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## Section 71 of the National Health Act: a call for a review of the consent requirement for child participation in health research

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### OPSOMMING

#### Artikel 71 van die Nasionale Gesondheidswet: 'n Pleit vir Hersiening van die Toestemmingsvereiste vir Deelname van Kinders in Gesondheidsnavorsing

Die Nasionale Gesondheidswet handel spesifiek oor die toestemming van kinders tot deelname aan gesondheidsnavorsing. Artikel 71, wat op 1 Maart 2012 in werking getree, het, verplig ouers of voogde om toestemming vir navorsing met kinders, ongeag hul ouderdom, te verleen. Daarbenewens moet die kind toestem as hy of sy voldoende begrip toon. Alhoewel die doel van die artikel is om kinders te beskerm, is dit nie sonder kritiek nie. Die artikel neem nie die outonomie van adolessente voldoende in ag nie en ignoreer ook die feit dat baie kinders nie ouers of voogde het nie, maar deur sorggewers versorg word. Die doel van die artikel is dan juis om na hierdie twee punte van kritiek te kyk en aanbevelings te maak. In die bespreking sal dit duidelik blyk dat die artikel in stryd is met bepalings van die Kinderwet en die Wet op die Beëindiging van Swangerskap en dat dit ook kinders se grondwetlike regte ondermyn. Spesiale aandag word ook gegee aan die vraag of sorggewers, veral kinderhoofde van huishoudings, toestemming tot navorsing kan gee.

## 1 Introduction

Children are regarded as vulnerable to exploitation in health research due to their physical and developmental immaturity. Codes of research ethics, such as the Declaration of Helsinki,<sup>1</sup> emphasise that vulnerable populations, such as children, need special protection.<sup>2</sup>

Prior to the implementation of the National Health Act,<sup>3</sup> there was limited specific legal protection for children: No specific South African

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1 World Medical Association Declaration of Helsinki Ethical principles for medical research involving human subjects Helsinki: WMA General Assembly, 1964 (revised 2008) ('Declaration of Helsinki').

2 *Idem* Principle 9.

3 61 of 2003.

legislation addressed health research with children.<sup>4</sup> Research ethical committees relied on principles of health law relating to the medical treatment of a minor in order to identify protection for children.<sup>5</sup> This determination was supported by ethical guidelines which provide that adolescents<sup>6</sup> may consent unassisted to research if the research meets certain criteria.<sup>7</sup>

The National Health Act is the first effort by government to protect child participants in health research by means of legislation. The National Health Act deals specifically with consent to children's participation in research. Section 71, enacted on 1 March 2012, mandates written consent from a parent or legal guardian for all research conducted with minors, irrespective of their age. In addition, minors, as well as their parents or legal guardians, must consent if they have sufficient understanding.<sup>8</sup> The National Health Act (the "Act") does not define the term "minor", but the Children's Act<sup>9</sup> and the Constitution<sup>10</sup> define a "minor"<sup>11</sup> as anyone under the age of eighteen years.

It is clear from section 71 that consent by a parent or legal guardian is a legal requirement for the inclusion of children in research. The purpose of the Act is to provide legal protection to participants, but the Act is not beyond criticism.<sup>12</sup> First, it does not sufficiently take into account the emerging autonomy of the adolescent. Second, the Act ignores the fact that many children in South Africa do not have a parent or legal guardian and are cared for by caregivers. Therefore, the Act prevents children without legal guardians from accessing research that could be of great benefit to them.

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4 National Health Research Ethics Council *Ethical-legal protection for vulnerable research participants in South Africa: An audit of relevant laws and ethical guidelines* (2011). See also Zuch *et al* 'Changes to the law on consent in South Africa: implications for school-based adolescent sexual and reproductive health research' 2012 *BMC International Health and Human Rights* 2.

5 For example, s 39 of the Child Care Act 74 of 1983 determined that any person over the age of 14 could consent independently to medical treatment without the assistance of a parent or guardian. The Child Care Act has since been repealed and replaced by the Children's Act 38 of 2005, which determines, in s 129(2), that a child may consent to his or her own medical treatment if the child is over the age of 12 and is of sufficient maturity and mental capacity to understand the implications of the treatment. See Nienaber 'Consent to research by mentally ill children and adolescents: the implications of chapter 9 of the National Health Act' 2013 *SAJP* 20; Zuch *et al* 2012 *BMC International Health and Human Rights* 2.

