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# WESTERN CAPE DEPARTMENT OF SOCIAL DEVELOPMENT POLICY ON RESEARCH ETHICS:

# ETHICAL GUIDELINES FOR SOCIAL RESEARCH

FEBRUARY 2013

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**FOREWORD** 

The Western Cape Department of Social Development is involved in the undertaking of

research, both by internal research staff as well as by external research service providers.

In addition, research is regularly undertaken by external researchers such as students who

require access to services, beneficiaries or staff of the Department for the collection of

primary data for the completion of their studies.

The Department established a Research Ethics Committee (REC) in 2009 in order to

promote ethically based research in the Department. The REC was mandated to develop

a Research Ethics Policy in order to provide guidelines for the undertaking of research. The

policy guidelines described in this document is the outcome of an extensive consultation

process with members of the REC.

Chapter 2 of this policy describes the duties of the researcher, while Chapter 3 focuses on

research with special populations. Chapter 4 deals with research with Departmental

facilities while Chapter 5 provides guidelines for data management. Finally, the area of

non-compliance is addressed in Chapter 6.

The implementation of these ethical guidelines will address a critical gap in the social

development sector and make an important contribution to the development of ethical

research practices in the sector.

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#### **CHAPTER 1**

#### **BACKGROUND AND REASONS FOR POLICY**

- 1. The background to and reasons for this policy are:
  - a) Social researchers, especially when commissioned or employed by the State, serve the interests of its governing institutions when conducting research.
  - b) Ensure research is motivated by Departmental goals and objectives, which are determined by broader climates of political governance.
  - c) Research done within the Western Cape Department of Social Development (internally or externally) meets the overarching needs of the Department as well as to serve the best interest of its subjects, who are researched while upholding national as well as international standards in research ethics.
  - d) It is within this context that a need for a comprehensive Social Research Ethics Policy within the Western Cape Department of Social Development has emerged.
  - e) This document therefore aims to provide a guideline for the ethical conduct of social research in the form of a Departmental Research Ethics Policy.
  - f) This is in response to the absence of such a policy in the Province as well as within the National Department of Social Development.
  - g) This policy borrows from the premises of the South African Council for Social Services Professions as well as the Health Professions Council of South Africa as a guiding framework for the content presented here and should be used in conjunction with these nationally accepted codes of conduct for social workers and social scientists alike.

## **Guiding principles**

- 2. This Policy seeks to promote ethical research in the Department and is underlined by the following ethical principles (HPCSA, 2008).
  - a) Human Rights:
    - In Chapter 2 of the Constitution of South Africa, Act 108 of 1996 ("Constitution"), the Bill of Rights protects the rights of all individuals and ensures the preservation of the nation's democratic values whereby human dignity, respect, equality as well as freedom are promoted. Researchers should therefore recognise, respect as well as protect the human rights of all individuals throughout all phases of

research, i.e. conceptualisation, operationalization, data collection, analyses as well as reporting and dissemination.

## b) Non-maleficence and Beneficence:

- i. The behaviour, actions and intentions of researchers should always serve the best interest of participants.
- ii. The interest of participants should always be protected, even if it is in conflict with the interest of the researcher.
- iii. It is the duty of the researcher to ensure that:
  - No harm comes to any individual who participates in social research (non-maleficence);
  - All potential risks involved are minimised and eliminated; and
  - That the benefits for participation in research outweigh any risks (beneficence).

## c) Autonomy and Respect:

- i. The rights of participants to self-determination and to make their own decisions should be respected at all times by the researcher and institutions alike.
- ii. The right of participants to assert their own beliefs, perceptions, values and preferences will be preserved by the researcher and institutions alike.

#### d) Confidentiality:

- All personal and private information from participants will be regarded, handled and processed as confidential by the researcher and the institution alike.
- ii. The participant's right to privacy will be respected and researchers will at all times ensure that all information of participants are safely stored, used and subsequently destroyed to protect the identities of participants.

#### e) Impartiality and Justice:

Researchers are obliged to assume responsibility for the fair and just treatment of all their participants and that the research questions and procedures selected do not lead to the exploitation of participants. In other words, it is "imperative that the study should leave the participant and or community better off or no worse off" (HPCSA, 2008, bk6, p.3). Participants should also not be unfairly

excluded from participating in research on the basis of their age, race, sex, sexual orientation, education, disability, religious beliefs, pregnancy, marital status, ethnic or social origin, conscience, belief or language. On the other hand, research should not impose unfairly on participants who stem from groups and communities that are exposed to over-researching. This practice becomes burdensome to these populations and does not serve the interest of justice owed to participants.

## f) Integrity and truthfulness:

The relationship between the researcher and the participant should be characterised by, as well as be established on a foundation of truth, truthfulness and integrity. All research practices should incorporate these ethical values and standards.

## g) Compassion and tolerance:

- Researchers should respect the rights, beliefs, and cultural views of participants even though these may be in conflict with the researcher's own ideologies and convictions.
- II. It is also expected of researchers to act sensitively towards the needs and preferences of their participants as well as provide comfort and support where necessary.

#### h) Professional competence:

Social researchers should be skilled, or be under the adequate supervision of a qualified professional within the relevant field of practice, when engaging in research.

#### i) Ethical reasoning:

- I. Challenges, problems and ethical dilemmas should be solved via the use of ethical reasoning.
- II. Ethical reasoning is applied when researchers debate potential ethical dilemmas, specifically in terms of:
  - Defining the problem;
  - Gathering the relevant information to make an informed assessment,
  - Considering all possible options and their potential outcomes;

 Making a moral assessment in terms of which option may render the least risk or harm to participants.

