

# PROTECTING CHILDREN'S RIGHTS IN SOCIAL SCIENCE RESEARCH IN BOTSWANA: SOME ETHICAL AND LEGAL DILEMMAS

CHARLES MANGA FOMBAD \*

## ABSTRACT

Debate has raged whether it is ever right to use children in conducting research in the social sciences. Some have argued that the use of a non-consenting subject or a subject whose consent is often doubtful, such as is the case with children, is wrong whether or not there is any risk posed to the subject. Others support such research provided it involves no discernible risk to the children. Social science researchers may enlist children in their studies of social processes for a variety of reasons. Such research raises a number of complex ethical and legal problems and challenges that have unfortunately not been addressed in many countries including Botswana. For example, may the researcher obtain the information he needs based on the consent of the child or his parent or both? What are the obligations of the researcher who learns of secrets that the child would rather keep from his parents, to his own detriment? These are some of the questions that this article will attempt to address. It begins by showing why children constitute a special research population that deserve special attention. It then considers some of the fundamental ethical principles that usually apply in social research involving children. This is followed by an attempt to identify some of the legal principles that could be invoked to protect children in such situations. It is contended that the sensitive nature of children and the fact that their use in social research, whilst sometimes unavoidable and beneficial, carries certain risks that justify the introduction of legislation in Botswana to regulate and protect them from any abuse they may be exposed to due to their immaturity.

## 1. INTRODUCTION

Although the origins of the children's rights movements can be traced back to the nineteenth century, it is only in the last 20 years that there has been a growing recognition of the importance of listening to children's views and wishes. The major turning point was the adoption of

\* Associate Professor of Law, Department Of Law, University of Botswana, Private Bag Ub 00705 Gaborone, Botswana

the UN Convention on the Rights of the Child in 1989. Article 12 states that 'State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'. Botswana, which ratified this Convention in 1995, has not yet taken any practical steps to incorporate its provisions in its laws.<sup>1</sup>

Nevertheless, the changes in emphasis in children's rights in the last decade is reflected in one of the major areas in which these rights are usually at risk, that is, the use of children in social science research. Debate has raged whether it is ever right to use children in conducting such research. Some have argued that the use of a non-consenting subject or a subject whose consent is often doubtful, such as is the case with children is, wrong whether or not there is any risk posed to the subject.<sup>2</sup> Others support such research provided it involves no discernible risk to the children used.<sup>3</sup>

In spite of the debate children are increasingly being used for a variety of reasons as active participants in research. Such research usually provides material for trying to solve some of the social problems confronting children such as sexual abuse, gang behaviour, teenage pregnancy, substance abuse and exposure to HIV/AIDS infection. In carrying out such research social science researchers are confronted with, amongst other things, decisions concerning not only the rights of the children directly involved but also the role of others, such as their parents or guardians, the institutions where these children are studying and even the community at large. What role do the latter play in decisions as to whether or not a child should participate in a research project? Besides this, social research may expose children to many risks, such as pain, failure, stress and manipulation.

One cannot simply treat children like adults. They are not adults. One must treat them like children, but in a way that adults normally do not treat children – as persons with rights rather than mere objects of concern. In general, social research involving the use of children raises a number of complex ethical and legal problems and challenges. For example, a researcher may want to conduct a research amongst first year law students about their sexual orientation. He is not sure all of them will want to participate. Is it proper for him to circumvent the consent of individual students by relying solely on the consent of the Head of the Law department? What are the obligations of a researcher who, in the course of his research amongst 16-year-olds, discovers widespread use of cocaine, marijuana and alcohol on a daily basis? Is he obliged to disclose this information to the children's parents or the school authorities? Is it proper for a researcher to allow children to participate in an HIV/AIDS prevention research without the consent of their parents? Thus, unless one is dealing with virtuous children in

a pristine context, a researcher will see things of which he may not approve that will place him in a dilemma. He must strike a balance between respecting the rights of parents and guardians, and protecting the interests of the child.

There is evidence to show that at international level, serious attempts have been made to take children's rights seriously.<sup>4</sup> Insofar as the position of children in research is concerned, there are countries such as Botswana where there remains considerable uncertainty over the ethical and legal restraints within which researchers should operate. A lot of research today, especially that dealing with the HIV/AIDS pandemic, is bound to involve children as active participants in one way or another. This article will look at some of the possible ethical and legal principles that may apply. It begins by looking at why children constitute a special research population that deserve special attention. It then considers some of the fundamental ethical principles that usually apply in social research involving children. This is followed by an attempt to identify some of the legal principles that could be invoked to protect children in such situations. It is contended that the sensitive nature of children and the fact that their use in social research, whilst sometimes unavoidable and beneficial, carries certain risks that justify the introduction of legislation to regulate and protect them from any abuse they are exposed to due to their immaturity.

## 2. CHILDREN AS A SPECIAL RESEARCH POPULATION

Although children as a class of research participants for reasons that are later examined deserve special attention, the term 'children' needs some explaining. It embraces a remarkably heterogeneous group of individuals who vary significantly in their developmental capabilities. As a result of this, in Botswana, as in many legal systems, the word 'child' is defined in various ways in different contexts. For example, in the law of contract, a child who has not celebrated his seventh birthday (an *infans*) is always regarded as being *incapax* (lacking capacity). The actual mental ability of such a child is irrelevant as there is an irrebuttable presumption that he lacks contractual capacity.<sup>5</sup> A child over the age of seven and under the age of 14 years (an *impubes*) also lacks contractual capacity. However, there is a rebuttable presumption that renders him *incapax* until the contrary is proved. The proof that he has such capacity lies with the party that alleges it.

