UNIVERSITY OF KWAZULU-NATAL SCHOOL OF LAW, HOWARD COLLEGE

Is Section 71 of the National Health Act 61 of 2003 Inconsistent with a Child's Constitutional Rights to Bodily Integrity and Equality?

by

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i

ABSTRACT

IS SECTION 71 OF THE NATIONAL HEALTH ACT 61 OF 2003 INCONSISTENT WITH A CHILD'S CONSTITUTIONAL RIGHTS TO BODILY INTEGRITY AND EQUALITY?

The South African Constitution entitles children to all the basic human rights. In addition, the concept of '[a] child's best interests' (section 28(2)) has been significant in the realisation of other rights contained in the Bill. This concept becomes more meaningful as the child grows older, where it is used to determine the range and limitations of all other competing rights. Maturing children then derive their partial to full self-determination from the rights to dignity, privacy, and freedom of religion, expression, and association.

In this study I submitted that the constriction of section 71 into 'nurturance' over a broad class of children violates the constitutional right to equality, human dignity, privacy, freedom, and safety of the person when read together with the ratified international and regional treaties relating to the rights of children. Section 71 provisions are deemed unfair because the direct differentiation is linked to the categorisation of a socially vulnerable group [children] by age. Moreover, section 71 failed to confer the equal protection and benefit of the law and to set other measures designed to protect or benefit persons, or groups of persons who are disadvantaged as a result of unfair discrimination.

Section 71 lacks a proper set of provisions or rules applying to research involving children, and the power grants and restrictions are not properly balanced to fit the protection and self-determination of children's rights. Moreover, the general principles that form the basis of children's rights were not fully considered. Principles relating to age, maturity, and stage of development are generally provided to make any law or conduct meaningful to children. The section 71 infringement of the right to equality and bodily integrity cannot be justified through analysis in terms of section 36. The limitations imposed are highly restrictive, unreasonable, and unjustifiable in a democracy based on human dignity, equality, and freedom. There are no less restrictive provisions that allow independent consent for, particularly, maturing children. This is inconsistent with the principle of the child's best interest contained in the Constitution and the UNCRC. Children have not been treated as individual rights bearers since the parent still stands as the final decisional maker and encroaches on the right of the child to control its body and its uses.

In conclusion, section 71 of the National Health Act is unconstitutional.

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CONTENTS

DECL	LARATION REGARDING ORIGINALITY	iii iv viii 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1 1
ABST	RACT	ii
ACKN	NOWLEDGEMENTS	iii
CONT	FENTS	iv
LIST	OF TABLES	. vii
CHAP	PTER 1	1
INTRO	ODUCTION	1
I	INTRODUCTORY PROVISIONS	1
II	SECTION 71 OF NATIONAL HEALTH ACT 61 OF 2003	3
III	LITERATURE REVIEW	5
IV F	RESEARCH METHODOLOGY	. 10
a)) RESEARCH QUESTIONS	. 10
b)) OBJECTIVES	. 10
c)) ETHICAL CLEARANCE	. 10
\mathbf{d}) STUDY RATIONALE	. 10
e)) STUDY SETTING	. 10
f)	DATA COLLECTION	. 11
g) DATA MANAGEMENT	. 11
h)) DATA ANALYSIS	. 11
CONC	CLUSION	. 11
CHAP	PTER 2	. 12
LEGA	L FRAMEWORK	. 12
I	INTRODUCTION	. 12
II	THE CONSTITUTION	. 12
(2	a) Children's Rights	. 13
(t	b) The Right to Equality	. 14
(0	c) The Right to Bodily Integrity	. 16
III	LIMITATION OF RIGHTS	. 21
IV	CHILDREN'S ACT 38 OF 2005.	. 21
(2	a) Child's Best Interests	. 22
V	DISCUSSION	. 24
(2	a) Right to Bodily Integrity	. 25
(t	b) Right to Equality	. 25

(c) Right to Access to Health Care Services	27
VI	CONCLUSION	28
CHA	PTER 3	29
CONS	STITUTIONAL EXAMINATION OF SECTION 71 OF THE NATIONAL HEALTH AC	CT 29
I	INTRODUCTION	29
II	VIOLATION OF CHILDREN'S RIGHT TO EQUALITY	30
III	PHILOSOPHICAL DIMENSION OF CHILDREN'S RIGHTS TO EQUALITY	32
(a) The Principle of Individual Assessment	33
(b) The Principle of Sufficiency	34
(c) The Principle of Social Inclusion	35
(d) The Principle of Autonomy	36
IV	INFRINGEMENT OF THE CHILD'S CONSTITUTIONAL RIGHT TO BODILY	
V		
Ι		
II		
III		
IV		43
V 36(· ·	43
VI	ACHIEVING THE PURPOSE IN LESS RESTRICTIVE WAYS (SECTION $36(1)(e)$)	44
VII	DISCUSSION	46
(a) Right to Equality	46
(b) Right to Bodily Integrity	47
VII	I SUMMARY	49
CHAI	### ACCUSSION *** ### ACCUSSION ** ### ACCUSSI	
CON	CLUSION	50
I	SUBMISSIONS AND FINDINGS	50
II	SUMMARY	51
(a) Right to Equality	51
(b) Mandatory Parental or Guardian Consent	51
(c) Section 71 Provisions or Limitations Clause	51
III	STUDY CONTRIBUTIONS	51
IV	RECOMMENDATIONS	52
V	LIMITATIONS	52

BIBL	IOGRAPHY	53
APPE	ENDIX	62
Ţ	ETHICAL CLEARANCE CERTIFICATE	62

LIST OF TABLES

Table 1 Difficult Research Recruitment under Mandatory Consent of Section 71 of the NHA9

LIST OF ABBREVIATIONS

ACRWC African Charter on the Rights and Welfare of the Child

BOR Bill of Rights

CRC Convention on the Rights of the Child

DOH Department of Health

HIV Human Immunodeficiency Virus

NHA National Health Act 61 of 2003

RECs Review Ethics Committees

S Section

S71 Section 71 of the National Health Act 61 of 2003

SS Subsection

UNCRC United Nations Convention on the Rights of the Child

CHAPTER 1

INTRODUCTION

I INTRODUCTORY PROVISIONS

The adoption of the Convention on the Rights of the Child (CRC)¹ in 1989 has had an impact on the concept of persons classified in terms of the South African Children's Act as minors regarding their age [this includes any child who is under the age of 18 years].² With the adoption of the CRC, there has been the recognition that the development of children's mental capacity is on-going which has led to the introduction of various statutory laws, which permit independent decision-making by children before the age of 18.³ For example, the Children's Act⁴ allows children to consent independently to various reproductive health services such as HIV testing, male circumcision, contraceptives, and medical treatment.⁵

Likewise, a woman, including anyone who is below the age of 18 years, is permitted to agree independently to end a pregnancy according to the Choice of Termination of Pregnancy Act.⁶ It is submitted that these laws are consistent with the Constitution of the Republic of South Africa, 1996⁷ [hereafter referred to as the Constitution].

Section 27(1) of the Bill of Rights, dealing with access to health care, food, water, and social security, states:

- '(1) Everyone has the right to have access to:
- (a) health care services, including reproductive health care'.8

Section 28(1), which deals with children, states:

- '(1) Every child has the right to:
- (c) basic nutrition, shelter, basic health care services, and social services'.9

¹ The Convention was adopted by the General Assembly on 20 November 1989. South Africa became a signatory on 29 January 1993 and ratified the UNCRC on 16 June 1995.

² Children's Act 38 of 2005.

³ Strode A and Essack Z Facilitating access to adolescent sexual and reproductive health services through legislative reform: Lessons from the South African experience (2017) 107(9) *SAMJ* 741–744.

⁴ Children's Act note 2.

⁵ Ibid.

⁶ Choice on Termination of Pregnancy Act 92 of 2007.

⁷ Preamble and s 7(2) Constitution of the Republic of South Africa, 1996 (hereafter 'Constitution').

⁸ Constitution, section 27.

⁹ Constitution, section 28.

In contrast, to this progressive legal framework relating to sexual and reproductive health services, section 71 of the National Health Act¹⁰ 61 of 2003 [hereafter referred to as s 71 of the NHA] prohibits independent consent by minors to health-related research. This section of the NHA permits research that involves human participants and outlines principles that protect research participants. Under this Act, minors can only participate in research if their parent/s or guardian give their consent.¹¹

Medical research data is essential for the development and approval of medical products. 12, 13 This ensures that healthcare products are safe and effective for human use. 14, 15 Research on children is legal, ethical, and widely accepted. 16 This is consistent with the fact that we need evidence about the health of this age group. 17

This is particularly important as some disorders affect only children, others are prevalent among children and the severity of certain diseases is different from the effects in adults. This means that it is essential for children to be part of any health-related research in order to ensure the full realisation of their right to health and access to sexual reproductive health products and services that are evidence-based. The absence of proper studies in children means there is no basis to justify the safety or effectiveness of drug use in children which may lead to harm. Yet, there has been a focus on protecting children from research by excluding them from research.

¹⁰ National Health Act 61 of 2003 (hereafter 'NHA'), s 71.

¹¹ Ibid, s 71(2)(*b*).

¹² Van Norman GA. 'Drugs, Devices and the FDA' *JACC Basic Transl Sci* (2016) 1 (3) 170–179. doi: 10.1016/j.jacbts.2016.03.002.

¹³ CFR – Code of Federal Regulations Title 21. Chapter I, Sec 312. 21, phases of an investigation.

¹⁴ Gassman AL, Nguyen CP, Joffe HV. 'FDA Regulation of Prescription Drugs' N. Engl. J. Med 2017; 376:674–682. DOI: 10.1056/NEJMra1602972.

¹⁵ Medicines and Related Substances Act 101 of 1965 GG 40577 dated 27 January 2017.

¹⁶ Fraser et al (2004) *Doing Research with Children and Young People* SAGE, in association with the Open University London 1–294.

¹⁷ Strode A, Richter M, Wallace M, Toohey J, Technau K 'Failing the Vulnerable: Three New Consent Norms that Will Undermine Health Research with Children' *S Afr J HIV Med* (2014) 15 (2) 46–49. DOI:10.7196/SAJHIVMED.1014

¹⁸ Hahn Y-S and Kim, J-G 'Pathogenesis and Clinical Manifestations of Juvenile Rheumatoid Arthritis' *Korean Journal Paediatric* (2010) 53 (11) 921–930; Maahs et al 'Epidemiology of Type 1 Diabetes' Endocrinology Metabolism Clinics North America (2010) 39 (3) 481–497.

¹⁹ Shaddy RE, Scott MD and Denne C 'Clinical Report – Guidelines for the Ethical Conduct of Studies to Evaluate Drugs in Pediatric Populations' *Pediatrics* (2010) 125 (4) 850–860; Roth-Cline M (2012) *Ethical Considerations in Evaluating Non-Therapeutic Studies in Children*. 3rd Annual Pediatric Pharmacogenomics and Personalized Medicine 29 March 2012. https://www.fda.gov/media/84865/download/ accessed on 19 March 2021.

²⁰ Shaddy et al. note 19.

²¹ Strode et al. note 17.

Part of this over-protection has been the requirement of parental consent for all forms of research. Strode et al²² alluded to a number of HIV-related research, teenage pregnancy, and studies involving orphans which would be undermined by the 'effective's 71 of the NHA'. A contemporary example is the Covid-19 vaccines, which have not been tested in children under 18 years old,²³ despite evidence showing that children have presented at varying degrees of mild to severe symptoms of covid-19.²⁴

II SECTION 71 OF NATIONAL HEALTH ACT 61 OF 2003

Section 71 of the NHA sets out norms regarding research on or experimentation with human subjects generally and also sets specific norms relating to research with minors.

Section 71 states:

- '71. (1) Notwithstanding anything to the contrary in any other law, research or experimentations on a living person may only be conducted—
- (a) in the prescribed manner; and
- (b) with the written consent of the person,

after he or she has been informed of the objects of the research or experimentation and any possible positive or negative consequences of his or her health.'

Section 71(1)(a) recognises that health research under the NHA is very broad as per the definition of health research in section 1 of the NHA.²⁵ By stating 'in the prescribed manner' it allows different forms of ethical research considerations, whereas s 7(1)(b) amounts to a so-called 'full disclosure'.²⁶ This highlights how important it is that research participants are properly and fully informed about any possible positive or negative implications for their health by the researchers before consenting. It further upholds the constitutional right to bodily integrity by setting out that no one may participate in research without informed consent.

Section 71 then moves on to deal directly with minors. It must be read with the NHA Regulations relating to Research with Human Participants. In the regulations, a minor is

²³ COVID-19 Treatment in South Africa https://clinicaltrials.gov/ct2/show/NCT04532931 accessed on 28 March 2021.

²² Ibid.

²⁴ Dong Y, Mo X, Hu Y et al. 'Epidemiology of COVID-19 among Children in China' *Pediatrics* (2020) 145 (6) e20200702. https://doi.org/10.1542/peds.2020-0702

²⁵ NHA, s 1(a)–(g).

²⁶ Carstens PA & Pearmain D Foundational Principles of South African Medical Law. (Durban: Lexis Nexis 2007 894-895).

described as any person under the age of 18 years.²⁷ This is consistent with the approach in the Children's Act. Section 71 deals with the involvement of children/minors in research by categorising the protections into those that relate to therapeutic research and those that relate to non-therapeutic research. Subsections (2) and (3) state:

- '(2) Where research or experimentations to be conducted on a minor for a therapeutic purpose, the research or experimentation may only be conducted—
- (a) if it is in the best interests of the minor;
- (b) in such manner and on such conditions as may be prescribed;
- (c) with the consent of the parent or guardian of the child; and
- (d) if the minor is capable of understanding, with the consent of the minor.'

Therapeutic research refers to research that has possible direct benefits to the participant, ²⁸ for example, research that attempts to remediate a health problem by providing treatment of impairment, injury, disease, or disorder. ²⁹

Section 71(2)(a) provides that therapeutic research can be done only if 'if it is in the best interests of the minor'. Even though, the principle of the child's best interest is generally applied in all matters concerning the child, as per section 28(2) of the Constitution, 1996. It is not clear how it applies in respect of so-called therapeutic research, since the legislature has not established a set of general criteria that specifically provide guidelines relating to a child's best interests. Moreover, limited literature exists relating to what this legal obligation means in the context of research.³⁰ In contrast, this principle is well established in a divorce or custody hearing.³¹

²⁷ National Regulations Relating to Research with Human Participants GN R719 in GG 38000 of 19 September 2014.

http://research.ukzn.ac.za/Libraries/Research_Document/National_Regulations_Relating_to_Research_With_H uman_Participants_R719_of_2014.sflb.ashx/ accessed 17 March 2021).