## **Purpose of Policy**

## 3. This policy aims:

- a) To serve as a guideline for social researchers, Research Ethics Committee members (REC), as well as research participants within the Western Cape Department of Social Development;
- b) To provide information on ethical principles and regulations for the planning, design and undertaking of social research within the Western Cape Department of Social Development;
- c) To provide information on the rights of all parties involved in research; To provide the process to be followed when conducting social research with individuals that include special populations as contemplated in section C of the policy;
- d) To stipulate special conditions to the management of research information that compliments the existing Western Cape Department of Social Development Policy on Records Management.

#### **Definitions**

- 4. In the context of research undertaken or approved by the Department:
  - I. "Assessment tools" refer to established test instruments and evaluation tools that have proven validity and reliability and are registered with, as well as been classified by, a recognised professional body or board for the proposed purposes it is intended for.
  - II. "Authors" refer to the writer of the first draft of a research publication.
  - III. "Code of Conduct" refers to the principles, values, standards or rules of behaviour that guide the decisions, procedures and systems of researchers as well as Research Ethics Committees in a way that contributes to the welfare of its key stakeholders, and respects the rights of all parties affected by its operations.
  - IV. "Confidentiality" refers to the researcher's agreement with the participant about how the participant's identifiable private information will be handled, managed, and disseminated. The research proposal should outline strategies to maintain confidentiality of identifiable data, including controls on storage, handling, sharing and disposal of data.

- V. "Conflict of interest" in social research refers to situations in which a researcher or Research Ethics Member could be unduly influenced by private interests in the exercising of public obligations.
- VI. "Constitution" means the Constitution of the Republic of South Africa Act 108 of 1996.
- VII. "Data" means any form or medium of data that relate or support research. These include primary or raw data (i.e. video recordings, paper questionnaires, images, notes, etc.),
- VIII. "Data and records management" refers to the process of acquiring, validating, storing, protecting and processing data and records and by which those who require the information are easily able to retrieve it timeously and reliably.
- IX. "Department" means the Western Cape Department of Social Development (WC DSD), unless otherwise specified.
- X. An "Editor" refines and finalizes a research publication and undertakes the required quality control i.e. verification of data.
- XI. "Electronic databases/datasets and records" means any data and records stored on a computer memory as well as any related storage devises.
- XII. "Ethical reasoning" refers to reasoning about 'right' and 'wrong' human conduct. It requires social researchers to be able to assess their own ethical values and the social context of problems, recognize ethical issues in a variety of settings, think about how different ethical perspectives might be applied to ethical dilemmas and consider the ramifications of alternative actions.
- XIII. "Informed consent" means that the researcher has provided the participant with sufficient information relating to the nature, purpose, potential consequences, risks and benefits to the participant of the intended research to enable the participant to make a fully informed decision whether to participate in the research or not.
- XIV. "Participant or participants" refers to an individual or individuals, who have been approached to participate in research or who have consented to become part of the research project and will provide the information requested by the researcher.
- XV. "Policy" refers to the document and includes all other documents referred to, which have been included in this policy, which among others regulates the conduct of researchers and all other persons, who are involved with research processes in the Western Cape Department of Social Development.
- XVI. "Privacy" in the context of social research relates to people, whereas confidentiality concerns data. The research proposal should outline strategies to

- protect privacy during the research process, i.e. when interviews are being conducted.
- XVII. "Research Ethics" refers to the moral principles guiding research, from its inception through to completion and publication of results and beyond.
- XVIII. "Research Ethics Committee (REC)" refers to the regulatory body established by the Department that assumes responsibility for the tasks and duties in the policy, which includes upholding the agreed ethical standards and code of conduct for the practice of social research commissioned as well as conducted by the Department; and "REC" has a similar meaning.
- XIX. "Records" mean processed data (i.e. analyses, interpretations, reports, papers, etc.) and published data (i.e. information/data disseminated beyond those involved in data collection and processing).
- XX. "Social development services" refers to 'a process of planned social change designed to promote the well-being of the population as a whole in conjunction with a dynamic process of economic development (Midgley, 1995).
- XXI. "Social research" refers to the following: "Social research is the systematic observation of social life for the purpose of finding and understanding patterns in what is observed. People interact with one another and create structures for those interactions. Social scientists seek to discover the nature of human relations, just as biologists seek to understand the functioning of physical organisms or astronomers the motions of heavenly bodies" (Babbie and Mouton, 2005, p.xxi).
- XXII. The "practice of social research" is defined as the deliberate act of observation and interpretation of human activity. These acts employ rational decision-making and presents evidence as objective and balanced approximations of reality. Research in its true sense is based on scientific principles whereby these deliberate acts of observation and interpretation are not confounded by (a) the opinions of individuals regarding the way phenomena should be; (b) misconceptions and superstitions they have learned throughout their lifetime; and (c) sloppy and erroneous observations (Babbie and Mouton, 2005). In fact, social research is based on the premises of observation and measurement of social phenomena and uses interpretation to organise these observations into evidence-based research findings and conclusions. Social research therefore bases its practice on the principle where what is observed is equally important as how it is observed and measured.
- XXIII. "Scientific knowledge" refers to "a set of statements which are better or worse approximations of reality [the ideal truth], but which are accepted by the scientific

community as being truthful, after having been scrutinized [the criterion of rationality], but which are based on the best supporting evidence gained through the application of rigorous methods and techniques [the criterion of objectivity]" (Babbie and Mouton, 2005, p.xxiii).

XXIV. "Vulnerable adult" refers to an individual over the age of 18 that is in need of social developmental services, including statutory intervention, or may be unable to take care or protect themselves from harm or exploitation.