An interesting series of definitions is provided by the Children's Act 1981. Section 2 defines an 'infant' as, 'a person under the age of seven years', a 'child', as 'any person who is under the age of 14 years', and a juvenile, as 'a person who has attained the age of 14 years and is under the age of 18 years'. On the other hand, Section 49 of the

Interpretation Act 1984 states that the age of majority is 21 years.<sup>6</sup> Children in this context therefore covers all persons who have not yet celebrated their 21<sup>st</sup> birthday, although they may in some cases and situations be referred to as infants, juveniles, young persons, adolescents or minors. What is however clear from all this is that the particular age of the person classified as a child matters.

There are several unique vulnerabilities of children that affect their role as research participants. These may be summarized in four main points.<sup>7</sup>

Firstly, because of their more limited cognitive competences and experiential backgrounds, children are likely to have more difficulties than adults in understanding the research process; the younger they are, the greater the difficulties. Their limited understanding of their role as research participant will also make it difficult for them to be able to fully appreciate the significance of informed consent, their freedom to withdraw from the research project at any stage and their right to resist unwarranted intrusion.

Secondly, because of their limited social power, children are vulnerable to external influence and pressure. Parents and other adults exercise proxy consent for children, and children's institutionalization in extra familial care centres, schools and other settings further reduces their power to exercise independent decision-making concerning their research participation. Although the assent of children is often encouraged, it will usually be difficult for them to dissent from participating in a research project which has already secured parental permission or the backing of the institution in which the children are found.

Thirdly, children are vulnerable as research participants because of their ambiguous legal status as minor that both protects and limits their rights.<sup>8</sup> Because of this status, parents tend to take important decisions not only on the participation of their offspring in research but also on other matters such as the disposition of research materials and the use of direct benefits from the research participation. The assumption is usually that the parents are acting in the best interest of their offspring but this may not always be the case as the decision of some parents may well be motivated by their own selfish ends.

Finally, participation in some forms of research may involve subjecting people to pain, to failure, or to some stressful manipulation that may violate their autonomy in the short term or could result in some enduring change. These risks are multiplied in the case of children because of their immaturity.

For these reasons children tend to have little control over many crucial aspects of their research participation that are guaranteed adult participants. The younger the child, the more vulnerable they are in their research participation because of the enhanced limitation in cognition and reasoning, experience, social power and other

features that limit their capacity to protect their rights as research participants.<sup>9</sup> In most cases, research procedures that would be extremely stressful for an infant may have a negligible effect on a juvenile. The general assumption is that vulnerability decreases with age but there are, however, some risks that increase with the child's increasing age. For example, a juvenile is uniquely vulnerable to risks such as threats to self-image when answering a questionnaire that may require disclosure of his poor academic performance, which is unlikely to be felt by an infant or a very young child.

These characteristics of children usually make it imperative that special consideration and protection is accorded them when they are used as research participants. This protection is usually provided in the form of ethical and legal rules and guidelines. The possible form and scope of this is now examined.

### 3. SOME RELEVANT ETHICAL PRINCIPLES

Ethical considerations have always accompanied all forms of research, especially where this involves the use of human participants but the historical origin of current ethical principles for conducting research with children arises from the Nuremberg Trials, which took place after the Second World War. The Nuremberg Code that emerged from this set out statements of certain moral, ethical and legal principles relating to research involving human subjects. In 1964 the World Medical Assembly adopted the Declaration of Helsinki to provide guidance for physicians in biomedical research with human subjects. This was amended in 1989 and 1996 and now includes an examination of the issue of children as research subjects.<sup>10</sup>

Certain fundamental principles have now become widely accepted and are particularly relevant as a guide in the conduct of social research involving children. The key ethical principles can be summarized under four main heads viz, autonomy; nonmaleficence; beneficence; and justice. Unlike legal principles, none of these principles is absolutely binding, although some philosophers argue that ethical principles are *prima facie* binding in the sense that they are binding in all situations except when in conflict with equal or greater duties.<sup>11</sup> It is, however, submitted that this is only true to the extent that the researcher is operating within the framework of a professional association that has adopted these principles in its code of practice.

#### A. *The Principle of Autonomy*

In this context, the principle of autonomy, which is often referred to in literature on ethics in the social sciences as the principle of self-determination or respect for persons, refers to behaviour that is both

voluntary and intentional.<sup>12</sup> Respect for the principle of autonomy means respect for the inherent freedom and dignity of each person, even children. In other words, because they are human beings, all children should be free to make choices for themselves because a person without the freedom to do so is a person without dignity. The principle of autonomy, which is the chief aspect of the principle of respect for persons, derives from Kant's concept of 'self-legislating will', and his notion that people are ends in themselves, and should never be treated solely as a means to another end.<sup>13</sup>

In its broadest sense, the principle of autonomy or respect for persons mandates the right to considerable self-determination in the research process and respect for the wishes and decisions of research participants as well as their values and beliefs.<sup>14</sup> This is reflected in the general requirement of informed consent, respect for privacy, confidentiality of research material and the recognition of their right to withdraw from the research process at any time. The right to privacy as part of the respect for autonomy means that a person should have the power to decide what information about himself he wants to share, and a right to control what others know about his private life.