6 Defined as 'persons who have reached puberty'.

7 See Department of Health *Ethics in Health Research: Principles, structures and processes* (2004).

8 S 7(2) & (3).

9 38 of 2005.

10 Constitution of the Republic of South Africa, 1996.

11 The terms 'minor' and 'child' will be used interchangeably in this article to denote the same subject.

12 See Zuch *et al* 2012 *BMC International Health and Human Rights* 2; Nienaber 2013 *SAJP* 22.

In light of this, the article elaborates on these issues and stresses that the Act (by placing stricter control on research with children under eighteen years) is clearly in contravention of the Children's Act and the Choice on Termination of Pregnancy Act,<sup>13</sup> and, further, undermines constitutional rights such as the right to the bodily and psychological integrity and dignity of children. Special attention is also given to the question whether caregivers, including child-heads of families, may give legally valid consent to health research.

Before addressing these issues, it is important to briefly look at the requirements for legally valid consent to health research.

## 2 Consent to Participation in Health Research

Research cannot be conducted without the participant's informed consent – it is absolutely essential.<sup>14</sup> This requirement is regarded as a primary way of ensuring that research participants are protected against exploitation. Informed consent is based on the recognition that all persons have unconditional worth on the basis of the ethical principle of respect for personal autonomy.<sup>15</sup>

Section 71 of the National Health Act requires the participant's informed consent to research participation. It provides that:

[R]esearch or experimentation on a living person may only be conducted in the prescribed manner; and with the **written** consent of the person after he or she has been informed of the object of the research or experimentation and **any possible** positive or negative consequences to his or her health (own emphasis).

Section 71 gives effect to the individual's right to autonomous self-determination protected by section 12(2) (the right to bodily and psychological integrity, which includes the right not to be subjected to medical or scientific experiments without their informed consent), section 10 (the right to inherent dignity), and section 14 (the right to privacy) of the Constitution.

To obtain valid consent the researcher must ensure that the research participant is sufficiently well-informed to make an informed decision.<sup>16</sup> The researcher must also determine that the person possesses the

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13 92 of 1996.

14 See also the Declaration of Helsinki Ethical principles for medical research involving human subjects Helsinki: WMA General Assembly, 1964 (revised 2008) principle 26; *Trials of war criminals before the Nuremberg military tribunals under control council law* Washington, DC: US Government printing office (1949) 181.

15 Beauchamp & Childress *Principles of Biomedical Ethics* (2001) 63; Nienaber 2013 *SAJP* 22.

16 Meadde & Slesnick 'Ethical considerations for research and treatment with runaway and homeless adolescents' 2002 *Journal of Psychology* 450.

cognitive capacity to understand the risks and benefits of participation and ensure that participation is voluntary.<sup>17</sup>

Young children may not be able to make autonomous decisions and, therefore, need special protection. Subsections 71(2) and 71(3) of the Act specifically pertain to research in children.<sup>18</sup> These subsections mandate, amongst other requirements, written consent from a parent or legal guardian for therapeutic and non-therapeutic research conducted with minors, irrespective of age. In the case of non-therapeutic research an additional procedural safeguard for child participation has been created by providing that the Minister of health must consent to the conduct of such research. The Act, in protecting children from harmful and exploitive research, excessively regulates the matter so that it discredits the autonomy of adolescents and it ignores the fact that many children are cared for by caregivers, as will be discussed below.<sup>19</sup>

As far as the issue of consent is concerned, it is important to note that the use of the terms “therapeutic research” (usually taken to mean that the participant benefits directly from the research) in subsection 71(2) and “non-therapeutic research” (usually taken to mean that it confers no personal benefit to the research participant) in subsection 71(3) have been criticised. It has been submitted, apart from the lack of a clear definition of these terms in the Act, that it is often difficult to distinguish between the two types of research.<sup>20</sup> Furthermore, it has been submitted by critics that the distinction in the Act between therapeutic and non-therapeutic research fails to take into account different risk standards.<sup>21</sup> It is suggested, as is the case in local and international guidelines, that, instead, the legislator should have used the different categories of risk or defined the research permissible in minors in terms of well-defined risk standards, such as research which involves only minimal risk or a minor increment over minimal risk.<sup>22</sup> Minimal risk means the probability or magnitude of harm or discomfort anticipated in the research is not greater, in itself, than that ordinarily encountered in daily life or routine medical or psychological examination. A minor increase over minimal risk is linked to risk commensurate with those risks in a child’s medical, dental, psychological, social or educational setting.<sup>23</sup>

