions, and ethics review boards.

⁷ This includes research attached to undergraduate and Honours level modules, dissertations for Masters and PhD degrees, and research conducted by staff members in their capacity as UP staff members.

The Faculty of Education Ethics Committee also makes provision for the annual review of all research protocols, especially those involving child-participants.

PRACTICAL ETHICAL GUIDELINES FOR GATHERING INFORMATION FROM CHILD-PARTICIPANTS adapted from Schenk, K. & Williamson, J. (2005).

The following guidelines provide a list of considerations that should be taken into account when research involve children.

1. Is this activity necessary and justified?
 - a. Is the purpose of the activity clearly defined, and are sufficient human and financial resources available to conduct it in an ethical manner?
 - b. Is the required information available elsewhere? Does it already exist in documents or can it be gathered from older informants?
 - i. Only use direct methods with children if the required information is not available any other way. If the required information is available from alternative sources then the interference with children's lives cannot be justified.
 - c. Will the young people involved in this activity benefit from it?
 - i. If the information-gathering activity will not directly benefit the children and adolescents involved or their community, do not proceed.
 - ii. Non-therapeutic research with children and adolescents is always subject to ethical review.
2. Is this activity designed to get valid information?
 - a. Is there an agreed description of how the information will be collected, analysed and used?
 - b. Does the sampling methodology ensure that all children have an equal opportunity to participate, recognizing gender, ethnicity and other barriers?
 - c. Have tools for gathering information been developed with qualified professionals? Have the tools been locally translated and field-tested?
 - d. Is the use of a comparison group for evaluation purposes appropriate? Can it be ethically justified?
 - i. Use under close ethical supervision
 - ii. A comparison group totally deprived of services is inappropriate with vulnerable children. Alternative approaches should be explored to strengthen the findings.
 1. The requirement to treat participants ethically is always more important than the scientific requirements of research methodology.

2. Alternatives include conducting a baseline survey, observing the programme in multiple settings, observing the program at different levels of intensity or using multiple methods to assess program impact. Also, find a natural comparison group that already exists especially in the case of different geographical areas.
3. Have community and stakeholder concerns been considered?
 - a. Have all appropriate community and related groups with an interest in the results been consulted for permission to work with children?
 - b. Have efforts been made to ensure that the community and potential participants understand the activity's purpose and possible outcomes to avoid raising false expectations?
 - c. Are local supervision mechanisms in place to monitor child protection and review ongoing activities?
4. Have adverse consequences of the activity been anticipated?
 - a. Have potentially harmful direct consequences of the activity been anticipated and safeguarded against?
 - b. Has the possibility of community stigma from participation been anticipated and safeguarded against?
 - c. Can the identities of participants be protected?
 - i. Anonymity: the identity of the individual participant is not collected and cannot be traced from the information provided.
 - ii. Confidentiality: Individual identifiers are collected but identifying information is not disclosed to others without permission from the participant.
 - d. Have field staff been appropriately selected, trained and supported?
 - e. Are field staff and community resources prepared to anticipate, recognize and respond to children's need for follow-up?
 - i. If interviewers are going to raise difficult topics for discussion with children they must make sure they can respond to children who are affected by the information they reveal.
 - ii. Facilitate access to appropriate local resources. Simply providing information about referral services is not enough as children cannot access these independently.
 - iii. Have field staff been trained to respond appropriately to the discovery of a child in serious danger?
 1. The team must be prepared for the possibility that they will discover dangerous situations such as abuse or neglect and they must be fully trained regarding legal issues, regulations and guidelines.

2. During the process of seeking informed consent, investigators must make it clear to participants that confidentiality will be breached and appropriate actions will be taken to protect the child in cases of any form of abuse.
 - iv. Do all staff know the circumstances under which participant confidentiality should be breached?
 1. When a child or adolescent requires immediate protection.
5. Are procedures in place to ensure that the activity proceeds ethically?
- a. Do all investigators know who can give informed consent when working with children and adolescents?
 - i. Children must give their agreement to participate. Consent is also required from appropriate adults. Active agreement, or assent, is an absolute ethical requirement. Lack of refusal is not enough.
 - ii. Agreement from other adults to act as child advocate for the best interests of the child can also be sought when appropriate.
 - b. Do interviewers know the important elements of consent to discuss with all children?
 - i. Interviewers must make sure that children know they can stop or withdraw at any time.
 - c. Have investigators ensured that child participants and adult guardians fully understand the nature of the activity?
 - i. At a minimum, investigators should explain the purpose of the activity, procedures involved in the activity, any risks or benefits the participants can reasonably expect and the circumstances under which the confidentiality of the information of participants will be breached.
 - ii. Additional helpful information includes the expected duration, investigator's responsibility, name and contact details of a person, conditions under which an investigator may ask the participant to leave the activity, potential conflicts of interest, how written records and biological specimens will be stored, how results will be communicated to participants and other audiences, other sources of information about the activity and whether an intervention that has been demonstrated to be effective will be made available.
 - d. Has the use of a child advocate to represent the best interests of the child been considered?
 - i. Use an independent advocate to represent the views of children if there is any doubt about the protection provided by their guardians

1. The independent advocate is responsible for
 - a. Verifying a minor's understanding of the assent procedures
 - b. Supporting the minor's preferences
 - c. Ensuring that participation is voluntary
 - d. Monitoring reactions
 - e. Ensuring adequate follow-up.
- e. Have procedures been put in place to avoid undue influence or coercion?
 - i. If incentives are used, they must be in line with local living standards
 - ii. Are children's needs for support and protection reflected in the interview procedures?
 1. Hold interviews in a visible place where they cannot be overheard or justify privacy to hide child's involvement.
 2. Additional presence of a caregiver or child advocate could be considered if the child is very young. A request from a child to have an adult present for reassurance should be respected.
 3. Information from interviews in the presence of an adult should be identifiable in case it affects the results.
6. Is there a clear plan and adequate funding for follow-up activities?
 - a. Secure storage of written records when the activity is over?
 - b. Is there a clear plan and adequate funding to give community members and partner organizations access to the results of the activity?
 - i. Share findings in an accessible, appropriate format.