#### **CHAPTER 2**

## **DUTIES OF DIFFERENT ROLE PLAYERS**

#### 5. Duties of the Researcher

## 5.1 Duties to research participants

## 5.1.1 Research Approval, Informed Consent and Capacity

It is the duty of the researcher, prior to commencing with the research study to:

- a) Acquire the necessary approval to conduct the research at the host facility, as well as its governing body/institution;
- b) Obtain informed, voluntary consent from the participant which should be in writing (see alternatives to written consent under section 30 (2);
- c) Ensure that where the participant is unable to provide written consent due to being illiterate, verbal consent is obtained, which should be done in the presence of an independent witness, who is literate and willing to verify this verbal consent in writing. Should the obtaining of verbal consent not be possible for any reason, an audio-visual recording of the consent process could be obtained that clearly demonstrates that the voluntary, informed consent has been received (i.e. Only in the case where the participant is illiterate, see 30 (2)).
- d) Ensure that the research is performed in accordance with the approved research proposal and all protocols, if the aforementioned approval is granted.
- e) View the process of informed consent as an ongoing process in which the researcher ensures the participants are fully informed of their rights at all times.
- f) Provide sufficient information to the participant at the outset of the research to allow the participant to make a fully informed decision.

- g) Provide potential participants with a balanced point of view of the options available to them to ensure that a voluntary decision is made.
- h) Treat all Individuals recruited for a study on the assumption that they have the capacity to give consent or refuse participation.
- i) Accept and respect the consent or refusal to consent by the participant even if the participant's decision appears to be irrational and/or not necessary in the best interest of the individual. In other words, just because the participant's decision does not appear rational to the researcher does not indicate that the person in question is incapacitated to consent. Participation in research activities should at all times remain completely voluntary. Special considerations are given to children/minors on these matters (See Chapter 3).

## 5.1.2 Act in the best interest of participants

Researchers must in their dealings with participants:

- a) Protect and preserve the interests, life, beliefs, privacy and dignity of participants, even when the interest of the participants is in conflict with the researcher's own interest;
- b) Be mindful of the relationship of power they hold in relation to the participants, ensure that this relationship is not exploitative and that the trust of the participants is honoured at all time;
- c) Ensure that any risks to participants should be continually assessed and minimised, eliminated, and effectively managed throughout the research process;
- d) Ensure that corrective action and redress should be taken immediately if risks to the participants were not satisfactory managed;
- e) Stop the research In the event that participation in the research may subsequently prove harmful to the participants;
- f) Address and respond immediately to questions, comments, criticisms as well as complaints from participants;
- g) Ensure that participants should not incur any expense when participating in the research and all expenses incurred should be compensated and specified in the research proposal or protocol;
- h) Act in the best interest of the participants if researchers believe that a research team member or colleague may be impaired which affects his or her objectivity, competence or effectiveness in performing his or her functions; and

- i) Not allow an unskilled individual (i.e. someone who is not appropriately skilled to perform a required task) to work directly with participants on the researcher's behalf.
- j) Respect the privacy and dignity of participants at all times, especially in relation to persons, institutions or governing bodies with whom the participant is associated.
- k) Ensure that participants are treated with due consideration and their views and opinions listened to, without attempting to sway their views in favour of that of the researcher.
- I) Avoid improper relationships (financial exploitative, sexual, etc.) with the participants, including the participants' family members and friends.
- m) Behave in a manner that is not harassing or demeaning to participants, including the participants' family members and friends if the research results in interaction with them.
- n) Avoid any labelling effects, prejudice and/or discrimination towards participants as a result of the research.
- o) Anticipate and prevent any human rights violations.

## 5.1.3 Providing sufficient information

Participants should be fully informed about:

- a) The nature and purpose of the intended research.
- b) Expectations of participants throughout the research process.
- c) The potential consequences, risks and benefits when choosing to participate in the research.
- d) The right to refuse participation, along with the assurance that there will be no negative consequences if they should choose to not participate in the research.
- e) The right to withdraw from the research at any stage, even if they have initially consented to participate; and that withdrawal from the research will have no negative consequences to participants who choose to not participate any longer;
- f) The fact that participation in research is truly voluntary and that participants are allowed to change their minds about participating at any stage of the research process and that no prior notice is required.
- g) What the findings of the research will be used for.
- h) Limitations to confidentiality, as well as information about members of the research team who will have access to the data and what their role and function is in handling the data (e.g. supervisors, etc.).

- i) Relevant stakeholders and sponsors of the research project, as well as those who may benefit from its findings.
- j) Potential conflicts of interest of researchers.
- k) The right of participants to ask questions of interest and clarification throughout the entire research process.
- Information that is necessary for the purpose of making an informed decision should not be withheld from participants.

## 5.1.4 Language and translation

- a) In providing sufficient information to participants, researchers should ensure that the information is communicated in a language that the participant understands and that corresponds with his or her level of fluency in that particular language.
- b) The researcher should ensure that the language employed to convey information to the participant is communicated at a level that is in line with the participant's literacy level and level of education.
- c) Where translators are used, the researcher should ensure that the translator is bound to the same code of ethics that applies to the researcher.
- d) The information provided by the participant should be reported by the translator without distortion or interpretation.
- e) The translator is required to apply the same skill and sensitivity in his/her interaction with participants as the researcher would have done.

## 5.1.5 The right to feedback, information and research findings

Participants have the right to access research information as well as feedback concerning:

- a) Their narrative contributions from interviews participated in;
- b) Any outcome, diagnosis, result and/or categorisation from any measurement or instrument applied, assessment undergone, and/or questionnaire completed; the findings of the report; any scientific papers and related material that results from the contributions made by participants.
- c) Limitations to participants' access to information include all documentation, audioand visual recordings that contain information / data of other research participants that have been assured confidentiality and anonymity by the researcher.