²⁹ Helgesson, G 'Can and Should the Research-Therapy Distinction Be Maintained? Reflections in the Light of Innovative Last-Resort Treatment' *Research Ethics* (2019) 15 (2) 1–14. s://doi.org/10.1177/174701611983546 ³⁰ Stobie, M, Strode A & Slack C 2005 'The Dilemma of Enrolling Children in HIV Vaccine Research in South Africa: What Is in "The Child's Best Interest"?' In Van Niekerk A, Kopelman L (eds.) *AIDS in Africa* (David Phillip 190–207).

³¹ Soller v Maintenance Magistrate of Wynberg and Others 12 (2003) (5) SA 430 (W). Soller v G was the court case concerning the custody of 15-year-old boy referred as K. The young boy after the divorce of his parents run and lived with his father, despite the custody being awarded to her mother and a restricted access to his father who was characterised of an inappropriate behaviour and parental role. In determining the best of interest of K, the court referred to a detailed list of factors provided in the McCall v McCall divorce settlement case (which awarded custody of a 12-year-old boy to his father).

The last part of section 71 deals with non-therapeutic research:

'(3) (a) Where research or experimentation is to be conducted on a minor for a nontherapeutic purpose, the research or experimentation may only be conducted—

- (i) in such manner and on such conditions as may be prescribed;
- (ii) with the consent of the minister;
- (iii) with the consent of the parent or guardian of the minor; and
- (iv) if the minor is capable of understanding, the consent of the minor.'

Non-therapeutic research pertains to research that does not necessarily imply direct benefit to the participant but rather relates to the prospect of generalisable knowledge.³² Where children are potential participants, a dual review is performed by selected RECs as per ministerial consent criteria and under the general research protocol review process.³³

The Regulations relating to Research with Human Participants affirm the mandatory parental consent approach. There have been criticisms levelled at these regulations as being overly restrictive because other consent norms validated by ethical guidelines have been omitted.³⁴ This prevailing parent-based permission has been shown to discourage adolescents from accessing sexual reproductive health services, including HIV testing because the adolescents are generally disinclined to admit to their parents that they are sexually active if they are to enrol in research.³⁵

III LITERATURE REVIEW

Children are mainly defined as human beings who have not reached full maturity and lack cognitive abilities. Ganya *et al* provide a comprehensive definition of a child as

'a developing person with evolving capacities that include autonomy, mental (decisional) capacity and capacity to assume responsibility'. ³⁶

Childhood development is a multi-stage process. There are four stages of childhood according to Piaget's theory of intellectual development: newborns, toddlers, pre-

³² Op cit note 27.

³³ Strode, A E & Slack C M Child research in South Africa: How do the new regulations help? *SAMJ* 2015 105 (11) 899–900. DOI:10.7196/SAMJ.2015.v105i11.9838

³⁴ Strode et al. note 17.

³⁵ Strode & Essack, note 3.

³⁶ Ganya, W, King S and Moodley, K 'Autonomy of the Child in the South African Context: Is A 12 Year Old of Sufficient Maturity to Consent to Medical Treatment?' *BMC Medical Ethics* (2016) 17 (66) 2–8.

school and elementary school age, and teenagers.³⁷ The process of human development generally involves progressive advancement from one stage to another through biological, emotional, cognitive, and social stages, and reaches maturity when a person has developed full reproductive organs and is capable of making an informed decision.³⁸ Blanket minority-based classification of children imposes prejudice towards children as rights owners.³⁹ Children are capable of making informed decisions without the assistance of adults.⁴⁰ The intellectual capacity of comprehension and making informed decisions⁴¹ is manifest as early as elementary school age and in teenagers who are fully functional.⁴²

The conceptualisation of children and their capacity needs to be viewed against the way in which section 71 of the NHA is drafted. There are numerous views on section 71. The promulgation of s 71 has been criticised for seemingly excluding children from participating in research.⁴³

Other criticisms include that the Act is ambiguous and inconsistent with human rights.⁴⁴ Buchner-Eveleigh and Vogel⁴⁵ claim that s 71 of the NHA ignored the emerging autonomy of adolescents by limiting legitimate consent to parents or legal guardians. The adolescent stage is well recognised in the Children's Act, where the autonomy and rights of a child from age 12 years old are respected and promoted in subsequent matters concerning child care, medical and reproductive health.⁴⁶ This makes the NHA out of step with the main piece of legislation dealing with children.

This has led to a dilemma – the section is rooted in the disjuncture between the Children's Act regarding the allowable age of independent consent. The Children's Act permits independent consent of the child to medical treatment, HIV testing, and contraceptives from

³⁷ Simatwa, EMW (2010) 5:7 Educational Research & Reviews 366–371.

³⁸ Ganya, King and Moodley note 36.

³⁹ Boezaart, T 'Child Law, the Child and South African Private Law' in Boezaart T eds *Child Law in South Africa* (Claremont: Juta 2009 3–37).

⁴⁰ Grootens-Wiegers P, Hein IM, Van den Broek JM and De Vries MC 'Medical Decision-making in Children and Adolescents: Developmental and Neuroscientific Aspects' *BMC Pediatrics* (2017) 17 (1) 120. DOI 10.1186/s12887-017-0869-x

⁴¹ Children's Act 38 of 2005 (note 2).

⁴² Piaget, J 'Part I: Cognitive Development in Children: Piaget Development and Learning' *Journal of Research* in Science Teaching (1994) 2 (3) 176–186.

⁴³ Strode et al. note 17.

⁴⁴ Buchner-Eveleigh M and Vogel F 'Section 71 of the National Health Act: A Call for a Review of the Consent Requirement for Child Participation in Health Research' *De Jure* (2015) 48 (2) 280–292.

⁴⁵ Ibid.

⁴⁶ Children's Act 38 of 2005 (note 2).

12 years old, while under s 71 of the NHA, only people over the age of 18 years have the right to consent independently with regard to research.⁴⁷

Concerningly, under s 71, all children are classified under one category, that of a *minor*, without due consideration to maturity or the capacity of the evolving child. Despite this, the Department of Health [DOH] Ethical Guidelines permit the unassisted consent of adolescents under certain circumstances.⁴⁸ This divergent approach has an unintended consequence – the burden is left with the Review Ethics Committees (RECs), where a research protocol is scientifically valid and ethical but inconsistent with s 71.⁴⁹ Moreover, the legal reference that married minors are emancipated to consent independently for themselves and their children is also not accounted in s71 and under the Regulations, relating to Research with Human Participants. ⁵⁰

The restrictive nature of e s 71 of the NHA consent with regard to children is not negligible when one considers the fact that millions of children are not living either with their parent/s or under legal guardianship. ^{51, 52} Children without parent/s or guardians are more vulnerable and prone to ill health than those who have parent/s or guardians; therefore it is especially important that there is research and consequent evidence-based intervention with these groups. ⁵³

Therefore, obtaining valid consent for this group of children is impossible. Strode et al have⁵⁴ argued that many forms of health research with the potential to improve healthcare services will exclude children because of the mandatory parental consent provisions.

⁴⁷ Strode & Essack, note 3.

⁴⁸ Makubalo L, Ratsaka-Mothokoa M, Bannenberg, W, Zijl, S & Cleaton-Jones, P Ethics in Health Research: Principles, Structures and Processes (Department of Health 2004).

⁴⁹ Strode, AE & Slack CM Child research in South Africa: How do the new regulations help? *SAMJ* (2015) 105 (11) 899–900. DOI:10.7196/SAMJ.2015.v105i11.9838

⁵⁰ Strode, Ann, & Catherine May Slack. 'Using the concept of 'parental responsibilities and rights' to identify adults able to provide proxy consent to child research in South Africa.' *South African Journal of Bioethics and Law*, 4.2 (2011): 69

⁵¹ Delany A, Jehoma S & Lake L (eds) 'Children and Social Assistance' South African Child Gauge (University of Cape Town Cape Town Children's Institute 2016). http://www.ci.uct.ac.za/ci/child-gauge/2016 accessed 22 August 2017; Adler, DH 'Inclusion of South African Adolescents in HIV Vaccine Trials' Journal of AIDS and HIV Research (2012) 4 (2) 30–35; UNICEF South Africa: 2009 Annual Report: Protection of Orphans and Vulnerable Children Programme (2010). https://www.unicef.org/southafrica/protection_6633.html

⁵² Strode et al. note 17.

⁵³ Ibid.

⁵⁴ Ibid.

According to Zuch et al.,⁵⁵ s 71 discriminates against studies investigating adolescent sexual and reproductive health.

The concerns of the undue restrictive parental consent arise from the empirical findings⁵⁶ that revealed that South African people aged from 15 to 24 constituted a large proportion of HIV infections, amounting to 40% of the overall number of infections and over 70% of the HIV-positive people.⁵⁷ Moreover, females between the age of 15 and 24 years old have shown an increasing prevalence of HIV infection.⁵⁸ The study findings concluded that there is high sexual activity amongst adolescents.⁵⁹ These findings correlated with the prediction made by McClure in 2004 that globally South Africa's HIV epidemic is the fastest-growing.⁶⁰ Given these points, research involving adolescents and consequent evidence-based interventions is a necessity.⁶¹

On the positive side, Strode et al. are of the view that s 71 of the NHA stand as a platform for crafting further legal norms for human subjects' research, as it explicitly mandates informed consent for health-related research that allows research participants to exercise rights and recognised the need to promote and protect children involved in health research.⁶²

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⁵⁵ Zuch M, Mason-Jones AJ, Mathews, C 'Changes to the Law on Consent in South Africa: Implications for School-based Adolescent Sexual and Reproductive Health Research' *BMC International Health and Human Rights* (2012) 12 (3) 1–5.

⁵⁶ UNICEF Children and AIDS: Fifth Stocktaking Report (2010) https://www.unicef.org/aids/files/ChildrenAndAIDS Fifth Stocktaking Report 2010 EN.pdf accessed on 30 July 2017.

⁵⁷ Adler, DH 'The Impact of HAART on HPV-related Cervical Disease' J AIDS HIV Res. (2012) 4 (2) 30–35.

⁵⁸ Gouws E and Lyerla R 'The Epidemiology of HIV Infection Among Young People Aged 15–24 Years in Southern Africa' *AIDS* (2008); 22 (Suppl 4) ss 1–16.

⁵⁹ UNICEF Children and AIDS: Fifth Stocktaking Report (2010) note 55

⁶⁰ McClure, CA et al, 'Challenges to Conducting HIV Preventative Vaccine Trials with Adolescents' *Journal of Acquired Immune Deficiency Syndrome* (2004) 36 726–733.

⁶¹ Strode et al. note 17.

⁶² Strode A, Slack C, Essack Z. Child consent in South African law: implications for researchers, service providers and policy-makers. South African Medical Journal (2010) 100(4):247-9. doi: 10.7196/samj.3609.

Table 1 Difficult Research Recruitment⁶⁴ under Mandatory Consent of Section 71 of the NHA

Type of research	Potential research participants	Potential exclusion reasons
1 Socially marginalised groups	Adolescent men who have sex with men are highly stigmatised in SA	 May face social harm Fear of disclosure of sexuality or sexual practices
2 Legal behaviours	Termination of pregnancy in young girls	Unwillingness to approach their parents for consent to a study based on a decision they had made autonomously to terminate a pregnancy
3 Illegal behaviours	Child drug use, orChild prostitution	 Children would not be prepared to seek parental consent. Parents might not provide consent to such studies
4 Minimal or no-risk research (For example, completing surveys about drug, alcohol, or sexual abuse, eating disorders, attitudes towards oral hygiene, exercise behaviour, or even experiences of healthcare provision)	Children over the age of 12, using a passive consent approach	Daunting Ministerial consent
5 Any other form of research	Orphaned and vulnerable children (OVC)	No parent or guardian to consent

Buchner-Eveleigh & Vogel note 44.Strode & Slack note 49.

9

IV RESEARCH METHODOLOGY

a) RESEARCH QUESTIONS

This dissertation explores the following research questions:

- (1) Does section 71 of the National Health Act violate a child's constitutional rights?
- (2) To what extent is it justifiable to limit a child's constitutional rights by requiring parent or guardian consent in all forms of health-related research?

b) OBJECTIVES

The objectives of this dissertation are to:

- (1) Evaluate to what extent section 71 of the National Health Act respects, protects, promotes, or fulfils children's constitutional rights.
- (2) To determine if the parental or guardian consent as a sole provision to allow children to participate in health research can be substantively justified by Section 36 of the Constitution.

c) ETHICAL CLEARANCE

The expedited ethical clearance [Protocol Reference No. HSS/1221/017M] was obtained from the Human and Social Sciences Research Ethical Committee.

d) STUDY RATIONALE

Health research involving children is complex as it is situated in the realm of law and ethics, which are considerably distinct. Balancing competing interests and establishing harmony between these distinct regulatory frameworks has never been an easy task.

This study has the potential to consolidate evidence justifying the constitutional or non-constitutional basis of section 71 of the National Health Act concerning children's rights to equality and bodily integrity. Moreover, it will suggest valid ethical-legal reasoning that stresses the need to recognise the emerging child's privacy coupled with autonomy, with due consideration given to the evolving capacity of the child and promotion of the child's privacy.

e) STUDY SETTING

The evaluation of section 71 of the National Health Act No. 61 of 2003 whether it is inconsistent with the child's constitutional rights on bodily integrity and equality was based on the qualitative analysis of legal documents and literature.

f) DATA COLLECTION

In the pursuit to answer the aforementioned critical questions of this study, an extensive search of medico-legal archives was conducted. Both primary and secondary sources were employed to develop more informed and conclusive arguments. However, the use of secondary data sources that is more up to date with the subject matter was used at a greater proposition because it is easily accessible through a computerized database free of charge.

g) DATA MANAGEMENT

Data files used in this study were stored on the computer hard drive and the Google Drive cloud system. Moreover, a bibliography of all content utilized is provided at the end of the dissertation.

h) DATA ANALYSIS

A meta-aggregative approach was applied in the data analysis to establish a comprehensive response to the research question of this study.

CONCLUSION

It is a fact that research that involves children is legal and ethical. Yet, section 71 of the NHA prohibits children from consenting unassisted in research that is aimed to provide a direct benefit or generalisable knowledge concerning their health and well-being. Whether this approach is constitutional or not, based on equality and the right to bodily integrity, is a matter to which the posed research questions will seek to provide answers in the subsequent chapters.