The exercise of Kant's 'self-legislating will' requires two basic ingredients; first an authentic, well-developed self; and an independent capacity to rule the self. One sense of autonomy that focuses on these cognitive elements has been termed 'autonomy as effective deliberation...'. This means action taken where a person believed that he or she was in a situation calling for a decision, was aware of the alternatives and the consequences of the alternatives, evaluated both, and chose an action based on that evaluation.<sup>15</sup>

The principle of autonomy is basically the first principle that research ethicists begin with and requires researchers to recognize and respect the self-concept and capacity for self-rule of children in all decisions related to the research process, although the extent to which this will apply will depend on a number of factors, particularly the child's age and maturity.

As Michael Freeman (1997) points out, to respect a child's autonomy is to treat that child as a person and as a right-holder.<sup>16</sup> It is clear that we can do so to a much greater extent than we have hitherto assumed. However, the principle does not prevent us from recognizing that children are sometimes and in certain situations not in a position to act in a fully autonomous manner.

### *B. The Principle of Nonmaleficence*

The principle of nonmaleficence has its roots in medical ethics and is often associated with the Hippocratic oath, which physicians take.<sup>17</sup> The Latin form of the principle of nonmaleficence, *primum non nocere*,

translated as 'first, do no harm', has been referred to as the 'most fundamental ethical principle for medical and human service professionals'.<sup>18</sup>

This principle requires researchers not only to avoid any harm to research participants, whether intentional or negligent, but also to minimize any risks of such harm however minor the risk may be. However, the duty of nonmaleficence, it has been said, does not require omniscience, just knowledge and careful, prudent judgment.<sup>19</sup> It does mean that a researcher should not use children in any research that he knows, or should know, is likely to do some harm, whether physical or psychological to them. Whilst he may weigh and balance the risks involved and the benefits to be derived, special considerations and regulations appropriate for weighing the risks and benefits of research involving the use of children are usually provided in many professional codes of practice.<sup>20</sup>

### *C. The Principle of Beneficence*

The principles of nonmaleficence and beneficence function hand-in-hand in the ethical analysis of research. Although the former is obligatory and the latter supererogatory in ethical analysis, both require some justification for research procedures that involve any meaningful and identifiable risk to participants. Beneficence, in essence, adds responsibility to the duty to avoid harm. It imposes on researchers, a duty to design and carry out research, especially where this involves children, in a way that maximizes possible benefits and minimizes possible harms. It thus suggests a more active and far-reaching category of moral obligation than nonmaleficence.

Because a large amount of social research with children does not benefit the research subjects directly, it is therefore imperative that the benefits to other children must clearly outweigh any risks to the subjects themselves.<sup>21</sup> For example, when research involves such sensitive matters like a child's use of drugs or alcohol at school, where a breach of confidentiality might include a disclosure to the school authorities or the child's parents, the principle of beneficence requires that the possible psychological and social impact of such disclosure must be considered in advance by the researcher. This principle requires that such risks must be fully discussed with the participants before the research is embarked upon.

### *D. The Principle of Justice*

In this context, the principle of justice simply means the obligation on researchers to act fairly, impartially and in a non-discriminatory manner. This requires the unique vulnerabilities of children to be taken into account in the design of the research procedures as well as its implementation.

The principle of justice also requires that there should be no bias towards the research subjects on the basis of age, race, gender, culture and any other variables that are irrelevant to the research process.<sup>22</sup> Nevertheless, the different backgrounds and characteristics of the children, which may affect the design and implementation of the research, should be taken into account. For as Aristotle said 'justice means treating equals equally and unequals unequally, in proportion to their inequality'.<sup>23</sup> The principle of justice is also at the root of codes of practice of many professional bodies that prohibit discrimination. Finally, this principle also demands that a research project should not unduly involve persons from a group that are unlikely to be among the beneficiaries of subsequent applications. This is particularly so when the researcher requires the involvement of children. However, if the only way to provide some possible benefit to children is to conduct research using other children, some 'minimal level of risk'<sup>24</sup> may be justified by the prospect of future benefits.

#### 4. SOME APPLICABLE LEGAL PRINCIPLES

There is no specific legislation in Botswana dealing with the conduct of research using children. Nevertheless, there are a number of well-established common law principles that can be applied by way of analogy. The main legal rights that can be inferred from the established common law principles to protect children involved in research are the rights to informed consent; privacy, and confidentiality.

##### *A. The Right to Informed Consent*

###### *General principles on informed consent*

As a general rule, a person can be involved in a research process only if he consents to it. Such consent, or strictly speaking, informed consent, is valid in law only if it is given willingly, without duress, force or fraud and is given by a person who is legally competent to do so and is based on a full knowledge of the nature of the research as well as an appreciation of any risks involved in the process. Informed consent is closely linked with the principle of autonomy, which acknowledges the right of every human being to a say in all matters that directly affect his person.

Voluntariness of consent presents special problems with children because they often lack the mental and legal capacity to consent to their own participation in the research process. They are unlikely to fully understand the abstract information relating to the research, including the fact that it is research.



Be that as it may, under the predominantly Roman-Dutch legal principles which apply in Botswana, the general rule appears to be that a child under seven (an *infans*) has no right to consent to participate in a research process unless this has been permitted by his parents or guardians. For a child over seven and below the age of majority, that is 21 years, his consent and in many situations, that of his parents or guardians, is required.