## 5.1.6 The use of incentives; false expectations, exploitation and undue influence

- a) Researchers should ensure that measures are in place to ward off false expectations from participants who believe that there may be some unexpected outcome, which they may benefit from directly, when consenting to participate in the research proposed, other than the potential benefits indicated to participants at the outset of the research.
- b) Corrective action should be taken when undue influence or coercion to participate is suspected from any member of the research team;
- c) Participants should not be given undue/inappropriate inducements incentives to participate in the research.
- d) A researcher should ensure that he or she does not engage in exploitative relationships with persons (participants) with whom an authoritative, supervisory or evaluative relationship may exist.
- e) Researchers may not have any sexual intimacies and/or relationships with persons who are participants as well as those related and/or known to current participants.

## 5.1.7 Use of deception in research

- a) A researcher "...shall not conduct a study involving deception unless he or she has established that the use of deceptive techniques is justified by the study's prospective scientific, educational or applied value and that equally effective alternative procedures that do not use deception are not feasible" (HPCSA, 2006, p.43).
  - b) The use of deception in research is prohibited on all matters that may affect the participants' willingness to participate and consent, for example the possibility of physical risk, discomfort, negative and unpleasant emotional experiences, as well as negative consequences due to the findings of the research.
  - c) Any deception used should be explained by the researcher as early as feasible, but no later than at the conclusion of the research.

#### 5.1.8 Use of recording devices (audio and visual)

- a) In order to increase data quality in data collection practices, the use of audio and/or visual recording devices are encouraged.
- b) When these devices are used (audio, visual) informed consent needs to be obtained from participants.
- c) Written consent should be collected as evidence that the participant is fully informed about:

- I. The nature of the research;
- II. What the recordings will be used for;
- III. The persons who will have access to data- who will listen, transcribe (if applicable) and analyse recordings/data;
- IV. All limitations to confidentiality and anonymity;
- V. How this data will be stored and handled; and
- VI. When it will be destroyed.

## 5.1.9 Confidentiality

- a) Researchers should ensure that all participants have the right to confidentiality in terms of their right to privacy in the Constitution.
- b) The researcher must ensure that all personal, confidential information of the participant is protected, safely stored and processed throughout the entire research process.
- c) Disclosure of the aforementioned information is only permissible if the participant has provided informed consent and such consent is in writing.
- d) The researcher may only divulge confidential information:
  - if a court of law makes an order to that effect;
  - with the consent of the participant;
  - with the written consent of the guardian/parent of a minor under the age of 18;
  - if a participant is deceased and, if a next of kin or an executor of the deceased's estate provides written consent.
- e) The researcher must ensure that participants are informed about the above exceptions to confidentiality before consenting to participate in the research. This discussion should occur between researcher and participants when obtaining informed consent, also as new circumstances warrants its discussion.
- f) Participants giving permission to disclose confidential information should be informed, in writing and on an official letterhead of the relevant institution about:
  - The implications of their decision;
  - What purpose the confidential information will serve;
  - Who the information will be revealed to.

#### 5.1.10 Debriefing and the reporting of abuse

a) When sensitive issues are researched, consideration should be given to offering appropriate debriefing services in order to mediate any potential effects of the research process.

- b) The goal of these services is to reduce the likelihood of any stress/traumatic reactions and/or psychological harm when sharing their experiences and/or listening to the experiences of others.
- c) The availability of debriefing services is strongly recommended; however the individual's participation in this process will be voluntary whereby informed, voluntary consent will be obtained.
- d) It is the professional as well as ethical responsibility of the researcher to report the abuse of any child or vulnerable adult to the appropriate authorities.

#### 5.1.11 Conflict of interest

- a) Researchers should not engage in research activities "...when personal, professional, legal, scientific, financial or other interests or relationships could reasonably be expected to (a) impair his or her objectivity, competence or effectiveness in performing his or her functions...; and (b) expose the client concerned to harm or exploitation" (HCPSA, 2008).
- b) All potential conflict of interest should be declared to the Departmental Research Ethics Committee (or other relevant body) before the research commences.
- c) The researcher should be excused from processes and proceedings in which conflicts of interest is anticipated.

#### 5.1.12 Use of assessment tools

- a) Researchers using assessment tools to administer assessments, evaluations and/or diagnostic services should ensure that informed consent is obtained from all participants, which should be in writing.
- b) Only use assessment tools if they are qualified to use those particular instruments.
- c) During the process of assessment, not unduly influence the responses in any way nor provide an opinion on the individual's characteristics before the completion of the assessment;
- d) Declare the limitations to their findings and only use assessment methods based on research and evidence of its usefulness to answer the proposed research questions or area of inquiry;
- e) Ensure that the use of the assessment techniques, interventions, results and interpretation is not misused in any way which includes releasing raw data or test results to persons other than the participants concerned, who are not qualified to understand, interpret and use that information;

- f) Only release test results or raw data after obtaining the informed consent of the participants;
- g) Refrain from using tests/assessments (as well as their results) that are outdated for their current purposes;
- h) Communicate the results of tests, assessments and evaluations in a manner that is understandable to the participants.

## 5.2 Duties to other Researchers and Society

## 5.2.1 Capacity building: transferring skills and knowledge

When embarking on research, researchers are encouraged to:

- a) Ensure that co-researchers and fieldworkers gain from the experience via skills development initiatives, especially with regards to persons from disadvantaged communities (HPCSA, 2006);
- b) Share knowledge and transferring skills via the process of research.