CHAPTER 2

LEGAL FRAMEWORK

I INTRODUCTION

This chapter describes the legal framework regulating health research with children. It does this in order to answer the key research question in this mini-dissertation – does section 71 of the NHA violate the constitutional rights of children? Alternatively, does the NHA advance children's constitutional rights and freedoms? The Bill of Rights (hereafter referred to as BOR) provides comprehensive principles that can be used to evaluate s 71 of the NHA's constitutional validity. The BOR

- '(1) re-affirms the democratic values of human dignity, and freedom and instructs the State to
- (2) respect, protect, promote and fulfil

the rights in the Bill of Rights'.²

However, under certain conditions, rights contained in the Bill are subject to limitation.³ Moreover, the right to human dignity and the right to freedom and security of the person are both non-derogable.⁴

II THE CONSTITUTION

South African law is guided by the principles and provisions contained in the Constitution of the Republic of South Africa, 1996 ('the Constitution'), which is our supreme law.⁵ The founding values of the Constitution are: (a) human dignity, and the achievement of equality and human rights and freedoms, 6 and (c) the supremacy of the Constitution and the rule of law.⁷ It further states that any 'law or conduct inconsistent with [it] is invalid, and the obligations imposed by it must be fulfilled'.⁸

¹ Bill of Rights (BOR) s 10.

² BOR s 9.

³ Ibid. s 36.

⁴ Ibid. s 39.

⁵ Ibid.

⁶ Constitution of the Republic of South Africa, 1996, chapter 1(a) and (b) (hereafter 'the Constitution').

⁷ The Constitution, 1996, chapter 1(c).

⁸ Section 172 of the Constitution, 1996.

The BOR has international recognition and is considered one of the most progressive Bill of Rights in the world because of its universal application to all law and the fact that it binds the legislature, executive, judiciary, and all organs state. The BOR does not uphold only civil and political rights but further extends to economic, social, and cultural rights.

'It is a cornerstone of South African democracy which enshrines the rights of all people in the country likewise to the children, and affirms the values of human dignity, equality, and freedom.' 10

(a) Children's Rights

The Constitution has a section that deals directly with the rights of children. ¹¹ In this regard, section 28 provides a set of rights that only apply to persons under the age of 18. ¹² Section 28 provides that every child has a right to the parental duty of care, basic nutrition, shelter, basic health care services, and social services. ¹³ Moreover, every child has a right to be protected from maltreatment, neglect, abuse or degradation, or exploitative labour practices. ¹⁴ In relation to the research questions, the Constitution does not explicitly state that a child has a right to individual self-determination. ¹⁵ Instead, it provides a concept of 'a child's best interests' which is used mainly to determine the extent to which a child can act on his or her own, and to limit or promote the ambit of the child's rights and other competing rights. ¹⁷

The best interest of the child is a right guaranteed in the Constitution. Section 28(2) states:

'A child's best interests are of paramount importance in every matter concerning the child'

This emphasises that children's rights are of paramount importance and must be safeguarded by the state. ¹⁸ Children's rights apply exclusively to issues affecting children but

¹⁰ Ibid. s 7(1).

⁹ BOR, s 8(1).

¹¹ Ibid. s 28.

¹² Ibid. s 28(3).

¹³ Ibid. s 28(1)(b) and (c).

¹⁴ Ibid. s 28(1)(d) and (e).

¹⁵ Kruger H 'The Protection of Children's Right to Self-Determination in South African Law with Specific Reference to Medical Treatment and Operations' PER/PELJ (2018) (21) 26.

DOI http://dx.doi.org/10.17159/17273781/2018/v21i0a4609

¹⁶ BOR s 28(2).

¹⁷ Skelton A 'Constitutional Protection of Children's Rights' in Boezaart T ed. *Child Law in South Africa* (2007 2nd ed 327–358).

¹⁸ De Reuck v Director of Public Prosecutions, Witwatersrand Local Division, and Others [2003] ZACC 19; 2004 (1) SA 406 (CC); 2003 (12) BCLR 1333 (CC) at para 63.

do not exclude them from the enjoyment, protection, and application of other human rights found within the Constitution. 19

(b) The Right to Equality

The transformative purpose of the Constitution is rooted in equality and freedom as it states in the Preamble the following as being one of the aims:

'to heal the divisions of the past and establish a society based on democratic values, social justice, and fundamental human rights',²⁰

This envisages the quality of life for all citizens and the realisation of the full potential of each person. Equality is a central theme of our Constitution. Its foundation is laid in the preamble where it states that it provides 'the foundations for a democratic and open society in which government is based on the will of the people and every citizen is equally protected by law'. ²¹ Equality thereafter appears in Chapter Two of the Constitution, in sections 9, 36, and 39. Section 9 states: ²²

- '(1) Everyone is equal before the law and has the right to equal protection and benefit of the law.
- (2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.
- (3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language, and birth.
- (4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.
- (5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.'

¹⁹ Preambles to the Constitution and Founding Provisions, s 1(a).

²⁰ Preamble to the Constitution.

²¹ Ibid.

²² Bill of Rights (BOR) s 9.

The text of the BOR has an open-textured character, thus allowing easy interpretation using principled guidelines.²³ The realisation of this right is based on state and other measures designed to promote and protect against any unfair discrimination by anyone. However, under certain circumstances, the court is bound to decide whether the law or conduct constitutes fair and justifiable discrimination. Any form of discrimination among the listed grounds in s 9(3) is presumed unfair unless a substantive justification is provided that the discrimination is fair.

The equality-related litigation mainly follows a three-stage approach of inquiry, as was set out in Harksen's case.²⁴ First, it must be established whether the law or conduct in question makes a distinction between individuals and groups of people.²⁵ If the differentiation exists, the court will raise inquiries into the following issues:

- (i) the purpose of the law or conduct;
- (ii) whether the purpose is a legitimate one; and, if so,
- (iii) whether the distinction in question is rationally connected to that purpose.

Under this consideration, any law or conduct infringes the right to equality if there is no rational connection between the differentiation and the governmental purpose.²⁶ Moreover, the limitations clause applies to justify the fairness of the infringement. Even if the differentiation in question has a rational connection, the specific law or conduct may still be considered to discriminate unfairly.²⁷ Consequently, leading to the second approach, a two-stage analysis is applied to establish whether differentiation can be considered as unfair discrimination:

- (i) First, is the differentiation is based on one of the grounds specifically listed in s 9(3)?
- (ii) Second, is the differentiation discrimination on an unspecified ground? This is a form of differentiation not listed in s 9(3). Moreover, does it impair fundamental human dignity or create a degree of harm or discrimination?

In addition, Harksen's case provides factors that the court should take into consideration when assessing the impact of the discrimination on the victim:²⁸

²³ O'Regan, K 'The Right to Equality in the South African Constitution' *Columbia. Journal of Gender and Law* (2013) 25 (1) 110–115.

²⁴ Harksen v Lane NO & others 1998 (1) SA 300 (CC); 1997 (11) BCLR 1489 (CC).

²⁵ Ibid. paras 42–53.

²⁶ Freedman W 'Understanding the Right to Equality' SALJ (1998) 115 243–251.

²⁷ Ibid.

²⁸ *Harksen* case paras 51–52.

- (i) It must be considered whether the differentiation is linked to any patterns of past discrimination, for example, if it is aimed at socially vulnerable groups or is genderbased, or racial, then it is highly likely that this will be considered as unfair discrimination.
- (ii) An assessment must be made of the nature of the provision/s used to achieve the legitimate purpose. Does it cause detriment to the complainant's dignity?
- (iii) The magnitude of discrimination towards the complainant's rights and dignity must be considered. Does it impair the complainant's basic human dignity or can the impairment be considered to be of a serious nature?

If, after a substantive examination of the law or conduct in question, the discrimination is found to be unfair, the law or conduct in question infringes the right to equality. And thereafter, the limitation clause is applied to determine whether unfair discrimination can be justified.²⁹ This approach involves the balancing of the extent of the infringement against the purpose of the law in question in order to determine whether the relationship between the purpose and the effect has been closely distinguished.³⁰

(c) The Right to Bodily Integrity

Therapeutic and non-therapeutic research involving children implicates/implies? the right to bodily integrity which may range from the collection of biological material such as blood to obtain generalisable knowledge or for the assignment to different 'arms' of HIV clinical trials or investigation of new radiotherapy or chemotherapy to treat leukaemia.

Section 12 of the BOR provides that each individual has the right to bodily and psychological integrity. This encompasses the right to safety and control over his or her body as well as the right not to undergo medical or scientific experimentation without his or her informed consent.³¹ This right is an autonomous right that details everyone's right to make choices about their body. It affirms that one has the right to determine what happens to one's body. This right is also enjoyed by children.³²

²⁹ Ibid. para 112.

³⁰ Ibid.

³¹ BOR s 12(2)(*b*), (*c*).

³² Teddy Bear case, para 38

(i) The Concept of the 'Body'

In order to understand fully what the right to bodily integrity protects, it is important to define the body or to have a comprehensive understanding of the concept of the body with regard to this right.

The right to bodily integrity is an exclusive right because it confers the power to exclude all others from one's body, thereby protecting the bodily state as being whole, intact, and free from physical interference.³³ Therefore, the right to bodily integrity is comparable to a property right.³⁴ As an exclusive right, it imposes strict duties of non-interference. The violation of bodily integrity may constitute grounds for legal action.³⁵

Our body is what gives us identity. Age, sex, race, or disability are primarily bodily characteristics that cannot be separated from our bodily state. The way we perceive the world is grounded on our thoughts, formulas, principles, preferences, standards, and values, and our engagements with the world all take place by means of the body.³⁶

The legal view of the body is that the body is sub-personal or objective and has an instrumental relationship with the subject. Where 'the body' is both a physiological and objective concept,³⁷ the 'body' in the right to 'bodily integrity' is considered as an 'object'. Therefore, the instrumental relationship between a person's rational agency [autonomy] and their body is protected by their right to bodily integrity. Moreover, in a broader sense, the right to bodily integrity protects the body as the point of convergence or point of integration [the body as a point of integration] of the subjective and the objective world. In this manner, the right to bodily integrity is concerned with the integration of a person's subjectivity and objectivity. Under this consideration,

³³ Re A (Conjoined Twins) [2001] 2 WLR 480 Fam. 147, 258, per Walker LJ.

³⁴ Nedelsky J 'Law, Boundaries and the Bounded Self' *Representations* (1990) 30 162–189 at 167.

³⁵ Wall J Being and Owning: The Body, Bodily Material and the Law (Oxford Scholarship Online 2015 145–155). See p. 149: 'To succeed in a claim for assault, battery, or unlawful detention, it is sufficient to show that there was the threat or the application of force to the body or the deprivation of the free movement of the body. The interference with the right to bodily integrity is itself sufficient for an action, without having to show a loss derived from the interference.'

³⁶ Kant I *Lectures on Ethics* (first published 1920, trans. I. Louis, London 1963), 147–148: '... our life is entirely conditioned by our body, so that we cannot conceive of a life not mediated by the body and we cannot make use of our freedom except through the body'.

³⁷ Herring, J and Wall J 'The Nature and Significance of the Right to Bodily Integrity' *Cambridge Law Journal* (2017) 76 (3) 566–588. doi:10.1017/S0008197317000605

'the right to bodily integrity is exercisable against an open set of persons and further imposes strict duties of non-interference, and infringement of the right to bodily integrity is actionable'. 38

(ii) The Nature and Significance of the Right to Bodily Integrity

The right to bodily integrity is considered as 'the most important of civil rights' and as 'the first and most important of the interests protected by the law of tort.' The concept of 'bodily integrity relates to the integration of the self and the rest of the objective world'. The right to bodily integrity is non-reducible with regard to the principle of autonomy. It is rather considered as enhancing and weighing with more special strength to autonomy-related claims, making the justification of interference especially difficult. Therefore, a breach of this right requires justification beyond what will be adequate for interference with autonomy.

The right to bodily integrity is simply understood as 'a right to be free from physical interference', 44 thereby covering negative liberties

'free from physical assaults, torture, medical or other experimentation, immunisation and compelled eugenic or social sterilisation, and cruel or degrading treatment or punishment. As well as positive duties on the state to protect people against inference by others'. 45

According to Herring and Wall, this view of the right to bodily integrity should be called bodily autonomy, because it entails the exercise of autonomy that has to do with the body.⁴⁶ An autonomous act can be merely defined as an

'exercise to identify standards, preferences, and values and to have your own actions and events in your life to conform to those standards, satisfy those preferences and realise those values'.⁴⁷

³⁸ Ibid.

³⁹ R. (on the application of Justin West) v The Parole Board [2002] EWCA Civ 1641; [2003] 1 W.L.R. See 705 at [49], per Hale L.J. in her dissenting judgment.

⁴⁰ Parkinson v St. James NHS Trust [2001] EWCA 530; [2002] Q.B. 266.

⁴¹ Herring & Wall note 37.

⁴² Ibid.

⁴³ Ibid.

⁴⁴ Feldman D Civil Liberties and Human Rights in England and Wales ((Oxford 2002 2nd ed. 241).

⁴⁵ Ibid.

⁴⁶ Herring & Wall note 37.

⁴⁷ Beauchamp TLand Childress J.F. *Principles of Biomedial Ethics* 7th ed. 101–102 (Oxford 2013); Atkins K. 'Autonomy and the Subjective Character of Experience' *J. Appl. Philos*. (2000) 17 71; Mackenzie C and Rogers W 'Autonomy, Vulnerability and Capacity: A Philosophical Appraisal of the Mental Capacity Act' *Int. J. Law Context* (2013) 9 (1) 37–52 at 42 (Cambridge University Press online); Christman J 'Autonomy, Self-Knowledge, and Liberal Legitimacy' in Christman J and Anderson J (eds.) *Autonomy and the Challenges to Liberalism: New Essays* (Cambridge: Cambridge University Press 2005, 330, 332–336).

Therefore, bodily autonomy affords protection of a person's capacity to make his or her own decisions regarding his or her body.

The right to bodily integrity is conceptually different from the mere right to bodily autonomy. It allows an individual to exclusive use and control over his or her body, where the body is the 'site' and 'location' of where our subjectivity engages with the world.⁴⁸ The right to bodily integrity is premised on a moral basis. It is for this reason that it cannot be reduced to respect for a person's autonomy⁴⁹ unless the right protects 'the body' as a set of physiological systems. In that case, the integrity of the body can be reduced to the autonomy of the body.⁵⁰ In contrast, if the right to bodily integrity protects 'the body' as 'the point of integration between a person's subjectivity and the rest of the objective world', the right to the integrity of the body cannot be reduced to autonomy of the body.⁵¹ Understanding that the right protects 'the point of integration' enables an explanation of

'the legal structure of the right to bodily integrity, the normative weight of the right to bodily integrity, and the troubled boundaries of the right to bodily integrity in contemporary medical law'.⁵²

The respect for autonomy does not completely necessitate the right to bodily integrity because when an individual infringes upon the bodily integrity of the other person, this amounts to a disrespect that is larger than disrespect for the person's autonomy [a capacity to live life according to reasons and motivations that one takes as one's own].

Since our subjective experience of the world is larger than recognising 'rationally formulated standards, preferences, and values', there are many moral reasons that carry more weight than those based on respect for autonomy, thereby protecting a person as the final judge as to what happens to his or her body. Moreover, given the multiplicity of moral properties that make up our subjectivity, we equally 'owe duties to others based on their interest in welfare or preference satisfaction' generally on the grounds of their human dignity. ⁵³

⁴⁸ Wall J *Being and Owning: The Body, Bodily Material and the Law* (Oxford Scholarship Online 2015 145–155 at 57–66).