*The child's right to consent*

Where the child's participation in a research process is based on a contract, then the ordinary rules relating to the contractual capacity of children will apply.<sup>25</sup> The general principle in Roman-Dutch law is that a child is considered to be immature throughout his minority and is thus not bound by any contract that he signs.<sup>26</sup> In the words of Tindal JA in *Dhanabakium v Subramanian*,<sup>27</sup> 'a minor cannot bind himself by contract without the assistance of his guardian subject to certain qualifications' The only situation where the child's consent alone to a contract to participate in a research process is entirely binding and enforceable at the behest of the child, is where the contract calls for performance only from the researcher and not from the child and is entirely to the child's advantage.<sup>28</sup> It is however difficult to conceive of a situation arising under these circumstances whereby the child will come under no obligation. Such an exceptional situation may well arise where the researcher undertakes to perform an obligation but stipulates that no action can be taken against the child who refuses to perform his part of the obligation; for example, an agreement to pay the child a certain sum of money irrespective of whether the child actually participates in the research process or not.<sup>29</sup>

It is possible to contrast this approach to what obtains under English law where the common law also applies and the situation in the US where it is subject to statutory law.

In England, the principles established in the epoch-making decision in *Gillick v Norfolk and Wisbech Area Health Authority*,<sup>30</sup> although dealing with the consent of children in the context of medical treatment, have been applied to a variety of other situations.<sup>31</sup> This decision lays down the principle under which a child under the age of 16 years, provided he has achieved a sufficient understanding and intelligence to enable him to fully understand, has the right to consent to participation in a research project. In the more recent case of *Re E*,<sup>32</sup> the court noted that although the child was intelligent enough to give his consent, he did not have a full understanding of the implications of such a decision. It held that whilst the court should hesitate to interfere with a decision taken by the child, in deciding whether to dispense with the child or the parent's consent, the welfare of the child is the first and paramount

consideration. The position in English law is therefore that the child has a right to consent arising under the common law and under some statutes, although the courts have a right to override such consent, if it was not made in the best interests of the child.<sup>33</sup>

In the US, professional codes, statutes and, administrative regulations have shaped the law on children's consent to research, with the courts playing a less important role.<sup>34</sup> Federal regulations for research using children explicitly recognize that children are entitled to exercise an influence on decisions about their research participation, independent of their parents' decisions.<sup>35</sup> Although these regulations require that parents should be adequately informed and that they must be asked to decide whether to allow their child's participation, their 'consent' is not a condition that automatically paves the way for the child to participate in the research. Their role is seen as that of deciding to 'permit' or 'deny' their child's participation. Whilst 'denial' blocks the child's participation, 'permission', unlike 'consent', does not automatically allow the child to participate because federal regulations give the child the role of deciding to 'assent' or 'refuse'. The child's research participation therefore involves a combination of parental permission plus the child's assent. Parental denial of permission or the child's refusal negates the child's participation. This approach seeks a balance in providing adequate protection in two respects. Firstly, to cater for the fear that the child may not adequately understand the research project to which he is consenting or lacks the capacity to give his consent voluntarily. Secondly, there is a safeguard in that the parents can be assumed to have the ability to make a voluntary, non-pressured consent or refusal, but this is balanced by the recognition of the fact that the child may have good reasons for not wanting to participate in the research that should not be ignored.<sup>36</sup>

#### *Dispute between parent and child and court involvement*

A difficult situation may arise where there is disagreement between the child and his parents. Where it is not possible to reconcile the parties, the matter may come before the courts. Insofar as the Roman-Dutch law is concerned, the rule that a child under seven has no contractual capacity means that the decision has to be taken by the parents or guardians. In spite of this, the courts have inherent powers not only to review all contracts involving children who have not reached their age of majority but also all those in which there is a dispute between the child and the parents or guardians over the issue of consent to the child's participation. In the exercise of this inherent power, the court could, acting in the best interests of the child, override the consent of either or both the child and the parents.<sup>37</sup>

The more developed rules in the US provide a useful guide as to when the courts can intervene and override the consent of either the child or the parents or both. The regulations allow for the child's decision-making power to be by-passed in two main situations. Firstly, where the research is very important for the health or well-being of the child, although it must be noted that social science research rarely offers any substantial direct benefits to the actual participants.<sup>38</sup> Secondly, where the child cannot reasonably be consulted. This has usually been taken to cover situations where the child cannot be made to understand what will happen in the research or why the research is being done as well as situations where the child has an impaired mental capacity. The regulations also provide for four circumstances where the requirement of parental or guardian's permission may be waived.<sup>39</sup> The first situation is where the parents are incompetent. This may arise where the parents have serious decision-making incapacities; for example, because of serious mental retardation or mental illness. The second situation is where the parents are competent but unavailable. This could arise where the parents' or guardians' participation would be impractical or impossible to obtain and the research itself is potentially very important for society and cannot be performed without the child's participation. For example, a researcher interviewing children who have run away from home or who are involved with a gang will certainly not get cooperation from the children if he were to insist on obtaining the permission of their parents. Here the unavailability of the parents or guardians is a consequence of the child's control of access to them. A third situation is where the parents are competent and available but in a non-beneficent posture. This usually arises where there is a breakdown in the normal parent-child relationship. Examples of this are where children have been neglected or abused by their parents or turned over to child welfare agencies. In such situations, it is no longer possible or safe to assume that the parents will act beneficently to protect the child's best interest when granting permission. Parents who have abused their children might be motivated by personal or self-protective interests to veto the children's participation in research designed to understand and meet the needs of such neglected or abused children. Finally, the permission of parents or guardians may be considered superfluous for research involving matured children or adolescents whose capacities to make research decisions are substantially the same as those of adults. However, the relevant regulations implicitly recognize that when parental and guardian permission will not be obtained, a need arises to take extra steps to protect children in such situations.<sup>40</sup> These should ensure that the children understand the proposed research and its purposes; that they are in an autonomous position to assent or refuse to participate and remain free throughout to discontinue their participation if they so desire.