## 5.2.2 Record-keeping

- a) When embarking on research, researchers must:
- b) Keep records of all research processes, procedures, and databases for the review of, or request by, other researchers for purposes that are not limited to:
  - the duplication of research;
  - validity and reliability checking; and
  - meta-analysis of data and findings.
- c) Ensure confidentiality is maintained throughout documenting, transferring and handling of records, i.e. whether in written or electronic forms (HPA, 2006).

## 5.2.3 Reporting Professional and/or Scientific Misconduct

- a) Researchers and all persons involved in the design, implementation and review of research should report any evidence of fraudulent activities or scientific misconduct to all relevant ethics bodies and research committees involved in the project.
- b) Scientific misconduct includes but is not limited to the following (HPCSA, 2006):
  - The fabrication in the proposing, performing, reporting and reviewing of research material. Fabrication refers to the inventing of data/information as well as recording and reporting it as if it is actual data.

- II. The act of plagiarism in the designing, proposing, performing and reporting of results and research findings. Plagiarism refers to the use of another's ideas and concepts, writing, analysis, processes and results, or words without appropriately acknowledging the source of this information and/or without giving appropriate credit for their contributions. This should be avoided at all stages of the research and all contributions, both conceptually and literary, should be formally acknowledged as well as reflected in all subsequent work resulting from the research.
- III. Failing to gain voluntary, informed consent.
- IV. Misrepresentation, deviation as well as deception in the research proposal and/or protocol.
- V. Inappropriate disclosure of confidential information as well as falsifying credentials.

## 5.2.4 Handling scarce resources

Researchers should respect the available resources of the institution / participants affected by the research, and refrain from being wasteful or engaging in improper financial arrangements that leads to escalated costs or any financial disadvantage for research participants and/or institutions involved (HPCSA, 2008).

#### 5.2.5 Legal obligations

Researchers and all parties involved in research planning, performing, reporting and reviewing should adhere to all legal requirements and in all their practices and processes, adhere to the highest level of legislation in the country (e.g. the Constitution, the Child Care Act, etc.).

## 5.3 Duties to the Social Research Profession

## 5.3.1 Review and Approval of Research Proposals

- a) No research should be undertaken by a researcher without the approval of the relevant research committees, ethical governing bodies and institutions involved in and/or influenced by the proposed study.
- b) Social researchers should contribute to their integrity of the profession by:
  - I. reporting inadequate or inappropriate reviews of research proposals and protocols to the highest authorities (HPCSA, 2008);

- II. prematurely terminating research that has already answered the research question(s);
- III. prematurely terminating research that proves harmful to, or violates the dignity and human rights of participants (HPCSA, 2006); and
- IV. informing all reviewing bodies (ethics and otherwise) of any changes in the proposed protocol and research design.

## 5.3.2 Perverse incentives & unethical business practices

Researchers as well as REC members should:

- a) Remain committed to preserving the best interest of all participants and parties involved in research.
- b) Avoid any conflict of interests, incentives or inducements that threaten that commitment should be avoided at all times.
- c) All parties involved in the execution of research as well as the review thereof should declare all potential conflict of interest (MacDonald et al, 2002). (Refer to the Departmental Policy on Conflict of Interest, 2011).
- d) The conflict of interest lies in the situation and is not limited to the behaviour, or lack of behaviour of the individual therefore the aforementioned parties should disclose all potential interests as well as withdraw themselves from the situation to maintain the appearance of objectivity and scientific/professional integrity.
- e) The aforementioned conflict of interest includes but is not limited to examples where:
  - REC members and reviewers have a personal relationship with research applicants;
  - II. Researchers have a personal relationship with participants and/or target institutions, for example, where the researcher is a child and youth care worker wanting to interview children at the facility where he/she works, or where the researcher is a manager wanting to interview own staff;
  - III. Researchers have family members, friends, and/or personal engagements/relations with persons at target institutions;
  - IV. Researchers have family members, friends, and/or personal engagements/relations with persons at the Department, who are directly / indirectly involved in the Research Ethics Committee (REC), as well as the Directorate: Research, Population and Knowledge Management of the Department.

## 5.3.3 Authorship and ownership of data

- a) All research conducted should be based on the principle that the contributions, ideas, writing, analyses, and interpretation of all persons involved in the research process should without exception be acknowledged.
- b) Any failure to comply with the aforementioned principle will be seen as a violation of accepted ethical standards and action taken against the individual(s) or they will be reported to the organisation that has jurisdiction over them.
- c) The aforementioned principle applies to all research conducted, internally and externally, as well as to all subsequent work resulting from the initial investigation, which is also applicable to Authors, Editors and Peer Reviewers.

## 5.3.4 Authorship and report-writing

Authorship of a document should be maintained by the individual(s) who are responsible for the writing of the research report and/or research findings and excludes the contributions and/or suggestions of an editorial nature that is not proportionate to that of the contributions of the writer/researcher; and does not add value to the conceptual, analytic and interpretive nature of the written product.

#### 5.3.5 Authors

- a) Authors are generally identified as, but not limited to, the researcher(s) or analyst(s) involved in generating the results as well as scientifically reporting these findings in a written form.
- b) In other words, these are the individuals, who provide their interpretations of the research findings/results generated and provide summations of these interpretations in written form.
- c) Authorship of a document should be maintained by the individual(s), who are responsible for the writing of the research report and/or research findings and excludes the contributions and/or suggestions of an editorial nature.