⁴⁹ Herring & Wall note 37.

⁵⁰ Ibid.

⁵¹ Ibid.

⁵² Ibid.

⁵³ See e.g. Donner W. 'A Millian Perspective on the Relationship Between Persons and Their Bodies' in Cherry MJ (ed.) *Persons and Their Bodies: Rights, Responsibilities, Relationships* (Dordrecht 1999 61).

(iii) The Right to Bodily Integrity and Consent

Several legal and ethical instruments protect research participants. The process of informed consent upholds both a legal obligation and an ethical dimension. In South Africa, everyone has a right to informed consent as per section 12(2) of the Constitution. The application of the right to informed consent requires participant competency; disclosure of all relevant information; comprehension level; and voluntariness of the consent without the unwarranted influence of anyone. In respect of the right of bodily integrity of the patients, section 6 of the NHA stipulates guidelines of information to be disclosed. Similarly, the Regulations relating to Research with Human Participants also provide a list of information that must be made available to potential research participants.

The researchers are obligated to give full disclosure of information about the study. Such information includes the description of research, purpose, study period, and experimental nature of the study; any reasonably probable risks or distresses to the subject; any reasonably expected benefits; better alternative procedures or treatments; measures to maintain privacy and confidentiality; compensation for research associated harm; contact details; and clauses that forbid penalties and affirm the right to withdraw from the study at any time.⁵⁷ The obligation of full disclosure is a duty grounded in the principle of respecting autonomy.⁵⁸

This warrants any person [potential research participant] with the ability to form an intelligent decision to make sense from the information provided, weigh benefits and risks, and voluntarily consent. This fulfils the requirement of informed consent, where a person makes his or her own decisions concerning his or her body. 'Consent' can be described as

'the exclusive use and control of your own body, in a way that encourages a person's subjectivity, [and] posits an understanding (on the part of the person) of the nature and quality of the actions that are to be undertaken to the body'.

⁵⁴ Chima SC 'Evaluating the Quality of Informed Consent and Contemporary Clinical Practices by Medical Doctors in South Africa: An Empirical Study' *BMC Medical Ethics* (2013) 14 (Suppl 1) s 3.

⁵⁵ Section 6 of the NHA stipulates that information disclosed to patients must include the following:

⁽a) The range of diagnostic procedures and treatment options generally available to the user.

⁽b) The benefits, risks, and consequences generally associated with each option; and

⁽c) The user's right to refuse health services and explain the implications, risks, obligations of such refusal. The NHA also requires that health care providers must inform the user of this information in a language that the user understands and in a manner which takes into account the user's level of literacy [28].

⁵⁶ South African Government. Regulations Relating to Research with Human Participants. GN R719 of 19 September 2014.

⁵⁷ Ibid.

⁵⁸ Chima note 54.

The right to bodily integrity is instrumental in the realisation of children's rights. Since, legally, any child below the age of 18 years cannot consent independently; however, the right to bodily integrity confers partial to full right to self-determination depending on age, competency, and level of maturity.⁵⁹ This currently forms a rational basis to allow children to consent independently to a wide range of health care services, including reproductive health care.⁶⁰

III LIMITATION OF RIGHTS

South African jurisprudence uses a similar approach to the Canadian Charter: a two-stage approach of determining whether a limitation of rights is justified.⁶¹ First, it is established whether the right in question is limited or violated by legislation or policy. Secondly, if it has been violated, this violation must be justified by an evidence-based rationale that establishes that the limitation may be acceptable according to the Constitution if it can be regarded as reasonable and justifiable in a society which is open and democratic and which is founded on human dignity, equality, and freedom.⁶²

IV CHILDREN'S ACT 38 OF 2005

The enactment of the Children's Act 38 of 2005 does not only fulfil the mandate of the Constitution 'to enact laws that protect, promote, or fulfil rights contained in the Bill of Rights';⁶³ it is also consistent with obligations imposed by international laws. In its preambles, it states that the Act has been passed to ensure respect for and to promote South Africa's international law obligations as provided for in, among others, the African Charter on the Rights and Welfare of the Child (ACRWC),⁶⁴ the United Nations Universal Declaration of Human Rights, entitling children to special care, and the United Nations Convention on the Rights of the Child (UNCRC).⁶⁵

The Children's Act 38 of 2005 plays an instrumental role in matters concerning the rights of children as it provides more detail on the children's rights as set out in the

⁵⁹ Kruger note 15.

⁶⁰ Ibid.

⁶¹ Freedman W 'Understanding the Right to Equality' SALJ (1998) 115 243-251.

⁶² BOR s 36.

⁶³ Section 7.

⁶⁴ African Charter on Human and Peoples' Rights 1981 (the African Charter) pre-dates the African Charter on the Rights and Welfare of the Child 1990 and is, for this reason, known as the 'parent' African human rights document. See also Davel V (ed.) *Introduction to Child Law in South Africa* (Juta & Co Ltd 2000 214–216).

⁶⁵ The Convention was adopted by the General Assembly on 20 November 1989. South Africa became a signatory on 29 January 1993 and ratified the UNCRC on 16 June 1995.

Constitution. Therefore, it becomes a quick reference for clarity in child-related matters as presented in this study dealing with children's participation in research. Even though the Children's Act does not have provisions that deliberately protect or promote participation in research, it sets out some general rights such as the 'child's best interest', which is also applicable in s 71 of the NHA.

(a) Child's Best Interests

The best interest of the child is a general provision that requires due consideration of what is best for children in any matters that may involve them. The Child Welfare Information Gateway provides a comprehensive definition of the child's best interests:⁶⁶

'The term "best interests of the child" generally refers to the deliberation that courts undertake when deciding what type of services, actions, and orders will best serve a child as well as who is best suited to take care of a child. "Best interests" determinations are generally made by considering a number of factors related to the child's circumstances and the parent or caregiver's circumstances and capacity of the parent, with the child's ultimate safety and well-being the paramount concern.'

The Convention of the Rights of the Child defines a child's best interests in Article 13 by saying that 'the best interest of the child must be a primary consideration in all matters concerning the child'.⁶⁷ Article 13 should be read with article 12, which provides that the views of the child [the interest of the child] must be heard and taken into account.⁶⁸

The Children's Act provides a comprehensive list of primary considerations of the child's best interests.⁶⁹ Key elements of this list are:

- '(b) the attitude of the parents, or any specific parent, towards—
 - (i) the child; and
 - (ii) the exercise of parental responsibilities and rights in respect of the child;
 - (iii) the capacity of the parents, or any specific parent, or of any other care-giver or person,

to provide for the needs of the child, including emotional and intellectual needs'.

⁶⁶ Child Welfare Information Gateway: Determining the best interests of the child. *Washington, DC: U.S. Department of Health and Human Services, Children's Bureau* (2016). https://www.childwelfare.gov accessed on 10 August 2017.

⁶⁷ United Nations Convention on the Rights of the Child (UNCRC), Art. 13.

⁶⁸ Ibid., Art. 12.

⁶⁹ Children's Act 38 of 2005, s 7 'Best interests of child standard'.

The Constitutional Court has emphasised that s 7 (1) is not a 'closed list of factors' as certain best interests of children may fall outside the list provided in s 7 of the Children's Act. The Constitutional Court has held that making a 'pre-determined formula' is antagonistic to the flexibility of the concept of a child's best interest. Additionally, according to Nevondwe, [w] hat is best for a specific child or children cannot be determined with absolute certainty'. The court must give due consideration to all non-exhaustive factors they deem necessary, notwithstanding the s 7(1) list of factors.

Section 10 of the Children's Act⁷³ creates a right to child participation in line with Article 12 of the Convention on the Rights of the Child:

'Every child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration.'

A synergy of s 71 of the NHA with the Children's Act also extends to the right to child participation. Despite the contradiction of 'dual consent', ⁷⁴ s 71 allows children to participate in health as it states that this is possible 'if the minor is capable of understanding, with the consent of the minor'.

Moreover, reading this provision after s 71(2)(c), which states 'with the consent of the parent or guardian of the child', one would expect the Act to provide further that if the minor is capable of understanding, with the 'assent' of the minor, a mere agreement to participation in the proposed research may be sufficient, thereby validating the legal incapacity of the child to consent. However, using the legal principle 'consent' confirms respect for child self-determination, embedded in the right to bodily integrity. The sought-after autonomy to consent is meaningless since a parent or guardian is mandated to act on behave of the child.

⁷⁰ S v M 2008 3 SA 232 (CC) para 24 [citing s 28(1)(g), (h) and {i}; s 28(2); s 28(3)].

⁷¹ Nevondwe L'Reflection on the Principle of Best Interests' *Bangladesh e-Journal of Sociology* (2016) 13 (1) 101–114.

⁷² Factor (m) of the list in *McCall v McCall* 1994 3 SA 201 (C) allows the court to consider 'any other factor which is relevant...'.

⁷³ Ibid.

⁷⁴ Nienaber, A 'Consent to Research by Mentally Ill Children and Adolescents: The Implications of Chapter 9 of the National Health Act' *South African Journal of Psychiatry* 19 (1) 4–11.

V DISCUSSION

In order to evaluate whether s 71 of the NHA is inconsistent with the Constitution, one must ask whether any of the rights described above are violated. First, with regard to children's rights, Justice Khampepe noted in the *Teddy Bear* case:⁷⁵

'[T]he correct approach is to start from the premise that children enjoy each of the fundamental rights in the Constitution that are granted to "everyone" as individual bearers of human rights. ⁷⁶

In South Africa, children are entitled to all the fundamental human rights contained in the Constitution in addition to section 28, which specifically confers protection in child-related matters.⁷⁷ Section 9 guarantees that everyone 'including children' has the right to equality before the law and the equal protection and benefit of the law.⁷⁸ However, this alone does not mean that children have the right to self-determination, as they are still subject to the parent's duty of care.⁷⁹ However, section 28(2), which provides that '[a] child's best interests are of paramount importance in every matter concerning the child', has played a significant role in the realisation of other rights contained in the Bill. It becomes more meaningful as the child grows older, where it is used to determine other competing rights in terms of what is permissible and what is not.⁸⁰ Maturing children then derive their partial to full self-determination from the rights to dignity,⁸¹ privacy,⁸² freedom of religion,⁸³ freedom of expression,⁸⁴ and association.⁸⁵ When these rights have been conferred on a child, justifying any infringement of the child's right to personal autonomy becomes problematical.⁸⁶

The constriction of section 71 into 'nurturance'⁸⁷ [or protection through parental authority] in respect of a broad class of children [including adolescents] interferes with the gradual promotion of several factors that allow children to consent independently in a medical-

⁷⁷ See s 28.

⁷⁵ Teddy Bear case.

⁷⁶ Ibid.

⁷⁸ Section 9 Right to equality.

⁷⁹ Kruger note 15.

⁸⁰ De Reuck v Director of Public Prosecutions, Witwatersrand Local Division, and Others [2003] ZACC 19; 2004 (1) SA 406 (CC); 2003 (12) BCLR 1333 (CC); Sonderup v Tondelli 2001 1 SA 1171 (CC); Skelton A 'Constitutional Protection of Children's Rights' in Boezaart T ed. Child Law in South Africa (2007 2nd ed 346).

⁸¹ Constitution, 1996, s 10.

⁸² Ibid s 14.

⁸³ Ibid s 15.

⁸⁴ Ibid s 16.

⁸⁵ Ibid s 17.

⁸⁶ Bekink B and Brand D 'Constitutional Protection of Children' Rights' in Davel CJ (ed.) *Introduction to Child Law in South Africa* (Juta: Lansdowne 2000 169–195 178).

⁸⁷ Farson Birthrights 165, as cited by Freeman 1980 CLP 17.

related juristic act. Therefore, it is submitted that section 71 violates not only the Constitutional right to equality, human dignity, privacy, freedom, and security of the person but also the sanctioned treaties on the rights of children, both international and regional.

I will further evaluate whether these provisions that limit the ability of 'all children to give their independent consent to health research requiring consent from parents and guardians is justifiable and consistent with the fact that the child is recognised as a potentially autonomous person under the certain juristic act and in consideration of a number of factors such as the child's age and level of maturity. 88

(a) Right to Bodily Integrity

The right to bodily integrity in minors confers protection against all vaguely justified state-imposed physical intrusion, including the well-known corporal punishment.⁸⁹ The Constitutional Court has proclaimed that children's rights to bodily integrity must be recognised and respected in the same way as other rights contained in the Constitution, such as the right to privacy.⁹⁰

Section 12 – the right to bodily integrity – protects children from exploitation within scientific experimentation. However, it is submitted that the stance adopted in the NHA is overly protective as it does not allow for any exceptions or any flexibility. Adults and children are not treated equally; children under the age of 18 years can be research participants only through proxy consent. Further, the proxy consenters are limited to parents and guardians. This excludes children with no parents or guardians. This is contrary to the approach in the Children's Act, which allows children to give their independent consent to a host of health interventions from the age of 12 years.

(b) Right to Equality

It is submitted that s 71 is a form of 'direct' 'age-based discrimination' [discrimination on the grounds listed in s 9(3)]. According to subsection 9(5), 'discrimination on one or more of the

⁸⁸ Kruger note 15.

⁸⁹ Ibid

⁹⁰ Minister of Health and Others v Treatment Action Campaign and Others (2002) ZACC 16 SA 703 BCLR 1075

⁹¹ Strode A, Richter M, Wallace M, Toohey J, Technau K Failing the vulnerable: Three new consent norms that will undermine health research with children *S Afr J HIV Med* (2014) 15 (2) 46–49. DOI:10.7196/SAJHIVMED.1014

⁹² Section 71 of the NHA.

⁹³ Strode et al. note 91.

⁹⁴ Ibid.

⁹⁵ Strode A and Essack Z Facilitating access to adolescent sexual and reproductive health services through legislative reform: Lessons from the South African experience (2017) 107(9) SAMJ 741–744.

grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair.' It is important to emphasise that this study is in support of neither the so-called 'child liberators' and 'child savers' nor the 'protectionists' and 'liberationists', but is concerned about the balance between the 'nurturance' and 'self-determination' of the child as per the Constitution and ratified treaties on the rights of the child. Therefore, our claim with regard to age-based discrimination is based on the undue consideration of

'[e]very child that is of such an age, maturity and stage of development as to be able to participate in any matter concerning that child has the right to participate in an appropriate way and views expressed by the child must be given due consideration'.⁹⁹

This claim is also supported by the Children's Act, as it mandates that a child must enjoy fair and equitable treatment and that the child should enjoy protection from unfair discrimination for any reason, including their health status or disability. Moreover, the general principles of the Children's Act apply in all matters concerning the child, including participation in health research.