Research that involves minimal risk generally takes the form of surveys which address sensitive topics, which include questions about

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17 *Ibid.*

18 Note that these subsections make no distinction between children and adolescents.

19 See also Nienaber 2013 *SAJP* 19; Zuch *et al* 2012 *BMC International Health and Human Rights* 1; Strode & Slack ‘Using the concept of “parental responsibilities and rights” to identify adults able to provide proxy consent to child research in South Africa’ 2011 *SAJBL* 69.

20 Nienaber 2013 *SAJP* 22.

21 *Ibid.*

22 *Ibid.*

23 *Regulations relating to research with human participants* GG 38000 GN R719 of 2014-09-19. See also Strode & Slack 2011 *SAJBL* 71.

illicit drug use, teenage pregnancies, physical or sexual abuse, experiences in receiving treatment for sexually transmitted infections and perceptions of school counselling services.<sup>24</sup> This research is valuable in understanding the needs of children and to develop and evaluate effective programmes or interventions and deliver adequate services promoting their welfare. The benefits of participating in research should not be underestimated and, therefore, may be in the best interest of the child participant.<sup>25</sup> This discussion focuses on research that involves minimal risk or a minor increment over minimal risk.

### 3 Independent Adolescent Consent

“Childhood” is a unique concept and has been described as a “process” rather than a “state”.<sup>26</sup> Childhood is a process of continuous change, which takes place as the child develops from newborn to adolescent. This process of maturation results in the gradual development of the child’s capacity for rational thought and action.<sup>27</sup>

In order for children to develop into rational autonomous adults who are capable of making decisions children should, initially, be protected against the consequences of their irrational actions. However, one cannot ignore the overwhelming findings of research done by developmental psychologists regarding the intellectual social and moral development of children,<sup>28</sup> which indicates that a child reaches decision-making capacities around adolescence.<sup>29</sup> Adolescents may be as competent as adults in their ability to make decisions and provide informed consent. Although not all adolescents mature at the same rate, the question of adolescent self-consent can be resolved by evaluating the child’s competence to understand that to which he or she is consenting<sup>30</sup> and to make the best choices for him or herself.<sup>31</sup>

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24 Strode & Slack 2011 *SAJBL* 73; Zuch *et al* 2012 *BMC International Health and Human Rights* 3.

25 Zuch *et al* 2012 *BMC International Health and Human Rights* 2.

26 Kruger ‘Traces of Gillick in South African jurisprudence: Two variations on a theme’ 2005 *Codicillus* 5.

27 *Ibid*.

28 *Idem* 6.

29 *Ibid*; see also Zuch *et al* 2012 *BMC International Health and Human Rights* 4.

30 In *Gillick v West Norfolk and Wisbech Area Health Authority and the DHSS* [1985] 3 All ER 402 at 422a the court held that a child acquires the capacity to make his own decisions when he or she reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision. The test formulated by Lord Scarman thus involves an individual assessment of a child’s level of maturity and intellectual ability.

31 S 28(2) of the Constitution provides that ‘the best interests of the child are of paramount importance in all matters concerning the child’. Therefore children should not be allowed to make decisions that, clearly, are contrary to their own best interest.