On account of the complexity of the whole concept of informed consent in this context and the uncertainty of the applicable legal principles in Botswana, it is suggested that a researcher involved in a project that requires the participation of children should follow the following guidelines:

- Ascertain the existence of any specific legislation or legal principles governing the situation;
- find out if any procedures or codes of practice apply;
- ensure that the interests of the children are adequately protected by their parents, guardians or any other competent person;
- fully identify and discuss the interests of all the parties involved. The wishes of the children should be elicited and fully taken into account;
- ensure that all what is done is in the best interests of the children.

### B. *The Right of Privacy*

The right to privacy is a well-recognized Roman-Dutch law principle.<sup>41</sup> It is one of those legal notions whose exact scope is still unsettled, fairly confusing and, some will say, even muddled. Nevertheless, the various definitions of privacy revolve around the idea of 'withdrawal', 'being let alone', 'solitude, intimacy, anonymity and reserve', and 'minimum interference with one's own life'.<sup>42</sup> An injury to privacy therefore involves any intentional and wrongful interference with a person's private and secluded existence that entitles the victim to sue for sentimental damages under the *actio injuriarum*. As a civil wrong, the theoretical division of the categories of invasion of privacy into four, originally suggested by Prosser<sup>43</sup> has proven useful in Roman-Dutch law.<sup>44</sup> According to this four-fold categorization, an invasion of privacy may take the form of an unreasonable intrusion into the private sphere; the public disclosure of private facts; the appropriation of a person's name or likeness; and placing a person in a false light.<sup>45</sup> In his illuminating work on privacy in research, Kelman (1977) has suggested three senses of invasion of privacy directly relevant to social science research: viz, exposure of damaging information, diminishing a person's control and liberty, and intrusion into a person's private space.<sup>46</sup>

The important question here, however, is whether this right of privacy that protects adults also extends to children. There is the assumption that the secret lives of adults is important, but children as well need freedom from total scrutiny in order to develop as persons, at first in distinction from their parents, then from other adults, and finally sometimes from their playmates and classmates.<sup>47</sup> Research has shown the importance of privacy to children.<sup>48</sup> It is easy for researchers to be cavalier about private matters, especially when

children are involved. Even where researchers do make an effort to protect the participants' privacy, they are usually insensitive to the idiosyncratic desires and concerns of children participants. This is often because the personal privacy interests of children, which sometimes overlaps and sometimes conflicts with their family privacy, are confused.

One of the few cases that directly raised the issue of the privacy rights of children in a research setting is the US case of *Merriken v Cressman*.<sup>49</sup> A Pennsylvania school district launched an experimental programme to reduce drug abuse. The programme included administration of a personality test purporting to identify potential drug abusers, followed by various compulsory interventions, including confrontational group therapy programmes, for those who met the screening criteria. The testing programme was intended to create a 'massive data bank' for use by 'superintendents, principals, guidance counsellors, athletic coaches, social workers, PTA officers, and school board members'. Parental consent was sought but without disclosure of the risks associated with the programme. Student consent or assent was not sought at all although the procedure ultimately was revised to permit submission of blank questionnaires. Although the court acknowledged that children have a fundamental right to privacy, it stopped short of deciding the case on such terms. Instead it held that the petitioner's mother had suffered an invasion of her constitutional right to privacy because the personality test included:

such personal and private questions as the family religion, the race or skin colour of the student... the family composition, including the reason for the absence of one or both parents, and whether one or both parents 'hugged and kissed me when I was small, tell me how much they love me, enjoyed talking about current events with me, and make me feel unloved'.<sup>50</sup>

The *Merriken* case illustrates how social science research involving children can infringe not just the privacy rights of third parties (for example parents or guardians) but also those of the children themselves. It also shows the degree of intrusiveness that may accompany what may pass for simple innocuous questions in a questionnaire. What is usually at risk in the research process is what has been referred to as the invasion of informational privacy. Informational privacy has been defined as encompassing an individual's freedom from excessive intrusion in the quest for information and an individual's ability to choose the extent and circumstances under which his beliefs, behaviour, opinions, and attitudes will be shared with or withheld from others.<sup>51</sup> Notwithstanding the absence of much litigation on this, it is not difficult to see how a researcher could easily be involved in a legal suit for invasion of privacy because of the perceived intrusiveness of some of the questions used in his questionnaire. A researcher should

therefore follow a number of important guidelines in order to avoid an action for invasion of privacy:

- The privacy interests of both children and their families must be taken into account when designing a research project involving children.
- The disclosure of deeply private information or one that can subject a child to shame or embarrassment should be avoided.
- The research should be designed to be no more intrusive than is absolutely necessary and no matter how minimal the intrusion, the participant must be informed about this and his consent obtained.

Although the exact rules are not well settled, there is no reason to assume that a violation of a child's right to privacy in a research project will not be sanctioned in much the same way as that of an adult. But perhaps the major problem with research using children is the high risk of disclosure of the information to third parties. Is there any guarantee of confidentiality?