The approach in the Children's Act is more consistent with international norms as it gives recognition to the concept of child participation. The Children's Act provides that a child of 12 years who possesses a combination of one or two criteria is qualified to make a valid consent to sexual and reproductive health services. ¹⁰² The minority status of the child and the requirement of a parent or legal guardian to approve a legally binding decision for the child are entirely excluded in rights pertaining to the ability to access health services relating to sexual reproduction. ¹⁰³

The Children's Act has also embraced the concept of the evolving capacity of the child and the ability to draw up a legally binding will, as was ruled in *Gillick v West Norfolk* and Wisbeck Area Health Authority and the DHSS.¹⁰⁴ This case held that adolescent children

⁹⁶ Coons JE and Mnookin RH 'Towards a Theory of Children's Rights' in Baxter IGF and Eberts M (eds.) *The Child and the Courts* (London: Sweet & Maxwell 1978 391–392).

⁹⁷ Bainham Children 98–99.

⁹⁸ Kruger note 15.

⁹⁹ Children's Act, s 10.

¹⁰⁰ Children's Act, s 6: General Principles:

^{&#}x27;(b) respect the child's inherent dignity;

⁽c) treat the child fairly and equitably;

⁽d) protect the child from unfair discrimination on any ground, including on the grounds of the health status or disability of the child or a family member of the child'.

¹⁰¹ Children's Act 38 of 2005, s 6(1)(a), (b).

¹⁰² Subsequent sections of Children's Act.

¹⁰³ Strode & Essack, note 95.

¹⁰⁴ Gillick v West Norfolk and Wisbech Area Health Authority and the DHSS (1985) 3 All ER 402.

with sufficient understanding and intelligence to comprehend fully what was proposed should be allowed to give their independent consent to medical treatment.¹⁰⁵

(c) Right to Access to Health Care Services

Section 71 of the NHA results in the exclusion of many children from the benefits of health research. This violates their right to have access to health care services as, without evidence-based information, we cannot improve health care for this age group. ¹⁰⁶ Such an approach excludes investigations on, for example, the safety and efficacy of drugs for terminating a pregnancy or any contraceptives, and studies on the side effects of HIV/AIDS treatment as requiring parental consent would deter many adolescents from research participation. ¹⁰⁷ These examples are set deliberately to problematise the scope of s 71 to show contradictions with regard to some children's rights that have been promoted by the state.

It is therefore submitted that the limitation of children's rights is not justified as it undermines our concept of children's rights. Justice Sachs, writing for the majority of the court in S v M (Centre for Child Law as amicus curiae), ¹⁰⁸ described children's rights in the following way:

'Every child has his or her own dignity. ... Children are not merely as a miniature adult waiting to reach full size, he or she cannot be treated as a mere extension of his or her parents.'

...

'Individually and collectively all children have the right to express themselves as independent social beings, to have their own laughter as well as sorrow, to play, imagine and explore in their own way, to themselves get to understand their bodies, minds, and emotions, and above all to learn as they grow how they should conduct themselves and make choices in the wide social and moral world of adulthood.'

Several authors submit that children's rights as crafted in the Constitution are very powerful, particularly concerning socioeconomic rights. ¹⁰⁹ Conversely, a constitutional analysis undertaken by Kruger revealed that many of the rights set out in section 28 are merely

¹⁰⁵ Christian Lawyers Association v Minister of Health and Others (Reproductive Health Alliance as Amicus Curiae) 2005 (1) SA 509 (TDP)

¹⁰⁶ Strode et al. note 91.

¹⁰⁷ Ibid.

¹⁰⁸ S v M (2007) ZACC 18; 2008 (3) SA 232 (CC); 2007 (12) BCLR 1312 (CC).

¹⁰⁹ Liebenberg S 'Socio-Economic Rights. Adjudication under a Transformative Constitution' *European Journal* of *International Law* (2013) 24 2 739–744. See also Rosa S and Dutschke M 'Child Rights at the Core: The Use of International Law in South African Cases on Children's Socio-economic Rights' *South African Journal of Human Rights* (2006) 22 (2) 244–260.

replications of those rights stated in the other sections of the Bill of Rights. Hruger further argues that section 28 is limited by its failure to re-affirm the most controversial human rights to, for example, equality and bodily and psychological integrity, which are always to be protected and promoted. This is because of the misconception that children solely enjoy constitutional rights in section 28 of the BOR.

VI CONCLUSION

Children enjoy constitutional rights and freedom contained in the Bill of Rights, including rights to bodily integrity and equality. This explanation of children's constitutional rights provided principles that will be used for the critical evaluation of s 71 in the next chapter/s. From this viewpoint, I submit that s 71 infringes fundamental human rights to equality and the right to bodily integrity. The Constitution is the supreme rule of law, and therefore any law that protects, promotes, or limits rights as set out in the Bill of Rights must be consistent with the obligations imposed by it.

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¹¹⁰ Kruger JM 'The Protection of Children's Rights in the South African Constitution: Reflections on the First Decade' *Tydskrif vir Hedendaagse Romeins-Hollandse Reg* (2007) 70 (2) 239–262.

¹¹¹ Ibid.

¹¹² Ibid.

CHAPTER 3

CONSTITUTIONAL EXAMINATION OF SECTION 71 OF THE NATIONAL HEALTH ACT

I INTRODUCTION

Before engaging to the constitutional argument concerning section 71 of the NHA, it is important to premise the aspiration and core values envisaged by the new Constitution of the Republic of South Africa:

'The Constitution strives for a substantively progressive society that recognises, in moving forward, past wrongs have to be righted constructively in a manner that eliminates the socio-economic inequalities fostered by the apartheid regime, restores basic human dignity, and espouses freedom in all spheres of an individual's life.'

Therefore, any law or conduct adhering to the values of the past will not easily be given constitutional endorsement as this would be contrary to the aspiration of a new democratic society that is founded on equality, human dignity, freedoms, and the improvement of human rights.²

The impugned section 71 of the NHA is contrary to the aspiration of a new democratic society envisaged in our Constitution by inadequately balancing children's protection and children's rights [respect or promotion dimension] in health research. Children cannot consent independently, even if they bear a 'capacity of understanding'. Section 71 is contrary to the gradual recognition of the ability of children to consent to various medical-related juristic acts without parental assistance, which is drawn from recognising the potential autonomy of the child. This is claimed from certain rights and freedoms as set out in the Bill of Rights, including the recognition of the child's stage of development, which takes into consideration the age, level of maturity, and capacity of understanding. The latter is linked to the children's rights movement such as the previously discussed UNCRC as well as the extensive research findings on children's levels of maturity and capacity of understanding.

¹ Bhana, D South African Journal of Human Rights (2013) 29 2 351–375.

² Constitution of the Republic of South Africa, 1996 Preamble to the Constitution and Ch 1.

³ Section 71(1) and (2).

⁴ Kruger H 'The Protection of Children's Right to Self-Determination in South African Law with Specific Reference to Medical Treatment and Operations' PER/PELJ (2018) (21) 26.

⁵ Mahery P 'Consent Laws Influencing Children's Access to Health Care Services' in Ijumba P and Padarath A (eds) South African Health Review 2006 (Health Systems Trust Durban 2006) 167–180. Hartman RG 'Coming of Age: Devising Legislation for Adolescent Medical Decision-making' 2002 AJLM 409–453.

II VIOLATION OF CHILDREN'S RIGHT TO EQUALITY

The law in question differentiates between two groups of research participants: adults and children. Therefore, section 71 of the NHA amounts to age-based discrimination as per s 9(5), which stipulates that discriminating in respect of one or more grounds mentioned in s 9(3) is unfair. If it is presumed to be fair, grounds for that presumption must be established. Section 71 protects all potential research participants against experimentation and scientific exploitation. Hence, the purpose of age-based discrimination is to protect children from research-related harm. This purpose is legitimate and consistent with general provisions of the 'nurturance' dimension of children's rights, in a situation where parents or guardians give their consent on behalf of their children in any legal transaction.⁶

However, there is a poor rational link between specified grounds [age-based differentiation] and the purpose of 'protection'. Section 71 is overly restrictive on children, and there are no provisions that promote children to be participants in research pertaining to health independently. The instrumental principle of children's rights, the child's 'best interest' and 'capacity of understanding', was not fully applied, since parental or guardian consent is compulsory even if the child has the ability to comprehend the 'risks and benefits' associated with the proposed research.⁷

In terms of the respect and promotion of children's rights, Freeman said the following:

'To take children's rights seriously requires us to take seriously nurturance and self-determination, demands of us that we adopt policies, practices, and laws which both protect children and their rights. *8

Therefore, it is important to premise the overview of the legislative mandate, which seems to be lacking under the impugned section 71. Dissecting the meaning of the legislative mandate [or enacted law] will help us to understand how section 71 has failed the constitutional commitment of the Bill of Rights.

Well-crafted legislation is a defined set of provisions or rules, which pertain to a well-defined sector and constructed to correspond to policy objectives. ⁹ It contains both empowerment and limitations, comprising both grants in respect of power and restrictions that

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⁶ Farson RE Birthrights (Macmillan New York 1978).

⁷ Section 71(2)(c) and (d).

⁸ Freeman 'Limits of Children's Rights' 39.

⁹ Margit Cohn, Fuzzy Legality in Regulation: The Legislative Mandate Revisited: Law & Policy. 2001 https://doi.org/10.1111/1467-9930.00121

are placed on the exercise of these powers. ¹⁰ Moreover, an essential feature of regulatory law relates to delegating powers and exercising discretion in their implementation, thus forming a critical control measure for the law's indeterminacy and rigidity. ¹¹ These features provide the flexibilities that enable dealing with complexity and reality, which is rapidly changing. ¹² Even though delegation and discretion are sometimes criticised, they play a significant role in the promotion of statutory flexibility and responsivity by offering a choice among a range of options. ¹³

Consequently, section 71, while protecting research participants, also promotes research participation that is considered to be safe, beneficial, or relevant as per the principles of their informed consent. An additional demand is the inclusivity of the act, and respect for various constitutional provisions, thus mandating the law to provide empowerments, restrictions, and flexibilities that encourage social inclusion, the exercise of rights and freedoms, and fair restrictions of certain conduct, actions, or groups or limitation of rights. 15

If the discrimination is against the category, which has previously suffered numerous patterns of discrimination, then that discrimination is ruled as being unfair. ¹⁶ Unfair discrimination relating to the grounds listed in s 9(5) violates the transformative purpose of the Constitution, 1996, to 'heal the divisions of the past and establish a society based on democratic values, social justice, and fundamental human rights'. This demands that any law or conduct should recognise that children require special provisions to receive equitable protection and benefit of the law. ¹⁷

A quick defence for the strict protection of children through parental consent mainly resides in a narrow view of children's rights, where parent/s perform juristic acts on behalf of their children as a protection in terms of their immaturity of judgment. However,

¹¹ Ibid.

¹⁰ Ibid.

¹² Ibid.

¹³ Ibid.

¹⁴ South African Government. Regulations Relating to Research with Human Participants. GN R719 of 19 September 2014.

¹⁵ Greschner, D. The main purpose of equality is to protect the interest of belonging and not to exclude members of protected groups from the benefits of full membership in social, economic, and political life.

¹⁶ Harksen v Lane NO and Others ZACC 12; (1997) (11) BCLR 1489 paras 51–52

¹⁷ https://www.unicef.org/child-rights-convention/child-rights-why-they-matter#:~:text=Children% 20are% 20neither% 20the% 20property, subject% 20of% 20their% 20own% 20rights.&text=The% 20Convention% 20recognizes% 20the% 20fundamental, their% 20well% 2Dbeing% 20and% 20development / accessed on 10 May 2021.

¹⁸ Cockrell 'Capacity to Perform Juristic Acts: Contracts' 756 et seq; Heaton Law of Persons 79 et seq; Himonga and Cooke 2007 IJCR 326, 338

children are not the property of their parents/guardians or helpless objects of charity. ¹⁹ This was affirmed in the *Gillick v West Norfolk and Wisbech Area Health Authority and the DHSS* ruling, ²⁰ where it was held that parental authority is not absolute, and diminishes when a child develops the ability to decide for him or herself. ²¹ The ruling also clarified how rights apply to children as per the distinction drawn by Farson, where it was affirmed that parental rights are only applicable while they are necessary as protection of the child's 'nurturance', in a situation where a child is not yet old enough to have the ability to think rationally. ²² Secondly, when a child matures and develops the ability to make an informed decision, parental authority loses its value, and 'self-determination' kicks in. The approach that is consistent with children's rights is the test for individually assessing how mature the child is and what his or her intellectual ability is. ²³ The Constitution and international law such as UNCRC provide that children are human beings with fundamental human dignity and are the subject of their rights. ²⁴

In equality litigation, the victim's human dignity is considered the determining factor. Human dignity is a highly recognised fundamental human right that is provided in section 10 of the Constitution. This right recognises that everyone [including children] has inherent worth, not only as community members but also extending to valuing the choices they make. Dignity is deeply personalised; it involves understanding of personal being and existence in society. In S v M (2007), the court affirmed that children's dignity is of special importance and that children are to be seen as independent from their parents. Fundamental human dignity cannot be limited nor derogated.

III PHILOSOPHICAL DIMENSION OF CHILDREN'S RIGHTS TO EQUALITY

The Dignified Lives Approach provides a comprehensive approach that relates to children's constitutional rights to equality. This theory is founded on the principles that respect individual assessment, social inclusion, and autonomy, as well as the principle of equal influence and the

¹⁹ United Nations Convention on the Rights of the Child (UNCRC).

²⁰ Gillick v West Norfolk and Wisbech Area Health Authority and the DHSS 1985 3 All ER 402 (hereafter Gillick). See, in general, Bainham Children 346 et seq; Eekelaar 1986 LQR 4 et seq; Eekelaar 1986 OJLS 177 et seq; Human 2000 Stell LR 71 et seq; Robinson 1993 TRW 52 et seq

²¹ Gillick 421e and 423j.

²² Farson RE Birthrights (Macmillan New York 1978).

²³Gillick 424b-d.

²⁴ UNCRC note 19.

 $^{^{25}\} President\ of\ the\ Republic\ of\ South\ Africa\ and\ Another\ v\ Hugo\ (CCT11/96)\ (1997)\ ZACC\ 4\ BCLR\ 708\ para\ 41.$

²⁶ BOR s 10.

²⁷ *Teddy Bear* case para 52.