The Children's Act and the Choice on Termination of Pregnancy Act<sup>32</sup> both recognise the autonomy of the child and allow them to give independent consent. The Choice on Termination of Pregnancy Act gives a pregnant minor,<sup>33</sup> irrespective of her age, the right to terminate her pregnancy without parental or guardian consent.<sup>34</sup> She must be advised to seek parental assistance, but cannot be refused access to a termination if she does not wish to do so. The constitutionality of these provisions was unsuccessfully challenged in *Christian Lawyers Association v Minister of Health and Others*.<sup>35</sup> In this case the court gave recognition to the autonomy of a child. The High Court held that the cornerstone of the regulatory framework for termination of pregnancy was the informed consent of the woman or girl.<sup>36</sup> Noting that this required the three legs of knowledge, appreciation and consent (i.e. subjective consent to the harm and risk posed by the procedure), the court said that the Act did not fix a rigid age for this, but opted for capacity to give informed consent as the yardstick, i.e. the girl must be mature enough to form an intelligent will.<sup>37</sup> Where such capacity exists, the Act recognises it in spite of the youthfulness or age of the person. The right to choose was granted by sections 12(2), 10 and 14 of the Constitution to everyone which, the court held, extends to girls aged below eighteen years. Furthermore, the court found that the Choice on Termination of Pregnancy Act, which was based on the girl's capacity rather than a specific age, promoted the best interest of the child because it was flexible and recognised that decisions taken to terminate pregnancy would depend on her intellectual, psychological and emotional maturity. The court also held that it cannot be in the interest of the pregnant minor girl to adopt a rigid age-based approach that takes no, little or inadequate account of her individual peculiarities.<sup>38</sup>

The Children's Act sets the minimum age of independent consent for medical treatment at twelve years. In addition, the Children's Act requires that the child must be sufficiently mature and have the mental capacity to understand the benefits and risks, as well as the social and other implications, of the treatment.<sup>39</sup> The Children's Act adopts a combined approach whereby maturity and age determine the capacity to consent to medical treatment. The legislature elected to adopt a fixed age approach, possibly in the interests of greater legal certainty for those involved in providing medical treatment in all its forms.<sup>40</sup>

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32 92 of 1996.

33 Defined as 'a female under the age of 18'.

34 S 5(3).

35 2005 1 SA 509 (T).

36 *Idem* par 515.

37 *Idem* par 516, citing Van Heerden *et al* (eds) *Boberg's Law of Persons and the Family* (1999) at 850.

38 *Idem* par 528.

39 S 129(2).

40 Sloth-Nielson 'Protection of children' in Davel & Skelton (eds) *Commentary on the Children's Act* (2007) 7-31.

From the above discussion it is demonstrated that adolescents are in the process of becoming fully-autonomous individuals. It is generally accepted that twelve year olds are old enough to make autonomous and informed decisions. The Act, by requiring parental consent, does not sufficiently take into account the emerging autonomy of the adolescent and, therefore, implies that all children lack the capacity to make decisions for themselves. In prohibiting children aged between twelve and eighteen from providing independent consent under certain circumstances, section 71 may compromise a child's right to autonomy and may be against the best interest of the minor.

If consistent standards are applied to adolescent participation in research they will be able to consent independently to research projects which pose minimal risk to them and parental consent need not be mandatory as long as the subject is deemed able to give informed consent for him or herself and the research is in the best interest of the child. The effect of this change is that researchers will have to establish the participant's level of understanding. Procedures should be in place and assessment may include verbal or written tests to gauge the participant's level of understanding of the consent form, knowledge of their rights as research subjects, as well as their rights to withdraw.<sup>41</sup>

It is important to note that allowing children to make important decisions about participation in health research, that involves minimal risk, does not mean leaving them to their own devices in making such vital decisions. The minor may seek assistance (consult with their parents/guardian) so that he or she makes an informed choice whether to participate or not.

#### 4 The Issue of Parental Consent

Subsections 71(2) and (3) mandate consent from a parent or legal guardian, despite the fact that many children in South Africa do not live with a parent or a legal guardian but with another caretaker. The exact number of children without a legal guardian is unknown: Statistics indicate that the number is high. The United Nations Children's Fund ("UNICEF") estimates that there are 3.7 million orphans in South Africa.<sup>42</sup> Most of these children are placed in the care of extended families and some of these children take on adult roles as caregivers of ill parents, or of siblings in child-headed households. According to a study by the South African Institute of Race Relations, 98 000 children were living in child-headed households as of 2008.<sup>43</sup> The Act prevents children without legal guardians from accessing research that could be of great benefit to them in terms of, for example, developing and evaluating

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41 Zuch *et al* 2012 *BMC International Health and Human Rights* 4.

42 UNICEF Protection for orphans and vulnerable children available from [http://www.unicef.org/southafrica/protection\\_6633.html](http://www.unicef.org/southafrica/protection_6633.html). See also Zuch *et al* 2012 *BMC International Health and Human Rights* 2.