### *C. The Right to Confidentiality*

#### *The nature of the duty to confidentiality*

Generally, the concept of confidentiality presupposes a relationship of intimacy or trust between two or more persons in whom private or secret information is shared on the understanding that this information will not be repeated to an unauthorized person or persons. The legal duty of confidence is a common law principle enforceable through an action for breach of confidences and has at least three features.<sup>52</sup> Firstly, that the information must be of a confidential nature in the sense that the information is inaccessible to the public. In other words, 'it must not be something that is public property and public knowledge'.<sup>53</sup> Secondly, the information must have been communicated in circumstances importing an obligation of confidence.<sup>54</sup> Finally, the enforcement of confidentiality in the circumstances must not be unreasonable.

Researchers, like other professionals, clearly owe a duty of care over keeping confidential information that they receive about those involved in the research project. What is less clear and somewhat controversial is whether this duty extends to information obtained in the course of research involving the use of children. The reasons for this uncertainty are aptly summarized by Mulvey and Phelps thus:

Decisions about... [the maintenance of confidentiality] are complicated in the case of juveniles because juveniles are not fully autonomous individuals in the eyes of either their communities or their parents, and the interests of

both the family and the community must figure into the calculation of the limits of the confidentiality contract. The community has a justifiable stake in fostering the development of responsible citizens and in maintaining public safety; the family has a privacy interest in raising children according to its own standards, rather than those of... [researchers] or state agencies. The confidentiality issue becomes troublesome when the... [researcher] possesses information that would be seen by either of these parties as essential to their professional role. The basic difficulty in these cases lies in the professional's felt sense of responsibility for pursuing the youth's best interest or for honouring privacy rights and placing the burden for intervention on other parties involved with the youth.<sup>55</sup>

These issues are still problematic even where one assumes that the interests of parents, state authorities and children were congruent. Sometimes, parents cannot properly discharge their parental duties towards their children without the benefit of information that their children would prefer to keep to themselves but which may have been disclosed in the course of a research project. It is arguable that a special relationship exists between a researcher and the children involved in his research project that imposes on him a duty to respect their confidences as part of the children's right of privacy as well as their fundamental human rights. In other words, the right to confidentiality applies to children in much the same way as it applies to adults.

#### *Exceptions to the right to confidentiality*

The right to confidentiality has never been absolute. The law, whilst recognizing the right of people to have private information disclosed in confidence to be protected, has also provided certain circumstances where this protection will for various reasons be lifted. These exceptions are particularly important in the case of research involving children because of the well-founded fear that strict insistence on keeping all information acquired in this way confidential might be detrimental to the proper rearing of children in certain situations or may deprive society in general of the benefits of such research. The main circumstances when a researcher may be compelled to disclose confidential information about children is now briefly examined.

The first exception is disclosure with the consent of the child or his parents. The consent of the parents alone may suffice for children below seven provided such disclosure is in the child's interest. For older children, depending on whom the information is being disclosed to, the consent of both the child and the parents may be necessary. Such consent will be valid only where there is understanding and voluntariness and is not impaired by any misrepresentation or fraud.

Secondly, a possible exception is the so-called doctrine of shared confidentiality, which arises from disclosure that the participants in

a research must have foreseen as routine amongst the researcher and his staff. An example of this is where clerical assistants in their normal course of duty see the confidential information.

Thirdly, there are usually certain very specific occasions where statute law requires disclosure of information regardless of whether the child or the parents consent. For example, Section 5(3) of the Botswana Public Health Act 1981 contains a list of notifiable diseases, such as smallpox and cholera. There is a duty to notify the Minister of Health of anyone suffering from any of these diseases. Sections 54 and 57 of the Botswana Criminal Procedure and Evidence Act 1986 also give the police powers to seize and take any property in the course of carrying out criminal investigations. In the absence of any qualification, these powers could be used to seize confidential records, the contents of which may eventually be disclosed in court.<sup>56</sup>

Fourthly, a court may order a researcher who has received confidential information and who had bound himself not to disclose the information to third parties to break his confidences. However, since courts are usually sensitive when dealing with matters concerning children a researcher who honestly believes that disclosure would not only be a breach of his duty of confidentiality, but may also be seriously prejudicial to the children involved in the research, may request the court to respect his silence, or if this is refused, request that he gives his information in writing so that it is not made public. In the unlikely event that this is rejected, he will have no choice but to divulge or risk imprisonment for contempt of court.

Finally, the researcher may also be compelled on grounds of public interest to divulge information obtained in the course of research using children. Lord Goff explained this exception in these terms:

...although the basis of the law's protection of confidence is that there is a public interest that confidences should be preserved and protected by the law, nevertheless that public interest may be outweighed by some other countervailing public interest, which favours disclosure. This limitation may apply... to all types of confidential information. It is this limiting principle which may require a court to carry out a balancing operation, weighing the public interest in maintaining confidence against a countervailing public interest favouring disclosure.<sup>57</sup>

This is probably the most controversial exception and requires the courts, in any given situation, to carefully weigh and balance the children's interest in maintaining confidence and the public interests in favour of disclosure, without allowing one to unnecessarily predominate over the other. The main conclusion that can be drawn by way of analogy from decided cases on this topic is that disclosure of confidential information obtained during a research project using children will be sanctioned, against the wishes of the children and even contrary to



their interests, where this is necessary for the protection of others potentially at risk.<sup>58</sup> But the risk must be really grave to justify this.

On the whole, the main conclusion here is that a researcher working with children is apparently bound by the same legal principles that impose a duty of confidence with respect to adults. Perhaps, the more sensitive or intimate the revealed information, the greater the responsibility for confidentiality. One very fundamental point that must act as a guide to researchers in such situations is the very important duty to inform the children involved in the research project of their right to confidentiality and the exceptions to this.