²⁸ S v M (2007) ZACC 18; 2008 (3) SA 232 (CC); 2007 (12) BCLR 1312 (CC). S v M 2008 3 SA 232 (CC)

²⁹ BOR s 37.

principle of sufficiency.³⁰ It upholds both philosophical and legal contexts.³¹ The Dignified Lives Approach is of Kantian origin, an ethical principle that is concerned with equal treatment of and respect for everyone and unconditional valuing of the inherent worth of every person, thus affirming that everyone is entitled to an equal level of appreciation³²

(a) The Principle of Individual Assessment

According to Sandra Fredman, age-based discrimination should be imposed only where a person because of his/her age cannot objectively protect himself/herself under the detriment imposed by law or policy.³³ This means that before parental or a guardian's consent may be imposed, a child must be given an individual assessment to determine whether he/she because of his/her capacity cannot objectively protect him-/herself. This prevents undue 'unequal' treatment which may result in unjust deprivation of benefits of the law or conduct associated with a stereotype.³⁴ A stereotype is defined as any form of generalisation or classification based on accurate or false connotations which can be either positive or negative in the characterisation of a group of people and applied to an individual member of the group without considering their qualities or situation.³⁵ The apparent form of stereotype is an inaccurate generalisation, which inaccurately infers certain features that are not complementary to a member of the group.

Moreover, in some situations, a generalisation may be accurate for numerous members of the group, but inaccurate for an individual because it does not acknowledge his/her situation or personal attributes.³⁶ According to s 71, all children cannot protect themselves from research-related harm since proxy consent is necessary for every child who is not yet 18 years old. This is inaccurate, as children not yet 18 years old can give their independent consent to various health-related services, particularly those with the mental capacity to comprehend the risk and benefits associated with healthcare services, including abortion without parental or

³⁰ Shenker, PA (2012) 25 Canadian Journal of Law. & Jurisprudence 243–282

³¹ Ibid.

³² Kant, E *Groundwork for the Metaphysics of Morals* translated by James W Ellington Indianapolis, ID: Hackett (1993) section 2 435–36 and also see Dworkin, R Cambridge, MA: Harvard University Press, (1977) 181: 272–273. Note that the Dworkin's interpretation of equal concern and respect is different from the one proposed here. It assesses inequalities based on a lifetime's accumulated resources. Furthermore, it is based on a comparison between individuals.

³³ Fredman & Spencer Oxford: Hart (2003).

³⁴ Moreau, SR 'The Wrongs of Unequal Treatment' (2004) 54:3 University of Toronto. Law Journal 291. Moreover, Cupit, G (1998) 108:4 *Ethics* 702–708 argues that the wrong of inferiority is *the ultimate* wrong of age discrimination. That is, age discrimination is unjust 'only if it constitutes treating people as inferior because their age'.

³⁵ Ibid.

³⁶ Ibid

guardian consent.³⁷ However, s 71 of the NHA used a negative-accurate generalisation, thus denying the individual assessment of the child. The adolescents who have experience of and knowledge about the risks of medical treatments or procedures would easily qualify in terms of the given criteria or provisions.³⁸ These individuals are capable, yet are denied individual consideration. It is for this reason that stereotypes may amount to discrimination because they are not based on intrinsic value and individual merits. Stereotypes are considered to be wrong because they impose group traits on an individual, rather than relying on actual characterisation.³⁹

Andersons and Young question current theories of justice with a predominant distributive paradigm.⁴⁰ They envisage a society characterised by all people being equal to others.⁴¹ Section 71 of the NHA has discriminative traces of prejudice and is of institutional and social origin,⁴² where it is universally assumed that parents will always act in the best interest of the child or are entitled to control the child, while contrarily perpetuating the social dominance of parents.⁴³

(b) The Principle of Sufficiency

The approach based on the principle of sufficiency differs from how the equality rule is generally applied; instead of considering a perspective that A has far more than B, it focuses on whether 'A' or 'B' has been given sufficient consideration concerning law or conduct.⁴⁴ The principle of sufficiency is not concerned with how much a person has *comparatively*, but it regards equality as an intrinsic value,⁴⁵ thereby bestowing sufficient concern [due consideration] on the child. The impugned s 71 of the NHA lacks due consideration, which is

³⁷ Strode A and Essack Z Facilitating access to adolescent sexual and reproductive health services through legislative reform: Lessons from the South African experience (2017) 107(9) *SAMJ* 741–744. DOI:10.7196/SAMJ.2017.v107i9.12525

³⁸ Moreau, SR 'The Wrongs of Unequal Treatment' (2004) 54:3 University of Toronto Law Journal 291. 291 (unequal treatment is wrong when it is associated with stereotyping and prejudice, oppression, and denial of basic goods)

³⁹ Ibid.

⁴⁰ Ibid.

⁴¹ Ibid.

⁴² Oppression is 'systemic constraints on groups that are not necessarily the result of the intentions of a tyrant. Oppression ...is structural, rather than the result of a few people's choices or policies. Its causes are embedded in unquestioned norms, habits, and symbols, in the assumptions underlying institutional rules and the collective consequences of following those rules' by Gillin, T et al Toronto ON: James Lorimer eds (2005) 45 'The Shifting Judicial Foundation of Legalized Age Discrimination'

⁴³ Ontario (Human Rights Commission) v Simpsons-Sears Ltd, (1985) 2 SCR 536.

⁴⁴ Frankfurt, H Cambridge: Cambridge University Press (1988) 134: 146–48. See also Raz, J Oxford: St Martin's Press (1986) 226–29) rhetorical egalitarianism, the wrong of poverty versus inequality and the concern for the alleviation of hunger versus the concern for equality.

⁴⁵ Parfit, D (1986) 96:832 *Ethics* 869–70. Subscribe that people hold multiple identities during their lives (see supra note 43), compensation within a life over time is not always possible.

a rule of thumb in determining the best criteria that are used to protect and promote children's rights.

(c) The Principle of Social Inclusion

Social inclusion entails the protection of belonging and allows full freedom in participating in activities relating to the social, economic, and political spheres. ⁴⁶ Contextually, it enhances the realisation of the capabilities of everyone in respect of his/her character and aspirations as well as his/her meaningful belonging to or participation in the area of interest. In addition, due consideration and special treatment are necessary to advance the interest of those oppressed, excluded, or disadvantaged in order to integrate the diverse groups into equal opportunities available in their respective area of interest or spheres. ⁴⁷

The wording of section 71 of the NHA amounts to the social exclusion of orphans, and to a group of adolescents with a capacity of understanding, who may wish to act independently as they do when accessing other healthcare services.⁴⁸ This form of exclusion suggests 'the lesser worthy of those denied',⁴⁹ and this may further imply a violation of essential human rights.

Section 71 displays features of regulatory measures that are crafted from the norms held by the dominant groups in the society, while contrary discriminating the minority group.⁵⁰ According to the judge L'Heureux- Dube:

The more socially vulnerable the affected group is to having its most fundamental needs and concerns overlooked or discounted, and the more fundamental to the popular conception of personhood the characteristic which forms the basis of the distinction, the more likely that the distinction will be discriminatory'.⁵¹

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⁴⁶ Greschner, D (2002) 6:2 Reviews of Constitutional Studies 291 (the main purpose of equality is to protect the interest of belonging and not to exclude members of protected groups from the benefits of full membership in social, economic, and political life)

⁴⁷ Young, IM *Justice and the Politics of Difference* Princeton, NJ: Princeton University Press (1990)(who focuses on the concepts of domination and oppression).

⁴⁸ Strode & Essack, note 37.

⁴⁹ Reaume, D (2003) 63:3 Louisiana Law Review 686–689.

⁵⁰ Fredman & Spencer

⁵¹ Harksen's case.

Health research and healthcare services are interlinked; all healthcare products originate from research.⁵² Therefore denying children the right to participate in research is inseparable from violating their right to health.⁵³

(d) The Principle of Autonomy

Everyone deserves equal concern and respect of law irrespective of his/her age, race, or gender, they are all entitled to free will.⁵⁴ Section 71 of the NHA lacks the substantive inclusion of section 10 of the Children's Act which focuses more on the individual worth of the child; it recognises childhood as a developmental stage:

"Every child that is of such an age, maturity and stage of development" ... also respects the views expressed by the afore-defined child "that must be given a due consideration". This principle forms the basis of child self-determination conferred by the Children's Act. The potential autonomy of adolescent children is not fully recognized under section 71.

IV INFRINGEMENT OF THE CHILD'S CONSTITUTIONAL RIGHT TO BODILY INTEGRITY

The Court of Protection in *Mental Health Trust v DD* expounded that the infringement of the right to bodily integrity is 'exceptional' and appropriate only in 'the most extreme of circumstances'

.55 Is medical research so extreme that 'a child of age, maturity, and a capacity of understanding' is harmed to the extent that his or her right to bodily integrity is violated? Or does the catastrophic human experimentation during World War II still haunt research?⁵⁶

Despite the promulgation of ethical and legal guidelines that primarily aim to protect research participants while advancing healthcare services, the recruitment of vulnerable groups is still lacking in research.⁵⁷ Research involving human participants is conducted in a

⁵² CFR – Code of Federal Regulations Title 21. Chapter I, Sec 312. 21, phases of an investigation. See also Van Norman GA. 'Drugs, Devices and the FDA' *JACC Basic Transl Sci* (2016) 1 (3) 170–179. doi: 10.1016/j.jacbts.2016.03.002.

⁵³ Strode A, Richter M, Wallace M, Toohey J, Technau K Failing the vulnerable: Three new consent norms that will undermine health research with children *S Afr J HIV Med* (2014) 15 (2) 46–49. doi: 10.7196/SAJHIVMED.1014

⁵⁴ Freeman, MDA *The Ideologies of Children's Rights* (1992) 34–35.

⁵⁵ Mental Health Trust v DD [2015] EWCOP 4.

⁵⁶ Mellanby & Edical (1948) 25 British Medical Journal 148–150; Baumslag, N 2005 The Journal of Clinical Investigation 115:12 (Murderous medicine); Vanderbrook, An Imperial Japan's Human Experiments before and during World War Two Electronic Theses & Dissertations (2013) 2589. http://stars.library.ucf.edu/etd/2589 accessed on 15 August 2017.

⁵⁷ Winter SS, Page-Reeves JM, Page KA, Haozous E, Solares A, Nicole Cordova C, Larson RS. Inclusion of special populations in clinical research: important considerations and guidelines. J Clin Transl Res. 2018 Apr

top-down approach manner, from laboratory tests to recruitment of a small number of participants before mass recruitment, all take place under strict regulation by ethical review committees and clinical trial boards, ensuring minimal harm.⁵⁸ Thus, this makes it safe for anyone to be a participant in health-related research. However, the lawmaker is still of the view that research is a greater risk to children. This is evident by the high off-label use of treatment for paediatric care because few treatment options have been tested [researched] on children.⁵⁹

Furthermore, the legal dimension further strengthens the protection of patients or research participants. It confirms everyone's right to bodily and psychological integrity, which encompasses the right to security in and control over one's body. Furthermore, everyone has the right not to be subjected to experimentation of a medical or scientific nature without informed consent.⁶⁰ Everyone enjoys the right to bodily integrity, including children and those people with disabilities.

It is generally difficult to justify any interference with the right to bodily integrity. Like the right to privacy, the right to bodily integrity gives a special strength to a claim to autonomy, regardless of age. 61 Children's right to bodily integrity takes into account the stage of development of the child. 62 For matured minors, the meaning of the right to bodily integrity is of an autonomous nature allowing the matured minor to exercise such *right*. It is presumed that they bear decisional capacity which allows them to access information and make an informed decision. 63 Exercising bodily security in matured children is unnecessary and may be contrary to their interests. The bodily security dimension is largely relevant to a child who cannot participate meaningfully in matters affecting him or her. 64 Consequently, the exercise of *this right* predominantly prohibits any form of physical abuse, unnecessary medical treatment, and severe chastisement. 65 It confers protection on children who cannot fully

PMC2219860.

^{7;4(1):56–69.} PMID: 30873495; PMCID: PMC6410628. UyBico SJ, Pavel S, Gross CP. Recruiting vulnerable populations into research: a systematic review of recruitment interventions. J Gen Intern Med. 2007 Jun;22(6):852–63. doi: 10.1007/s11606-007-0126-3. Epub 2007 Mar 21. PMID: 17375358; PMCID:

⁵⁸ CFR – Code of Federal Regulations Title 21.

Chapter I, Sec 312. 21, phases of an investigation.

⁵⁹ Heather, L., Mullins-Owens, HL., Henderson, ML., & Henderson, J *Journal of Contemporary Health Law & Policy* (2012) 29 36–71.

⁶⁰ Section 12 Bill of Rights.

⁶¹ Herring, J and Wall J 'The Nature and Significance of the Right to Bodily Integrity' *Cambridge Law Journal* (2017) 76 (3) 566–588. doi:10.1017/S0008197317000605

⁶² Hill, BJ 'Constituting Children's Bodily Integrity' (2015) 64 Duke Law Journal 1295–1362.

⁶³ Ibid.

⁶⁴ Ibid.

⁶⁵ Ibid.

exercise their right to bodily integrity through informed consent.⁶⁶ In this manner, age differentiation [stage of development] amounts to fair or justifiable discrimination and is consistent with the purpose of promoting group equalisation, which prevents cases of individual protection or consideration of law to be brought into the courtroom.⁶⁷

Application of the right to bodily integrity in this manner shifts the claimed autonomy dimension from decisional capacity to having security in and control over one's own body. Upon reaching the age of understanding, a child has the right to make decisions regarding his or her body; no one has the right to touch or interfere with someone's body without their consent.⁶⁸

It is largely accepted that a person has a broad subjective experience of the world, far more than the standards and values systems which align him/her to conformity with those standards for the realisation of those values.⁶⁹ This experience of the world is also broader than the capacity a person has to make rational decisions, signifying a unique and broad basis of each person's moral duties. Therefore

'we owe duties to others on the basis of their interest in welfare or preference satisfaction, on the grounds of their human dignity and the aggregate of objective human thriving, or largely on the ground of substantive communitarian or relational basis of their decision making. ⁷⁰

A misunderstanding of a person's right to bodily integrity may be based on the fact that the multiplicity of our moral properties that make up our subjectivity, together with rationally inclined standards, preferences, and values, all have a single point of convergence, namely the body. This makes it relatively difficult to single out autonomy from well-being, and all other personal experiences because they are all located in the same place, which is the body. Our welfare, rational standards, and values are all experiential states that are 'identical'

⁶⁶ Ibid.

⁶⁷ J Donald C Galloway 'Three Models of (In) Equality' (1993) 38 McGill LJ 64 at 79–80).

⁶⁸ Feldman D Civil Liberties and Human Rights in England and Wales ((Oxford 2002 2nd ed. 241).

⁶⁹ Herring & Wall note 61.

⁷⁰ See e.g. Donner W. 'A Millian Perspective on the Relationship Between Persons and Their Bodies' in Cherry MJ (ed.) *Persons and Their Bodies: Rights, Responsibilities, Relationships* (Dordrecht 1999 61). See also Foster C Human Dignity in Bioethics and Law (Oxford 2011), 15; Mackenzie C 'Relational Autonomy, Normative Authority and Pe

rfectionism' (2008) 39 *J.Soc.Philos.* 512; Nedelsky J 'Reconceiving Autonomy: Sources, Thoughts and Possibilities' (1989) 1 *Yale J.L. & Feminism* 7; Oshana MAL 'Personal Autonomy and Society' (1998) 29(1) J.Soc.Philos. 81; Mackenzie C and Stoljar N (eds.), *Relational Autonomy: Feminist Perspectives on Autonomy, Agency, and the Social Self* (Oxford 2000).