43 Zuch *et al* 2012 *BMC International Health and Human Rights* 4.

programmes or interventions and reducing rates of sexual risk behaviour, teenage pregnancy and sexually transmitted infections. This issue is especially problematic given that the health of orphans and vulnerable children, precisely those without legal guardians, is at risk.

By mandating consent from a parent or legal guardian, the Act is in direct contrast to section 129(4) of the Children's Act which allows consent for the medical treatment of a child to be provided, amongst others, by a parent, guardian or care-giver, if the child lacks capacity to consent. Section 132(2), dealing with HIV testing, provides that a caregiver can give the required consent if the child does not have the capacity to consent. The Children's Act defines a caregiver as:<sup>44</sup>

[A]ny person other than a parent or guardian, who factually cares for a child, such as a foster parent, a person who cares for a child with the implied or express consent of a parent or guardian, a person who cares for a child while the child is temporarily in safe care, the person at the head of child and youth-care centre where the child has been placed, the person in charge of a shelter, a child and youth-care worker who cares for a child that does not have appropriate family care in the community, and the child at the head of a child-headed household.

These persons who voluntarily provide day-to-day care for children do not have parental responsibilities and rights.<sup>45 46</sup>

However, although those persons who provide day-to-day care do not have parental responsibilities and rights in our law, they are the bearers of a number of duties or responsibilities (which include decision-making powers). According to Strobe and Slack these duties correspond to the nature of decision-making relating to consent to certain forms of health research.<sup>47</sup> Their duties include an obligation to safeguard the child's health, well-being and development and to protect the child from maltreatment, abuse, neglect, degradation, discrimination, exploitation, and any other physical, emotional or mental harm or hazard.<sup>48</sup> Their responsibilities are also mentioned in the broad definition of care which is an element of parental responsibilities and rights.<sup>49</sup> They may consent

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44 S 1.

45 The concept 'parental responsibilities and rights' is defined in s 18(2) of the Children's Act and consists of four elements, namely guardianship, care, contact and maintenance. Care is very broadly defined in s 1: It includes what used to be referred to as custody. Custody referred to a person's capacity physically to have the child with him or her and to control and supervise the child's daily life. Thus it includes caring for the child, supporting and guiding the child, and assuming responsibility for the child's upbringing, health, education, safety and welfare. However, care also includes the duty to support and contact.

46 For a detailed discussion of who has parental responsibilities and rights and how they can be acquired see Strobe & Slack 2011 *SAJBL* 71.

47 Strobe & Slack 2011 *SAJBL* 71.

48 S 32(1) of the Children's Act.

49 See s 1 of the Children's Act and n 45 *supra*.



to a child's medical treatment and HIV testing which, in turn, promotes a child's health and well-being.<sup>50</sup>

Strode and Slack,<sup>51</sup> with whom we agree, submit that consent from caregivers ought to be permissible where the research approximates minimal risk or represents a minor increase over minimal risk (and other requirements are met, such as that the adolescent cannot consent independently, no person with parental responsibilities in respect of the child is available or not reasonably available). The reason is that in many instances decisions regarding children's participation in minimal risk research approximate decisions regarding children's day-to-day care.<sup>52</sup> As already mentioned, minimal risk is anchored to risks encountered in daily life or routine medical or psychological examinations.<sup>53</sup> A minor increase over minimal risk is linked to risks commensurate with those in a child's medical, dental, psychological, social or educational setting. This permission would not only facilitate research with children but also act as an important protection for them.

According to Strode and Slack<sup>54</sup> caregiver's consent should not be extended to research with potentially higher risk involved, such as clinical trials. The reason is that decisions about participation in clinical trials cannot as easily be equated with decisions about day-to-day care. The Children's Act has excluded caregivers from making some highly exceptional decisions, such as granting permission to a marriage.<sup>55</sup>

It is accepted that there will be complexities associated with allowing caregivers to consent to minimal risk research.<sup>56</sup> One of the complexities mentioned, that needs further discussion, is that some caregivers, such as heads of child-headed households (children under the age of eighteen, but older than sixteen years) may be too vulnerable to take on this adult responsibility to consent to minimal risk research. The question that arises is whether heads of child-headed households should be excluded even though they are recognised as caregivers?