#### 5.3.6 Editors

- a) Editors are those individuals, who:
  - Assume a supervisory role in guiding the editorial development of the research report and/or relevant documentation;
  - II. Provide input on both the aesthetic qualities as well as content-related nature of the written work.

- III. Can also assume the responsibility of compiling a collation of works from other authors, and presenting it as written works to a relevant topic and/or area of investigation.
- IV. The collation of works/texts should however at all times formally acknowledge the original authors and/or researchers in the text as well as in all subsequent publications/writing/reports.
- b) Editors will in all instances contextualise the collated work by:
  - I. describing to the reader the nature of the collation;
  - II. describing to the reader the purpose and function of the collated works;
  - III. acknowledging the original authors, researchers and analysts involved in the original works;
  - IV. acknowledging and thanking all contributing authors and /or assistants in compiling the collated works.

#### 5.3.7 Peer Reviewers

These consist of individuals that are experts in the relevant field/area under investigation and who provide input on the scientific value of the research findings, validity and reliability of the results, as well as content-related issues relevant to their field of expertise and how it relates to the research in question.

## 5.3.8 Ownership of data

- a) The Department will be the owner of all research that it has commissioned.
- b) Permission shall be obtained from the Department's REC to access, analyse and disseminate research findings, relevant datasets as well as other research-related materials and resources in respect of commissioned research of the Department.

#### 5.3.9 Ethical reviews

- a) All proposed research involving beneficiaries, beneficiary records and officials of the Department should be subject to a formal ethical review by the REC.
- b) The Department reserves the right to undertake an ethical review of all completed research.
- c) All related processes (e.g. REC Guidelines and procedures) and deliberations should be based on the ethical principles outlined in this policy, for example (but not limited to) impartiality, privacy, beneficence, justice, equality and respect.
- d) A panel of reviewers should be knowledgeable in the content area relevant to the proposed research, as well as in research methodology, techniques and practices.

- e) All review processes should be conducted and documented impartially, fairly as well as systematically, whereby the scientific principles of social research are upheld and enforced.
- f) The approval or refusal of proposed research studies should be communicated to all relevant parties.
- g) Once a research application has been approved it should be registered on the Research Ethics Committee's Register of Applications.

#### **CHAPTER 3**

#### SPECIAL CONSIDERATIONS

## 6. Research with Special Populations

#### 6.1 Research with Children

- a) In line with a human rights approach and the Constitution, children have the right to participate in research and not be excluded on the grounds of age, gender, race, sexual orientation, education, disability, religious beliefs, pregnancy, marital status, ethnic or social origin, conscience, belief or language.
- b) Children should be encouraged to participate in research that is relevant to them and be allowed to voice their views, beliefs and experiences especially when the area of research has a direct relation, influence or effect on their livelihood.
- c) However, research involving children should be strictly regulated to protect their rights by promoting justice, equality, respect and human dignity throughout the research process.

## 6.1.1 Considerations when planning to conduct research with children:

- a) The researcher has to demonstrate that all other available sources of information from which to extract the information required has been exhausted.
- b) Doing primary research involving children should only be considered once no other informants/sources exist from which the information can be gathered from.
- c) The researcher has to demonstrate, taking into account the maturity and developmental stage (Human-Vogel, 2007) of the children, that their participation in the research will be age appropriate in terms of their ability to understand:
  - I. the nature of the research:

- II. their role and participation;
- III. what the findings are intended to be used for.
- d) Children under the age of 18 when approached to participate in a research project have to be assisted by preferably their parent, guardian or caregiver and if this is not possible by any other adult indicated by the child.
- e) Research with children should be done non-intrusively, namely information should not be collected in an insensitive manner whereby children are placed in a position to reveal unnecessary information that is not part of the focus of the research.
- f) Research with children should not result in the child's re-living of past traumatic experiences. Investigating sensitive issues/potentially traumatic experiences should only be permissible if the child has access to appropriate psycho-social services.
- g) When collecting data/information from children the researcher needs to be qualified / skilled to administer the relevant data collection tools, instruments, methods and techniques.
- h) Research that involves vulnerable groupings, for example orphaned, separated or unaccompanied children, can only be considered once a direct benefit to participating in the research has been established (HPCSA, 2008). The proposed research has to be relevant to the status of the child (e.g. his/her current environment, social status, lived experiences) and it is the responsibility of the researcher to show a clear and immediate benefit for participation in the study.

## 6.1.2 Informed consent: Exceptions to parental consent

- a) Even if parental consent is obtained, the minor still has the right to decide not to participate.
- b) The autonomy of individuals is questioned when dealing with adolescents, especially when it is accepted practice to obtain parental consent for adolescents' participation in research.
- c) A conflict exists when the rights of parents to control the experiences of their adolescent children conflicts with the adolescent's right to control their own experiences. However convincing, arguments in favour of adolescent autonomy as well as to consent without parental consent are epitomised when "the risk [in participating in the research] is minimal, parents do not act in the best interest of their children, and the adolescent is herself a mother (as adult status is conferred following motherhood regardless of the age of the young mother)" (Brooks-Gunn & Rotheram-Borus, 1994, p.110).

- d) Respecting adolescents' right to protection, confidentiality and privacy is further threatened when informing parents of their participation in research, which topic provides personal information about the adolescent that the parent may not be aware of (e.g. participating in a study on risky sexual behaviours). Therefore "when the best interests of youth are believed to be in jeopardy, parental consent can be waived" (Brooks-Gunn & Rotheram-Borus, 1994, p.112).
- e) In all instances when research with children is considered it is essential that the researcher assess the capacity of the child in terms of whether he or she is capable, as well as mature enough to consent to or refuse to participate in an investigation (research) or treatment of any kind.