⁷¹ Herring & Wall note 61

to the body. A state of pain, pleasure, success, or interactions with others are all located in the body. Moreover, singling out decision-making capacities from the body does not equate to the limitation of the right to bodily integrity because the rest of the relevant moral properties of the subject continue to be embodied properties.⁷³ Thus, it remains firm and demands non-interference. What is often overlooked is the position of the body in terms of its right to bodily integrity, even though the text clearly provides 'exclusive use of and control over their body'.⁷⁴ In this manner, the body is the focal point and medium where we experience all moral states [subjectivity] and rational agency that include a wide and all-inclusive right over our bodies.⁷⁵

The right to bodily integrity empowers a person to protect all these morally valuable states by conferring a right to his or her body to the exclusion of all others.⁷⁶ The right to bodily integrity is comparable to a property right because it literally and figuratively provides rigid walls or a fine filter to separate oneself from others.⁷⁷

Indeed, much self-fulfilment can be found by means of bodies interchanging and interacting with one another. Nevertheless, those interactions and interchanges are only meaningful and valued if they have been chosen, valued, and cherished by the individual.⁷⁸

If the right to bodily integrity did not exist and no subsequent right to exclude, there would be no need for the right to invite. .⁷⁹ Indeed, the rightful or accepted interaction through the body from general conversation to bodily touches is very fulfilling when being chosen, valued, wanted, or desired by an individual.⁸⁰ This cannot be said of sexual harassment, because the touching that was not invited could be soul-destroying.⁸¹ Parental intrusion into adolescents' use and control over their bodies is not 'invited' [by them] or desired by the children; consequently, it amounts to an infringement on children's right to bodily integrity.

⁷² Ibid.

⁷³ Ibid.

⁷⁴ Ibid.

⁷⁵ Carman, Merleau-Ponty, p. 141: 'Merleau-Ponty's alternative account rests on a recognition of the bodily medium of social perception, a medium common to myself and others, and which always already constitutes us as a community prior to our application of concepts such as mind and consciousness, which abstract from the bodily character of the person they describe' (emphasis added); Wall J *Being and Owning: The Body, Bodily Material and the Law* (Oxford Scholarship Online 2015 145–155).

⁷⁶ Cf Harris JW Property and Justice (Oxford 1996), 160; Penner JE The Idea of Property in Law (Clarendon 1997 71). See also Wall op cit note 75.

⁷⁷ Nedelsky J 'Law, Boundaries and the Bounded Self' *Representations* (1990) 30 162–189 at 167.

⁷⁸ Herring & Wall note 61.

⁷⁹ Ibid.

⁸⁰ Ibid.

⁸¹ Ibid.

A section 71 infringement of the right to bodily integrity affects the fundamental interest of children to participate fully in matters concerning them. According to the learned Judge L'Heureux- Dube, 'the more serious the consequences of the distinction, the more likely that the distinction will have an unfairly discriminatory impact'. Under the current Constitution, it is no longer acceptable to mete out oppressive or disadvantageous treatment to historically disadvantaged or socially vulnerable groups simply because they are not in a relatively privileged position. Instead, there should be to meet the needs of those who are socially vulnerable or disadvantaged and have been discriminated against. In this way, equal protection and benefit of the law are promoted.

V SUMMARY

Section 71 lacks a proper set of provisions or rules applying to research involving children. Power grants and restrictions are not properly balanced to provide protection and ensure the self-determination of children's rights. Moreover, the general principles that form the basis of children's rights have not been fully taken into consideration. Principles relating to children's age, level of maturity, and stage of development are generally provided to make any law or conduct meaningful to children. The denial of categorisation of children has led to age-based differentiation which fails the constitutionality test of the principles of equality. The discrimination of s 71 against the independent consent of children in health research lacks rational justification. It is overly restrictive, inconsiderate of the child's evolving capacity, and provides no exception where children with the capacity of understanding can exercise their right to participate in research independently. Consequently, the discrimination of s 71 is deemed to be unfair.

Poor crafting of the s 71 legislative mandate has further resulted in the violation of the right to bodily integrity since it has failed to account for the stage of development of the child when instituting a provision to participate in health research. As in the case of the right to privacy, the right to bodily integrity underscores any autonomy claim regardless of age; consequently, it is generally difficult to justify any intrusions on the right to bodily integrity. The basis of the 'exclusive use of and control over their body' takes into account that states of pain, pleasure, success, or interactions as properties are embodied in the body.

⁸² Harksen case.

⁸³ Ibid.

⁸⁴ Ibid.

LIMITATION OF CHILD'S CONSTITUTIONAL RIGHTS

I INTRODUCTION

Even though in the previous chapter it was established that s 71 infringes children's constitutional right to equality and bodily integrity, limitation of rights stands as a final arbiter for constitutional validity of impugned laws or conduct. The legislature may develop common law rules to restrict the right entrenched in the Bill of Rights; however, such prescribed limitations should be in accordance with constitutional provisions in section 36(1). Moreover, no other law may limit any right entrenched in the Bill of Rights.

The limitation of rights re-affirms that the law of general application can institute a limitation clause in the exercise of rights entrenched in the Bill; however, such limitations need to be reasonable and justifiable in any open and democratic society founded on human dignity, equality, and freedom.⁴ Any limitation needs to be consistent with the founding provision of the Constitution.⁵ However, the impugned section lacks coherence with democratic norms that are used to assess the constitutional validity of the imposed limitations. It fails the limitation of rights provisions from the outset because the rights in question, namely human dignity [self-determination, privacy], equality [age differentiation], and other freedoms are also the provisions used to justify limitations imposed by law or policy of 'democratic society based on human dignity, equality, and freedom' as per section 36(1). This submission is further justified by the fact that South Africa is not a 'closed, authoritarian society based on the violation of human dignity, equality, and freedom'.⁶

II NATURE OF THE RIGHT (SECTION 36(1)(a))

The right to bodily integrity is directly applicable to the participation of children in health research. Section 71(2)(c)–(d), as well as section 71(3)(a)(iii)–(iv), provide that the consent of parents or guardians is required for any research that is either therapeutic or non-therapeutic,

¹ BOR s 8: Application of rights.

² BOR, s 36(1): Limitation of rights.

³ BOR, s 36(2): Limitation of righs.t

⁴ Ibid, s 36(1).

⁵ Founding provision, s 1(a) 'Human dignity, the achievement of equality and the advancement of human rights and freedom'

⁶ Rautenbach I 'Proportionality and the limitation clauses of the South African Bill of Rights' *Potchefstroom Electronic Law Journal* (2014) 17(6), 2229–2267. https://doi.org/10.4314/pelj.v17i6.01

even when the child has a required capacity of consenting.⁷ This confirms the factual limitation of the right to bodily integrity, including the right to human dignity, equality, and privacy. These limited rights are the key provisions that must be always respected whenever the limitation clauses are imposed. As it is stated:

'The rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality, and freedom.'

As regards the nature of rights, it has been concluded by the court that limited rights are very important; that is why they are entrenched in the Bill of Rights.⁸ The abstract weight of the limited rights [human dignity, privacy, and equality] can be accorded a greater weight as a result of importance in the open and democratic society.

III IMPORTANCE OF THE PURPOSE OF THE LIMITATION (SECTION 36(1)(b))

The importance of the purpose of limitation as provided for in section 36(1)(b) can be determined by posing the question that interrogates the benefits offered by limiting the rights of children to self-determination in health research and why it is so important to achieve these benefits. It is difficult to answer this question because the legislative mandate of s 71 favours the category of children who lack the capacity to exercise their rights. In this manner, the limitation clause imposed is concerned only with the nurturance dimension of children's rights or protection. Of course, if children do not consent to research, they will not be exposed to research-related risks; consequently, they will be safe. However, the same cannot be concluded for those children who are able to consent independently by virtue of the fact that children are not the property of their parents or guardians nor are they helpless objects of charity, that parental authority is not absolute, and that it diminishes when a child acquires the capacity to

⁷ Section 71(2): 'Where research or experimentations to be conducted on a minor for a therapeutic purpose, the research or experimentation may only be conducted—

⁽a) if it is in the best interests of the minor;

⁽b) in such manner and on such conditions as may be prescribed;

⁽c) with the consent of the parent or guardian of the child; and

⁽d) if the minor is capable of understanding, with the consent of the minor.'

Section 71(3)(a): Where research or experimentation is to be conducted on a minor for a non-therapeutic purpose, the research or experimentation may only be conducted—

⁽i) in such manner and on such conditions as may be prescribed;

⁽iii) with the consent of the Minister;

⁽iii) with the consent of the parent or guardian of the minor; and

⁽iv) if the minor is capable of understanding, the consent of the minor.'

⁸ Rautenbach I note 6.

make his or her own decisions.^{9, 10, 11} This makes the imposed limitation clause unreasonable and non-justifiable in a society which is open and democratic as well as being based on human dignity, equality, and freedom.

IV NATURE AND EXTENT OF THE LIMITATION (SECTION 36(1)(c))

A discretionary limitation of rights in an authorising law is one of the means of limiting rights. The methods used for rights limitation should fall within constitutional ambits; therefore, the extent or limitation of the discretion is the significant component of right limitation clauses. The extent of the s 71 limitations is extremely narrow as the powers of children do not extend to carrying out the limitation. This is despite the use of informed consent as the method and instrument to limit the rights instead of applying the principles of informed consent to differentiate between children who need additional institutional protection [or parental/guardian protection] from those who can protect and promote their interests. Section 71 legitimises parent or guardian consent as the sole provision for protecting or promoting the interests of child participation in health-related research.

The s 71 limitation clause is intrusive regarding the interests that are protected or promoted in health research¹³ as there has been no evidence demonstrating that there is a negative effect if the limitation is not imposed on protecting and promoting the interests or rights of children in terms of health research. The anticipated negative effects of parental or guardian consent is not mandatory when a child has the capacity of understanding are seemingly illusive.

V RELATIONSHIP BETWEEN THE LIMITATION AND ITS PURPOSE (SECTION 36(1)(d))

Protection or promotion of children's rights to participate in research is marginally served by mandatory parental or guardian consent. According to the German weight formula. if the limitation is not capable of contributing to or marginally serving the purpose, it leads to a conclusion that 'not having imposed the limitation would have hampered only slightly the

⁹ United Nations Convention on the Rights of the Child (UNCRC).

¹⁰ Gillick v West Norfolk and Wisbech Area Health Authority and the DHSS 1985 3 All ER 402 (hereafter Gillick). See, in general, Bainham Children 346 et seq; Eekelaar 1986 LQR 4 et seq; Eekelaar 1986 OJLS 177 et seq; Human 2000 Stell LR 71 et seq; Robinson 1993 TRW 52 et seq.

¹¹ Gillick 421e and 423j.

¹² Rautenbach I note 6.

 $^{^{13}}$ Cohen-Eliya M and Porat I 'Proportionality and the culture of justification' *American Journal of Comparative Law* (2011) 59 (2) 463–490. doi:10.5131/ajcl.2010.0018

purpose of the limitation'. ¹⁴ Of course, any child of any age or stage of development lacking the capacity to consent independently would still be protected through the general provision of parental or guardian consent, and the interests of a mature child or some children who may wish to act independently would also be promoted, provided that a parental or guardian consent is not mandatory where the child has the required capacity for consenting. The limitation which is imposed advances neither protection nor promotion of children's participation in health-related research; instead, it infringes on the right to human dignity, privacy, bodily integrity, and equality. It is unconstitutional owing to its not being consistent with the general provision of limitation of rights, which 'must be reasonable and justifiable in an open and democratic society based on human dignity, equality, and freedom'.

VI ACHIEVING THE PURPOSE IN LESS RESTRICTIVE WAYS (SECTION 36(1)(e))

Section 71(2)(c)–(d) and subsection (3)(a)(iii-iv) provide two approaches to ensure that the purpose of promotion or protection of children from research-related harm is effectively realised. Nevertheless, the intensity of these approaches is extremely restrictive since they function in duality. The clause 'if the minor is capable of understanding, with the consent of the minor' correlates with less restrictive means and general norms that promote children's rights, particularly access to health services. ¹⁵

In an open and democratic society based on human dignity, equality, and freedom, it is 'reasonable and justifiable' to allow a child to consent independently on the condition that the child has developed the required ability of understanding. ¹⁶ The principle of informed consent is proportionate to the purpose of the limitation [protection, or promotion] based on various permissible ranges of consent set by the relevant institution. Independent informed consent of children with the capacity of understanding would result in less interference with the limited right. Thus, children's right to being secure in and having control over their bodies should be respected; they should not be participants in medical or scientific experiments unless they have been able to give their informed consent. ¹⁷

¹⁵ Strode A and Essack Z Facilitating access to adolescent sexual and reproductive health services through legislative reform: Lessons from the South African experience *SAMJ* (2017) 107 (9) 741–744.

¹⁴ Ibid.

¹⁶ Kruger H 'The Protection of Children's Right to Self-Determination in South African Law with Specific Reference to Medical Treatment and Operations' PER/PELJ (2018) (21) 26.

¹⁷ Freedom and security of the person. Section 12(2) 'Everyone has the right to bodily and psychological integrity.'

Self-determination through informed consent has been gradually endorsed in South African jurisprudence since *Castell v Greef*.¹⁸ Subsequently, *In C v Minister of Correctional Services*,¹⁹ the court ruled that informed consent gives effect to self-determination; which is paramount in order for one to enjoy the right to freedom, inherent dignity, privacy and bodily autonomy.²⁰ Moreover, the court has maintained that the informed consent of a child under the age of 18 years is valid and constitutional. In *Teddy Bear* Case, it was held that

'[t]he cornerstone of the regulation of the termination of pregnancy of a girl and indeed of any woman under the Act is the requirement of her "informed consent". No woman, regardless of her age, may have her pregnancy terminated unless she is capable of giving her informed consent to the termination and in fact does so'.

Christian Lawyers' Association v National Minister of Health and Others applauded the fact that the Choice on Termination of Pregnancy Act provides more explicit provisions that affirm the right to self-determination of any woman of any age.²¹

It would be unconstitutional for s 71 to silence the primacy of the provision if the minor has the ability to understand and to give his or her consent. The provision of the less restrictive clause means giving effect to self-determination in children who are under the age of 18 years. Seemingly, the impugned section legitimised the particular claims of the plaintiff in *Christian Lawyers' Association v National Minister of Health*, which failed to disclose the cause of action, and the plaintiff claimed that girls who are under 18 years are incapable of giving their independent consent to an abortion. ²² The plaintiff was of the view that rigid age-based regulation must be instituted and that the best interest of the child is solely dependent on the parent. This indicates that s 71 lacks the view that informed consent embraces the right to self-determination for children who are capable of demonstrating the emotional and intellectual capacity to understand and appreciate any risk associated with health research.