## 5. CONCLUSION

It is clear from the preceding discussion that although children as a class of research participants deserve special concern because of their unique vulnerabilities, as compared to adults, little attention has been paid to this in Botswana, as in many countries, with perhaps the exception of the US. The result of this is that researchers using children in their research projects are left with no established legal and ethical framework to ensure that the interests of these children are adequately protected. Nevertheless, a number of ethical and common law principles, whose exact scope of application is uncertain, can be invoked in certain situations. It can be argued that every research project that involves children, more than any other, needs both morality and legality: the first without the second potentially exposes the researcher to legal liability; the second without the first may make him cruel.

Children are not little adults but are developing and growing up beings who have their own specific characteristics that must be taken into account when involving them in research. There is therefore need for legislation that defines the minimum standards of fair and decent treatment of children who are research participants. Such legislation must regulate the procedure to be followed in using children in research, their rights vis-à-vis third parties such as their parents, guardians, schools or other agencies responsible for their welfare, the research setting and risks and the extent to which the age and developmental stage of children will determine their participation. A combination of clear ethical guidelines that should feature in a code of practice and legal principles that should feature in any law on the matter has many advantages. It will reduce the research risks involved in using children, whose participation is in many cases unavoidable not only for their individual benefit but also for the benefit of society as a whole. Legal certainty will also enable researchers to carry out their work without fear of legal action.

## NOTES

<sup>1</sup> In fact, nothing is said about the wishes and feelings of children in its Children Act of 1981, which, inter alia, deals with the custody and protection of children.

<sup>2</sup> See, Ramsay, P. (1970) *The Patient as Person*, New Haven: Yale University Press at 17.

<sup>3</sup> See, McCormick, R. (1974) 'Proxy consent in the experimentation situation', 18 *Perspectives in Biology and Science* 13-14.

<sup>4</sup> See generally, Freeman, M. (1997) *The moral status of children. Essays on the rights of children*, The Hague: Martinus Nijhoff Publishers.

<sup>5</sup> A person is accountable (*incapax*) if he has the necessary mental ability to distinguish between right and wrong and if he can also act in accordance with such appreciation. See generally, Neethling, J., Potgieter, J. M. and Visser, P. J. (2001) *Law of Delict* 4<sup>th</sup> ed, Durban: Butterworths, at 121-22.

<sup>6</sup> There are however various pieces of legislation that give different definitions of who a child is for particular purposes. For example, a person is a child if he is under 19 years for purposes of adoption (Section 2 of the Adoption of Children Act 1952), under 21 years for purposes of being maintained by his parents after divorce (Section 28(2) Matrimonial Causes Act 1973) and under 16 for purposes of being maintained by his father if born out of wedlock (Section 4(2)(a) Affiliation Proceedings Act 1970).

<sup>7</sup> Thompson, R. A. develops these in, 'Development changes in research risk and benefit: A changing calculus of concerns' in B. Stanley and J. E. Sieber (1992) (ed) *Social Research on Children and Adolescents: Ethical Issues*, London: Sage Publications at 38-41.

<sup>8</sup> See, Baumrind, D. (1978) 'Reciprocal rights and responsibilities in parent-child relations', 34 *Journal of Social Issues* 179-96, and Melton, G. B. (1983) 'Minors and privacy: Are legal and psychological concepts compatible?', 62 *Nebraska Law Review*. 455-93.

<sup>9</sup> See n 7 at 40.

<sup>10</sup> See generally, Greig, A. and Taylor, J. (1999) *Doing Research with Children*, London: Sage Publications at 144-54.

<sup>11</sup> See Welfel, E. (1998) *Ethics in Counseling and Psychotherapy: Standards, Research, and Emerging Issues*, Pacific Grove: Brooks/Cole Publishing Co at 32.

<sup>12</sup> See Miller, B. (1981) 'Autonomy and the refusal of lifesaving treatment', 11 *Hastings Center Report* 22-8.

<sup>13</sup> Kant (1959) *Foundations of the Metaphysics of Morals*. New York: Macmillan.

<sup>14</sup> See n 7 at 36.

<sup>15</sup> See Miller, B. (1981) 'Autonomy and the refusal of lifesaving treatment', 11 *Hastings Center Report* at 24.

<sup>16</sup> In Freeman, M. (1997) *The Moral Status of Children. Essays on the Rights of the Child*, at 36.

<sup>17</sup> The Hippocratic oath admonishes physicians to heal the sick and never injure them.

<sup>18</sup> See n 11 at 34.

<sup>19</sup> See n 18.

<sup>20</sup> See Committee for the Protection of Human Participants in Research (1982) *Ethical Principles in the Conduct of Research with Human Participants*, Washington DC: American Psychological Association at 22.

<sup>21</sup> See Macklin, R. (1992) 'Autonomy, beneficence, and child development: An ethical analysis' in B. Stanley and J. E. Sieber (ed) *Social Research on Children and Adolescents Ethical Issues*, London: Sage Publications at 93.

<sup>22</sup> See n 11 at 37.

<sup>23</sup> Cited in Kitchener, K. S. (1984) 'Intuition, critical evaluation and ethical principles: The foundation for ethical decisions in counseling psychology', 12 *The Counseling Psychologist* 43-5.