## 6.2 Research with persons with disabilities

- a) In line with ethical principles and a human rights approach, all participants have the right to equality, protection, justice, respect and autonomy throughout all phases of the research process.
- b) Participants should therefore not be excluded from participating in research on the basis of their disability but concessions should be made when recruiting and including participants with disabilities for research purposes, especially participants with intellectual disabilities.
- c) It is vital that researchers take into consideration the following issues:
  - The capacity of participants with intellectual disabilities to communicate effectively, as well as expressing their emotions and experiences (Bropin & Renblad, 2000).
  - ii. The situation in which this participant enters a research session is characterised by a power-imbalance as participants with intellectual disabilities are viewed as a marginalised group (MacDonald et al, 2002).
  - iii. Researchers are thus expected to take these aforementioned issues into consideration when planning and executing research and should make the necessary concessions to ensure that the rights of these participants are protected at all times; that researchers act in the best interest of these participants; and that there is a clear and direct benefit for participants when participating in the research.

#### 6.3 Research on vulnerable communities / populations

- a) 'Vulnerable' communities/populations include those participants that have:
  - limited capacity to provide informed consent;

- ii. limited access to social support services;
- iii. limited or no schooling.
- b) 'Vulnerable' communities/populations include the elderly, the sick, the illiterate, the poor and/or unemployed as well as foreign nationals, refugees and asylum seekers.
- c) When conducting research with the aforementioned it is the responsibility of the researcher to ensure that concessions are made when gaining informed consent to participate in the research.
- d) Communication between researchers and the aforementioned should be appropriate while effective measures should be in place to ensure that the research serves the best interest of the them at all times, and that these participants are not harmed or exploited by the process.

#### **CHAPTER 4**

#### **RESEARCH AT STATE FACILITIES**

## 7. Guidelines for research with Departmental Facilities

- a) In this chapter the term, "facilities" refers to a state institution funded by the Department and "facility" has a similar meaning.
- b) Research conducted involving any Departmental facility should be permitted only once all of the following criteria have been met:
  - I. The criteria relating to non-maleficence and beneficence (refer to point 1.2) have been complied with.
  - II. The proposed research does not interfere, compromise or prevent the facilities' daily operations.
  - III. The programme, Regional office and/or facility of the Department should be able to accommodate the proposed research and any related requests within existing time frames, spatial arrangements and operational demands.
  - IV. The Departmental REC has to provide clear, descriptive conditions of approval for the proposed research to ensure that the best interest of all participants (particularly vulnerable populations) are safeguarded throughout the research process, and that operations at facilities are not disrupted or compromised.

- V. In addition to applying for formal approval from the REC for conducting research, voluntary informed individual consent has to be obtained from every participant (refer to point 2.4).
- VI. The relevant Facility Manager should be consulted during the application process and be included in the review discussions and decision-making processes.
- VII. The REC, in consultation with the Facility Manager(s), should identify an available contact person for the researcher where possible.
- VIII. The proposed research should not be in conflict or violate existing Departmental policies.

#### **CHAPTER 5**

#### 8. RECORDS AND DATA MANAGEMENT

This section highlights the responsibilities of the researcher as well as the Department with regard to research data and records management.

## 8.1 Guidelines for records and data management

- a) Data should be stored, accessed, transferred as well as disposed in a manner that maintains confidentiality and protects against unintentional disclosures.
- b) "Anonymised data" refers to data whereby all identifying information about research participants has been removed in order to remain anonymous throughout the research process.
- c) Researchers should ensure that they handle and store anonymised data as early as feasible in order to secure the anonymity and confidentiality of participant's personal information.
- d) A proper record-keeping system is in place and maintained to help facilitate subsequent processes such as the replication of the research design and analyses, as well as the development and design of professional interventions.

## 8.2 Responsibilities of the Researcher

All procedures and protocols developed for the following responsibilities should be in line with the ethical principles and standards accepted in this policy:

a) Procedures developed for the ethical collection of data;

- b) Use and transit (electronically or otherwise) of data;
- c) Storage and Security of data and records (particularly primary or raw data);
- d) Easy retrieving of data;
- e) Anonymising data.

## 8.3 Responsibilities of the Accounting Officer:

The responsibilities of the Accounting Officer is to:

- a) Ensure that all staff are aware of their responsibilities in relation to research-related activities;
- b) Ensure that all staff are aware of the role and function of the REC, as well as related protocols and procedures;
- c) Provide secure storage facilities for internal researchers;
- d) Ensure that staff research practices conform to Departmental policies and procedures and that deviation and/or breaches to relevant ethical codes are reported to the Accounting Officer.

#### 8.4 Ethical guidelines for service providers

## 8.4.1 Confidentiality clauses for all persons handling data

- a) Service providers contracted to perform entire, or any part of, an approved research project should ascribe and adhere to the same ethical principles, practices and philosophy as expected of all researchers outlined in this document.
- b) Researchers entering any legally binding agreement with service providers should ensure that a confidentiality agreement is signed in which the main principles of ethical research are stipulated.
- c) Any ethical violations should be reported and immediate steps taken to redress the situation and alleviate any harm caused by the aforementioned practices.

#### 8.4.2 Guidelines to handling data: Data security issues with service providers

Upon entering an agreement with a service provider that involves the handling of data, strict conditions and specifications should be set that takes the following (but not limited to) into account:

- a) Handling of personal information;
- b) Use of electronic sources when using service providers and transferring information/data (e.g. selecting designated recipients);

- c) Use of non-electronic methods (paper, postal services, hardware such as CD's, flash-drives, etc) when using service providers and transferring information/data;
- d) Data storage and security;
- e) Returning data to the Department: Specifications for handover;
- f) Destroying electronic copies after completion of accepted research report.