Section 137 of the Children's Act provides for the identification, legal recognition and support of child-headed households. Section 137(1) provides that a provincial head of social development may recognise a household as a child-headed household if:

- (a) The parent, guardian or caregiver of the household is terminally ill, has died or has abandoned the children in the households;

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50 See ss 129(4) & 130(2) of the Children's Act. It is clear that caregivers have more or less the same decision-making powers and responsibilities as private law custodians.

51 Strode & Slack 2011 *SAJBL* 71.

52 *Ibid.*

53 See par 2 *supra*.

54 Strode & Slack 2011 *SAJBL* 71.

55 In terms of s 18(3)(c) only the guardians of a child may consent to a child's marriage. See Strode & Slack 2011 *SAJBL* 71.

56 For a discussion of these complexities see Strode & Slack 2011 *SAJBL* 71.

- (b) no adult family member is available to provide care for the children in the household;
- (c) a child over the age of 16 years has assumed the role of caregiver in respect of the children in the household and
- (d) it is in the best interest of the children in the household.

From the above it is clear that all four factors need to be present before a household may be recognised as a child-headed household. The last two mentioned factors or conditions are important for this discussion. A child heading a child-headed household must be at least sixteen.<sup>57</sup> It is clear that if the child-head of the household is under the age of sixteen, then, even if all the remaining three factors exist, the household cannot be recognised given the young age of the child-head: Subsection (c) above merely refers to the fact that a child has assumed the role of a caregiver and does not explicitly encompass whether the child is able to perform that role effectively. The quality of care which is available to members from within a household, and, in particular, that the child-head is able to provide, is surely crucial? Clearly, if the child who provides leadership is not able to carry the responsibilities of the household and provide proper care for the other children then the care available to them is not sufficient to meet the best interests standard mentioned as the last factor that needs to be considered when taking a decision on whether or not to recognise a household as a child-headed household.<sup>58</sup> In other words, an important factor to consider when deciding whether it would be in the best interests of the children to recognise their household as a child-headed household is whether the older child is sufficiently mature to take charge of the needs of the children in the household (i.e. the child, developmentally, is mature enough to understand the decisions and the responsibilities involved and has realistic expectations and experience in caring for a household, in making decisions and understanding advice given).<sup>59</sup> The child will have to undergo a developmental assessment to determine if he or she has certain core capabilities to be able to take on the responsibility of the head of the household (taking on a *de facto* adult/parental role) and to make day-to-day decisions relating to the household and the children in the household as provided for in section 137(7) of the Children's Act.

Once a household is classified as a child-headed household it is registered in a provincial register and, in terms of the provisions of the Act, an adult designated by the children's court, a government organ, or a non-governmental organisation (NGO) as determined by the provincial

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57 Not only is a child of 16 beyond school leaving age and able to work, but the Social Assistance Act 13 of 2004 defines a caregiver 'as a person 16 years or older'. For the purpose of social grants, a child aged 16 can qualify as a primary care giver of its siblings.

58 Couzens & Zaal 'Legal recognition for child-headed households: An evaluation of the emerging South African framework' 2009 *International Journal of Children's Rights* 310.

59 Kassan & Mahery 'Special child protective measures in the Children's Act' in Boezaart (ed) *Child Law in South Africa* (2009) 198.

head of social development, is appointed as a supervisor.<sup>60</sup> Although not explicitly stated, the mentioned adult is likely to be a paid community worker (albeit on a stipend basis) rather than acting on a purely voluntary basis.<sup>61</sup>

The role of the supervising adult is to support the child heading the household to care for the other children. The adult must perform the duties set out in Regulation 50. These include a range of issues: Assisting with health care requirements, including the supervision of the taking of medicines and assistance to members with disabilities, and ensuring that the children access health care facilities and that their health needs are met; assisting members of the household with legal documentation when required; and assisting the member heading that household with his or her responsibilities.

It should be borne in mind that a supervising adult cannot take decisions concerning the household or the children in the household without consulting the child that heads the household as well as the other children, depending on their age, maturity and stage of development.<sup>62</sup> As already stated, all the day-to-day decisions relating to the household or children in the household fall within the exclusive domain of the child-head's responsibility. The autonomy of the child-head is further strengthened by section 137(7), which affords the child the opportunity to report the supervising adult to the relevant authority that initially designated such an adult if dissatisfied with the manner in which the adult is performing his or her duties.