<sup>24</sup> The whole concept of 'minimal risk' in research involving children has been the subject of much controversy. Minimal risk has been defined to mean that the risks of harm anticipated in the proposed research is not greater, considering the probability and magnitude, than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. But see a critique of this in Macklin, R. (1992) 'Autonomy, beneficence, and child development: An ethical analysis' in B. Stanley and J. E. Sieber (ed) *Social Research on Children and Adolescents Ethical Issues*, London: Sage Publications at 93-5.

<sup>25</sup> See generally, Christie, R. H. (1991) *The Law of Contract in South Africa*. 2<sup>nd</sup> ed Durban: Butterworths at 273-83 and Joubert, D. J. (1987) *General Principles of the Law of Contract*, Cape Town: Juta and Co at 120-21.

<sup>26</sup> See the leading judgement of Van den Heever JA in *Edelstein v Edelstein* 1952 3 SA 1 (A).

<sup>27</sup> 1943 AD 160 at 167.

<sup>28</sup> See n 25 at 279.

<sup>29</sup> See Van den Heever JA in *Edelstein v Edelstein* 1952 3 SA 1 (A). Grotius 1 8 5 states this rule thus: 'any contract entered into by minors unassisted, even though confirmed by oath, has no binding force (*buiten rechts-dwanck*) as unknown to the civil law: except that they may stipulate for something to their advantage . . . '.

<sup>30</sup> [1986] 1 AC 112.

<sup>31</sup> See Dimond, B. (1996) *The Legal Aspects of Child Health Care*, London: Mosby at 55.

<sup>32</sup> [1993] 1 FLR 386.

<sup>33</sup> See *Re W* [1993] 1 FLR 1.

<sup>34</sup> See generally, Berg, J. W. *et al* (2001) *Informed Consent: Legal Theory and Clinical Practice*, 2<sup>nd</sup> edn, Oxford: Oxford University Press.

<sup>35</sup> See Grisso, T. (1992) 'Minor's assent to behavioural research without parental consent' in B. Stanley and J. E. Sieber (ed) *Social Research on Children and Adolescents. Ethical Issues*, London: Sage Publications at 109–27.

<sup>36</sup> See n 35 at 110.

<sup>37</sup> See *Magano v Mathope* 1936 AD 502 507.

<sup>38</sup> See n 35 at 111.

<sup>39</sup> For a full discussion of this see Grisso, T. (1992) 'Minor's assent to behavioural research without parental consent' in B. Stanley and J. E. Sieber (ed) *Social Research on Children and Adolescents. Ethical Issues*, London: Sage Publications at 114–21.

<sup>40</sup> See n 35 for further discussion of this.

<sup>41</sup> This is also guaranteed by the Botswana Constitution of 1966, although this is limited in Sections 3(b) and 9(1) to the search of a person and the privacy of his home and property.

<sup>42</sup> See McQuoid-Mason, D. J. (1978) *The Law of Privacy in South Africa*, Cape Town: Juta and Co at 99.

<sup>43</sup> See Prosser and Keeton, *Prosser and Keeton on Torts* (1984) 5<sup>th</sup> edn, St. Paul: West Publishing at 866–67.

<sup>44</sup> See, Burchell, J. (1993) *Principles of Delict*, Cape Town: Juta and Co at 208.

<sup>45</sup> See generally, n 42 and Prosser and Keeton, (1984) 5<sup>th</sup> edn, *Prosser and Keeton on Torts*, St. Paul: West Publishing.

<sup>46</sup> Kelman, H. (1977) 'Privacy and research with human beings', 33 *Journal of Social Issues* 169–95.

<sup>47</sup> See Gaylin, W. and Macklin, R. (1982) *Who Speaks for the Child: The Problems of Proxy Consent*, New York: Plenum Press at 248.

<sup>48</sup> See generally, Melton, G. B. in B. Stanley and J. E. Sieber (1992) (ed) *Social Research on Children and Adolescents. Ethical Issues*, London: Sage Publications at 65–87.

<sup>49</sup> 364 F. Supp. 913 (E.D. Pa. 1973).

<sup>50</sup> *Ibid.* at 916.

<sup>51</sup> See Duncan, G. T., Jabine, T. B. and De Wolf, V. A. (1993) (ed) *Private Lives and Public Policies: Confidentiality and Accessibility of Government Statistics*, Washington DC: National Academy Press at 22.

<sup>52</sup> See generally, Fombad, C. M. (2001) 'The crisis of confidentiality in the control of the HIV/AIDS pandemic in Botswana', 170 *International Social Science Journal* 643–56.

<sup>53</sup> Per Lord Greene (1948) in *Saltman Engineering Co Ltd v Campbell Engineering Co Ltd*, 65 RPC 203; 215.

<sup>54</sup> As Megarry, J. pointed out in *Coco v AN Clark (Engineering) Ltd* [1969] RPC 41, at 47–8, if the circumstances are such that any reasonable man standing in the shoes of the recipient of the information would have realized that upon reasonable ground the information was being given to him in confidence, then this will suffice to impose upon him the obligation of confidence.

<sup>55</sup> Melvey and Phelps (1988) 'Ethical balances in juvenile justice research and practice', 36 *American Psychologist* 66.

<sup>56</sup> Also see, Section 36(b) of the Penal Code that punishes the concealment of information about a person who intends to commit treason.

<sup>57</sup> *Attorney-General v Guardian Newspapers Ltd (No.2)* [1988] 3 All ER 545, 659.

<sup>58</sup> See further discussion of this see n 52 at 652–54.