#### 8.4.3 Retention of data and records

It is the obligation of the researcher to ensure the continued safeguarding of all research data, information and records and to ensure that appropriate steps are taken to safely dispose of data, information and records within a reasonable time period after the completion of records.

## 8.4.4 Access to Raw (unprocessed) data

- a) Raw (unprocessed) data refers to all audio and/or visual recordings, paper- and/or electronic questionnaires, as well as researcher-, reflexivity (i.e. reflection notes) and facilitation notes.
- b) This includes transcripts from audio/visual recordings that have not been anonymised.
- c) Any access to data that involves human participants should be limited to the relevant researcher(s) if permission has not been obtained by the REC to access this data.
- d) Participants should be made aware of these limitations to confidentiality at the outset of the research.
- e) Furthermore, participants should have access to their own contributions (i.e. recordings, transcripts, questionnaires, etc.) and reserves the right to withdraw these without any negative consequences to the relevant participant(s).

#### 8.4.5 Access to Anonymised (processed) data and records

- a) This refers to all data that is anonymised (e.g. transcripts, electronic databases and datasets, etc.).
- b) It also includes all documents and records that contain analyses of data/information as well as research findings and interpretations (e.g. draft/final reports, thematic summary notes, data processing notes, data summations, etc.).
- c) Access to the aforementioned forms of data and records should be limited to the named researcher's project-related staff, service providers, research supervisor(s), and the REC.

- d) All the above-mentioned persons shall be bound to the ethical code of conduct as prescribed in this policy.
- e) Permission to access any related data and records should be obtained from the REC.

#### 8.4.6 Published data and records

- a) This refers to all information that is distributed to persons, organisations, and institutions that are beyond those involved in the research.
- b) Access to this type of data/record, if not classified as confidential, can be accessed via the Department's:
  - I. Head of Department;
  - II. Directorate Research, Population Development and Knowledge Management's Information Officer;
  - III. Research Ethics Committee Secretariat: and
  - IV. The Ulwazi Resource Centre Manager.

## 8.4.7 Criteria for granting permission to access departmental data and records

- a) Permission can be granted to access departmental data and records to all who were specified in the agreement between researcher and participants during the informed consent process whereby the limitations to confidentiality were clearly defined. For example, if a researcher has indicated that individuals other than the researcher(s) will have access to the data and/or records (e.g. supervisors, REC members, and reviewers) permission can be granted to those specified in this original agreement only.
- b) Persons not included in the aforementioned agreement should submit a formal application to the REC in which they clearly define the nature and purpose of their request for access to departmental data and records.
- c) Applicants should comply with REC application procedures as well as conditions provided regarding the use of data/records if permission has been granted.
- d) If data/records is intended for use beyond that which was originally agreed to between researcher and participants, revised informed consent needs to be obtained from all participants where the new purpose and use of data is renegotiated. Evidence of any new agreements with participants need to be provided.

- e) The use of data should contribute to the existing knowledge base as well as add value to existing service delivery practices.
- f) The REC can give ethical approval for a researcher to access information; however all applicants still has to follow and abide by the processes of the Promotion of Access to Information Act (PAIA) where applicable.

#### CHAPTER 6

#### NON-COMPLIANCE

## 9.1 Reporting ethical misconduct

- a) It is the responsibility of the researcher to ensure that the process of obtaining informed consent includes the provision of information pertaining to the rights of participants to report any misconduct of social researchers and their assistants.
- b) Participants should be furnished with the details of suitable contact persons that are appointed to act within a supervisory role over the relevant research.
- c) All reports of misconduct by social researchers and/or Departmental officials should be directed to a relevant senior official within a supervisory capacity and handled with confidentiality, anonymity as well as ensuring processes that are impartial and fair to all the parties involved.

#### A short title and commencement date:

## WESTERN CAPE DEPARTMENT OF SOCIAL DEVELOPMENT POLICY ON RESEARCH ETHICS

This policy is effective from the date of signature of the MEC on page 4.

#### **ANNEXURES**

## Legislative and policy framework influencing the Research Policy

This policy makes reference to the following legislation and Policy:

- The Constitution of the Republic of South Africa Act, 108 of 1996
- Health Profession's Act 56 of 1974)
- The Health Care Professions Council of South Africa (HCPSA): Guidelines for good practice in Health Care Professions, May 2008, Booklets 1, 6, 9 and 10.
- Children's Act 38 of 2005 as amended by Children's Amendment Act 41 of 2007
- The Promotion of Access to Information Act .54 of 2002
- The Promotion of Administrative Justice Act .3 of 2000
- The Western Cape Department of Social Development Policy on Records Management, Aug 2011. Cape Town: Provincial Government of the Western Cape.
- The Western Cape Department of Social Development Policy on Conflict of Interest,
   Oct 2011. Cape Town: Provincial Government of the Western Cape.
- South African Council for Social Services Professions: Policy Guidelines for the Course of Conduct, Code of Ethics and the Rules for Social Workers

#### List of persons/institutions consulted

- 1. DSD's Research Ethics Committee (REC)
- 2. Social Development's Policy Unit Ms Veronica Cloete
- 3. Social Development's Policy Unit Ms Tugfha Hamdulay
- 4. Social Development's Policy Unit Ms Luyanda Tabata
- 5. Legal Advisor Adv Collin Dickinson

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## List of Acronyms

DSD - Department of Social Development

**HOD** - Head of Department

**REC** - Research Ethics Committee

HPCSA - Health Professions Council of South Africa

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