The child's best interest further demands less restrictive means that protect and promote children's participation in health-related research. It is important to stress the universal

¹⁸ Ackermann J on behalf of the full bench of the CPD) in Castell v De Greef (1994) (4) SA 408 (C) (supra) made it clear that the ratio for that requirement was to give effect to the patient' fundamental right to self-determination. At 4203 J the court said that it was 'clearly for the patient to decide whether he or she wishes to undergo the operation, in the exercise of the patient's fundamental right to self-determination'.

¹⁹ *C v Minister* of Correctional Services (1996) [27] (4) SA 292 (T).

²⁰ Ibid. at 300.

²¹ Christian Lawyers' Association v National Minister of Health and Others (2004) (10) BCLR 1086 (T) page 8 'Perspective of the right'.

²² Ibid.

nature of section 28 (2) of the Constitution, namely that 'a child's best interests are of paramount importance in every matter concerning the child.' This right is both a stand-alone and a guiding principle in all matters concerning children.²³ The child's best interest and the capacity of consenting in health research are poorly described in the Department of Health (DOH) Ethical Guidelines.²⁴ The absence of legal references such as court rulings or review or acknowledgment of the legal practitioner in these guidelines may justify the indication of minimal comprehension in terms of respecting, protecting, and promoting children's rights.

In addition, the provisions of home affairs regarding detention and deportation of unaccompanied foreign children in *C* and *Centre for Child Law* were regarded as contrary to the child's best interest because they were inflexible and unable to accommodate the circumstances of these children.²⁵ To summarise, the relevance of section 28(2) applies beyond the case-by-case of a particular child as it is also used as a principle to ensure that children's rights are respected, protected, and promoted. ²⁶

Assuming that a mere statement cannot be sufficient to justify impugned provisions as it was held in $S \ v \ Steyn$, 27 an additional investigation based on the Regulations relating to Research with Human Participants and the Department of Health (DOH) Ethical Guidelines concluded that there are no less restrictive provisions that allow child independence. Even though the DOH Ethical Guidelines recognise the importance of independent consent of adolescent children, no robust provisions have been made. 28

VII DISCUSSION

(a) Right to Equality

The equality debate is a very sensitive topic in South Africa. The central theme of our Constitution is equality, which is laid out in the preamble, Chapter one, and intensively in the Bill of Rights, thereby emphasising the transformative mission where the State and government ensure that the law protects every citizen equally. In this study, it has been established that

²³ Minister of Welfare and Population Development v Fitzpatrick and Others [2000] ZACC 6; 2000 (3) SA 422 (CC); 2000 (7) BCLR 713 (CC)at paras 17–8

²⁴ Makubalo L, Ratsaka-Mothokoa M, Bannenberg, W, Zijl, S & Cleaton-Jones, P Ethics in Health Research: Principles, Structures and Processes (Department of Health 2004).

²⁵ Minister of Welfare and Population Development v Fitzpatrick and Others [2000] ZACC 6; 2000 (3) SA 422 (CC); 2000 (7) BCLR 713 (CC)at paras 17–8

²⁶ Skelton A 'Constitutional Protection of Children's Rights' in Boezaart T ed. *Child Law in South Africa* (2007) (2nd ed 327–358).

²⁷ Steyn v S (2009) ZASCA 152; SACR 411 (SCA) para 37.

²⁸ DOH Ethical Guidelines 3.2.2.4 Minors' independent consent.

s 71 differentiates on the grounds listed in s 9(3), and adversely impairs in a serious manner fundamental human dignity and the right to bodily integrity. As much as s 71 legislators may contend that the imposed differentiation has a rational connection, the law or conduct in question may still amount to unfair discrimination.²⁹ Section 71 provisions are deemed unfair because the differentiation is linked to two patterns of past discriminatory practice: socially vulnerable groups, and violation of their rights. The whole of s 71 views children as subordinate to their parent/s or guardian/s. This is entirely inconsistent with the right to equality which stipulates that everyone is equal before the law and everyone has the right to equal protection and benefit of the law. The view of children's rights in this manner has failed constitutional endorsement on numerous occasions. Children are bearers of their own individual rights, not mere extensions or possessions of their parents. The right to equality demands that any law must be designed to ensure that everyone enjoys full and equal benefits of all rights and freedoms, in order to redeem the unfair discrimination. Children require special provisions to enjoy the protection and benefit of the law equitably.³⁰

Disregarding children's right to equality constitutes an impairment of a serious nature by allowing parent/s or guardian/s to cross over a physical and psychological barrier to control the right to bodily integrity of the child. The magnitude of discrimination is intrusive because parental or guardian consent is mandatory in all stages of development of every child [toddler or adolescent]. Therefore, this means that parents exercise unjustifiable control over the dignity and privacy of the child. Section 71 denies children their rights, even under circumstances where the child has the capacity of understanding. This is unreasonable and unjustifiable in an open democratic society which values human dignity, equality, and freedoms. This concludes the argument that the limitation clause cannot establish the fairness of the infringement that arises from s 71.

(b) Right to Bodily Integrity

The right to bodily integrity is often viewed from the autonomy perspective that autonomous choices of people can be limited, and such limitations are justified based on competing values. In addition, when a person loses autonomy or lacks the capacity to act autonomously, someone else makes decisions on his or her behalf based on the best interest criterion. Section 71 of the

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²⁹ Freedman W 'Understanding the Right to Equality' SALJ (1998) 115 243–251.

³⁰ https://www.unicef.org/child-rights-convention/child-rights-why-they-matter#:~:text=Children% 20are% 20neither% 20the% 20property, subject% 20of% 20their% 20own% 20rights.&text=The% 20Convention% 20recognizes% 20the% 20fundamental, their% 20well% 2Dbeing% 20and% 20development.accessed 10 May 2021

NHA is literally written in this manner, thus overlooking that the right to bodily integrity is non-reducible to the 'principle of autonomy' and is not lost when autonomy is lost.³¹ Instead, any infringement [competing interest] must meet criteria of considerable moral weight and practicable urgency. The Mental Capacity Act 2005 is a good example that provides all-encompassing provisions in applying effective additional justification to infringe the right to bodily integrity on the body of the person lacking capacity.³²

The respect for autonomy does not necessitate the right to bodily integrity as there is no right to act autonomously but there is a morally relevant property which is morally relevant and which requires to be considered in all matters relating to moral deliberation.³³ The principle of autonomy plays a fundamental role in all-encompassing rights and duties regarding a range of legal issues, while the right to bodily integrity is a specific common law right, similar to the right to privacy.³⁴ It is our moral and legal right to be able to use and control our bodies. It draws legal effect from criminal provisions and tortious actions,³⁵ by conferring that everyone has the right to the exclusive use of and control over his or her body. Moreover, the right to bodily integrity is protected by excluding all others, and further imposing duties of non-interference from a third party.³⁶

The narrow understanding of the depth of the right to bodily integrity could be the only reason to justify that a parent has an absolute right to decide on the participation of a child in health research. This correlates with the view that the right to bodily integrity is commonly interpreted as the right to respect the autonomous act of a person regarding the use of his/her body. However, we have learned from the previous chapter that the right to bodily integrity is far more than mere respecting a person.

The right to bodily integrity confers strict non-interferences, disregarding any form of relationship. Even physically punishing a child is considered a breach of the right of bodily integrity.³⁷ The exclusivity of this right is supreme; parent/s do not have the right to

³¹ Herring J and Wall J 'The Nature and Significance of the Right to Bodily Integrity' *Cambridge Law Journal* (2017) 76 (3) 566–588. doi:10.1017/S0008197317000605

³² Coggon J 'Mental capacity, law, autonomy, and best interests: An argument for conceptual and practical clarity in the Court of Protection' *Medical Law Revie*, 24 (3) (2016) August 396–414. https://doi.org/10.1093/medlaw/fww034

³³ Cornell Law School Legal Information Institute 'Personal Autonomy' https://www.law.cornell.edu/wex/personal_autonomy accessed 3 July 2021

³⁴ R. (on the application of Nicklinson) [2013] EWCA Civ 961; [2015] 1 A.C. 657, at [50].

³⁵ Herring & Wall note 31.

³⁶ Currie I and De Waal . *The Bill of Rights Handbook* (Cape Town: Juta 2005 287).

³⁷ A v UK.

interfere with the right to bodily integrity, not only in the form of harassment but also including disciplinary purposes.

The right to bodily integrity is not equivalent to respect for a person owing to its being premised on a moral basis.³⁸ If the right to bodily integrity of a child was reducible, or absolutely controlled by parents or guardians, no child would freely engage in an intimate relationship without the consent of the parent or guardian, bearing in mind the consequences that go with sexual conduct; which range from typical sexually transmitted diseases to more burdensome diseases such as HIV/AIDs, pregnancy, and costs related to accessing reproductive health products. But still, no parent or regulator has the right to prohibit teenage intimate relationships. Instead, less restrictive means are considered. In the *Teddy Bear* case, the court suggested various less restrictive means that include comprehensive sex education that should be instituted towards reducing risky sexual behaviour by teenagers.³⁹ The nature of such limitation does not infringe using and controlling the bodies of teenagers exclusively and is within the constitutional ambit.

VIII SUMMARY

Section 71 infringement of the right to equality and bodily integrity cannot be justified through analysis in terms of section 36. The limitations imposed are highly restrictive, unreasonable, and unjustifiable in an open and democratic society which is founded on human dignity, equality, and freedom. Section 71 is restrictive in the sense that no less restrictive provisions that allow child independent consent have been set forth, particularly for maturing children. This is inconsistent with the child's best interest principle as set out in the Constitution, and further elaborated on in the Children's Act and child-related movements such as UNCRC. It is unreasonable and unjustifiable because the child's independent consent is acceptable and legal in the access of healthcare services. Lastly, children are not treated as individual rights-bearers since the parent stands as the final decisional maker and encroaches on the use and control of the body of the child. In conclusion, section 71 of the National Health Act is unconstitutional.

³⁸ Herring & Wall note 31.

³⁹ Teddy Bear Clinic for Abused Children and Another v Minister of Justice and Constitutional Development and Another (CCT 12/13) [2013] ZACC 35; 2013 (12) BCLR 1429 (CC); 2014 (2) SA 168 (CC); 2014 (1) SACR 327 (CC) (3 October 2013) 'Less restrictive means' para 95–101.

I SUBMISSIONS AND FINDINGS

In this study, I submitted that section 71 of the NHA infringes children's right to equality and bodily integrity. After the substantive examination of children's rights, I found that it was unconstitutional for s 71 to violate the right of the child to equality and bodily integrity, together with other rights contained in the Bill, such as human dignity and privacy. In addition, their right in terms of section 28(2) of the Constitution is not treated as being of paramount importance in consideration of their participation in health research.

After establishing that the constitutional rights of children to equality and bodily integrity have been limited, I further engaged in a justification analysis in terms of section 36 as per the general requirement regarding limitation of rights contained in the Bill and as an acknowledgment of the fact that there may well be legitimate reasons for the limitation of a child's fundamental rights to protect him or her under particular circumstances in light of the stage of development. But, before endorsing any form of limitation, I premised the jurisprudence approach that children are bearers of their own individual rights rather than being mere extensions or possessions of their parents as per the Court ruling in *S v M (Centre for Child Law as Amicus Curiae)*.

It was established in S v M that there was no justification for the imposed limitations that restrict the child's independent consent in terms of section 36 of the Constitution and as a result of lack of evidence from National Regulations on research that involves human participants and the Department of Health Ethical Guidelines. The limitations imposed were highly restrictive, unreasonable, and unjustifiable in an open and democratic society which is founded on human dignity, equality, and freedom as a result of silencing the less restrictive means provisions that could have been used so that the child may exercise the right to equality and bodily integrity if participating in health-related research.

I found that the extent or breadth of these provisions intended for the protection of children in health-related research is harmful to the child. The instituted encroachment of parent or guardian on the decision of the child with a required capacity of understanding which also translates to the ability of independent consent is at variance with the best interest

principle. The independent child consent alone is deemed sufficient in the various juristic acts that promote the child's access to health care services and reproductive services.

II SUMMARY

(a) Right to Equality

Direct discrimination on the listed ground of age infringes the right to equality which is guaranteed in section 9 of the Constitution. This is deemed unconstitutional because the provision that aims to promote equal treatment and benefits of the law has not provided for children with the capacity of understanding. In addition, this discrimination entrenches the direct violation of section 27 of the Constitution [which includes access to health care services and reproductive health care], as it may lead to the use of unlabelled health products without safety and efficacy data that justify their use on children.

(b) Mandatory Parental or Guardian Consent

Mandatory parental or guardian consent for all children (including adolescents) violates the right to bodily integrity. This right confers strict non-interference. The exclusivity of this right is supreme; parent/s do not have the right to interfere with the right to bodily integrity, not only in the form of harassment but also including disciplinary purposes. However, the Act has instituted the invasion of a child's human dignity and private realm without due consideration.

(c) Section 71 Provisions or Limitations Clause

The s 71 provisions or limitations imposed cannot be justified by section 36 of the Bill of Rights since the rights limitation is the Constitutional guideline. Therefore, s 71 of the National Health Act is unconstitutional.

III STUDY CONTRIBUTIONS

This study consolidated evidence justifying the non-constitutional basis of the impugned section, clarified the interpretation and the practical application of s 71 provisions to enrol children in health research with regard to their fundamental human rights, and suggested measures to further its commitment to promote research and protection of children participating in research.

IV RECOMMENDATIONS

This study recommends a court review of section 71 of the NHA followed by an amendment to ensure that the impugned section is consistent with the Constitution, 1996. The amendment of s 71 will ignite the robust right to health for all and give full meaning to section 28(1)(c) [basic health care services] of the Constitution and the scientific advancements contained in the Children's Act. The provision of the less restrictive means to regulate research involving children will encourage more research that promotes access to safe and effective medical interventions for children.

V LIMITATIONS

The research setting of this study was confined to a qualitative approach which limited the research findings on readily available data. The medicolegal argumentative discussion provided in this study was solely based on public and freely available data. Therefore, the most recently published literature available on purchases that may have strengthened or influenced outcomes of the constitutional validity of s 71 of the NHA was not considered.

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Bill of Rights: s 28(2), (3)

Bill of Rights: s 36

Bill of Rights: s 37

Bill of Rights: s 39

Section 7

Section 172

Children's Act 38 of 2005

Section 6: General Principle.

Choice on Termination of Pregnancy Act 92 of 2007

National Health Act 61 of 2003

Section 71

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APPENDIX

I. ETHICAL CLEARANCE CERTIFICATE



Founding Corrouses # Edgewood # Howard College

Medical School
 Pletermanitzburg
 Wastville