It is clear that the responsibilities of a child-head are significant and that he or she can play a significant role in the health needs and care of those under their care. This process, whereby a child-head takes on the responsibilities of a household, is referred to as parentification.<sup>63</sup> Therefore it is essential that we look beyond the child-only label and duly recognise the autonomy of child-heads who are tasked with taking on the full burden of their household's responsibilities. The important role which child-heads play in family and kinship structures is indeed duly recognised by the Children's Act. The main purpose of section 137 of the Children's Act is to respect the rights and responsibilities of children heading households as a head of a household – assisting and enabling them to perform their responsibilities as caregivers to younger siblings and to protect their rights as children and, therefore, accommodate their

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60 S 137(2).

61 Sloth-Nielson 'Protection of children' in Davel & Skelton (eds) *Commentary on the Children's Act (2010)* 7-48.

62 The Act requires consultation only with the children in the household, but if there is an adult in the household who is ill, steps should be taken to include them in the dialogue.

63 Le Roux-Kemp 'Child-headed households in South Africa: The legal and ethical dilemmas when children are the primary caregivers in a therapeutic relationship' in Bray & Mak (eds) *People being Patients: International, Interdisciplinary Perspectives* (2013) 122.

needs and rights as children while they perform their responsibilities as a head of a household.

In view of the above, child-heads of a legally recognised child-headed household should not be excluded from giving consent to minimal risk research with children (under the age of twelve or over, but is of insufficient maturity or is unable to understand, the benefits, risks, and social implications of the research) under his or her care. The effect thereof will be that researchers will have to consider each case on its merits.<sup>64</sup> They will have to consider factors such as whether the research participant is a member of a child-headed household recognised in terms of section 137, whether the child-head has undergone a developmental assessment to determine if he or she has certain core capabilities to be able to take on the responsibility of the head of the household (taking on a *de facto* adult/parental role) and to make day-to-day decisions relating to the households and the children in the household as provided for in section 137(7) and whether a supervisor has been appointed. The child-head's decision with regard to participation in research by his or her household members must also be considered with due cognisance of that child-head's psycho-social state, maturity and decision-making capabilities (thus a researcher will have to establish the child caregiver's level of understanding).<sup>65</sup>

It is important to note that a child-head may seek assistance from the supervising adult (consult with a supervising adult) before he or she gives consent. Researchers must advise the child-head to obtain assistance from the supervisor: The assistance is definitely in the best interests of the minors concerned.

## 5 Conclusion

On the one hand, adolescent research, as pointed out in paragraph two, is important. On the other hand, a high standard of protection is required to keep children from harm. Yet, to preserve their right to self-determination and to recognise the social circumstances, and based on the comments made in this article, we call for a review of the Act to bring it in line with other legislation. The following recommendations are made as to who ought to consent and the conditions attached to consent for research:

- (1) The risk of the research should be minimal or represent a minor increase over minimal risk.
- (2) If a child is an adolescent (a child under eighteen but older than twelve years) and understands the nature and consequences of the research which poses minimal risk to him or her, the child should be able to give independent consent.

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64 *Ibid.*

65 *Ibid.*

- (3) If the child does not understand the nature and consequences of the research, then the parent or legal guardian (person with parental responsibilities and rights in respect of the child) should consent.
- (4) If no parent or legal guardian is available or if they are not reasonably available, then a caregiver should consent. The adult from whom consent is sought ought to be a caregiver as defined in the Children's Act. If the caregiver is a child-head (i.e. a child of sixteen years and older in a legally recognised child-headed household) then he or she should also consent. If a child headed household has not been legally recognised in terms of section 137 of the Children's Act, then the minor should not be able to consent as being too vulnerable.

Lastly, it is important to note that any human research must receive prior approval by a relevant human research ethics committee in order to ensure an adequate balance between the risks and benefits and to determine that the research meets the ethical standards of that.<sup>66</sup> The research ethics committees, therefore, will have the last say in granting or denying approval.

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<sup>66</sup> S 73(2)(b) of the National Health Act.