INCLUSIVE EDUCATION FOR CHILDREN ON MOBILE OXYGEN: ETHICAL AND LEGAL ISSUES

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DECLARATION

I, Omphile Tshegofatso Mekgoe (Student number 0420060e), declare that this report titled 'Inclusive Education for Children Carrying Mobile Oxygen: Ethical and Legal Issues' submitted for the degree MSc Med (Bioethics and Health Law) is my own unaided work. I have followed the required conventions in referencing the thoughts and ideas of others. This report has not been submitted prior to this date for any other degree or examination at this or any other university.

Signed:

Date: 15 / 09 / 2021

DEDICATION

This is dedicated to all children with special needs who are not able to access main stream schools.

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ABSTRACT

In 2001, the government implemented Inclusive Education (IE), with the aim of integrating children with special needs in mainstream schools. However, the guidelines on IE that were put in place to implement the system, including other school guidelines from Department of Education, do not include learners with chronic lung disease carrying mobile oxygen.

To answer the research question, ‘Is it ethically justifiable to exclude children carrying mobile oxygen in school guidelines?’, I searched for literature on children carrying mobile oxygen, both nationally and internationally. I also explored the legal framework with regard to the right to education and integrating children with special needs in mainstream schools. I reported that the right to basic education is a fundamental right. Everyone has the right to education without being discriminated against and any kind of discrimination is unlawful and unethical.

I applied the Utilitarian and Deontology moral theories, and focused on Kant’s Categorical Imperative to support the argument, it is unethical to exclude learners carrying mobile oxygen in the school guidelines. I also used ethical principles such as autonomy, maleficence, non-maleficence, and justice to support my assertion. The implications of excluding children carrying mobile oxygen in school guidelines is also discussed.

I conclude that everyone has the right to basic education. It is the responsibility of the state to make sure that the 4As of the right to education, i.e., availability, accessibility, adaptability and acceptability, are achieved. Therefore, children carrying mobile oxygen must be included in the school guidelines like all other children with other barriers to learning have been included.

LIST OF ABBREVIATIONS

AIDS: Acquired Immune Deficiency Syndrome
BOR: Bill of Rights
BTS: British Thoracic Society
CRC: Convention on the rights of children
CRDP: Convention on the Rights of Persons with Disabilities
CESCR: Committee on Economic, Social and Cultural Rights
DBE: Department of Basic Education
DOE: Department of Education
DOH: Department of Health
HIV: Human Immunodeficiency Virus
HOD: Head of Department
ICESCR: International Convent on Economic, Social and Cultural Rights
IE: Inclusive Education
ISHP: Integrated School Health Policy
MEC: Member of the Executive Council
NSNP: National School Nutrition Programme
RSA: Republic of South Africa
SA: South Africa
SACE: South African Council for Educators
SMT: School Management Team
TB: Tuberculosis
UDHR: Universal Declaration of Human Rights
UN: United Nations
UNCRC: United Nations Convention on the Rights of the Child
UNCRPD: United Nations Convention on the Right of Persons with Disabilities
UNESCO: United Nations Educational, Scientific and Cultural Organization
UK: United Kingdom
WHO: World Health Organization

CHAPTER 1 - BACKGROUND AND LITERATURE REVIEW

1.1 Background and Literature Review

In 2001, the government White Paper 6, implemented the Inclusive Education (IE) system (Department of Education, 2001) in order to integrate children with special needs in mainstream schools. Inclusive Education is outlined as:

'Transforming the education system to effectively respond to and support learners, parents and communities by promoting the removal of barriers to learning and participation in that education system in an incremental manner' (Department of Education, 2015: p7).

This meant putting educational support systems in place at ordinary schools so that learners with barriers to learning could attend mainstream schools. Barriers to learning refer to 'any difficulty that arises within the educational system that might prevent a learners' access to learning and development' (Department of Education, 2010; p6). Some of the barriers include, no ramps for children on wheelchairs and teachers not knowing that a child with diabetes might need frequent breaks to get a snack. Nine years after the inception of IE in 2001, there was progress made in implementing the IE system and removing barriers to learning (Department of Education, 2010), but the system is still far from reaching the target set.

I had an encounter with two children of school going age at a clinic I work at who were not attending school because they suffered from chronic lung disease. They could not attend school because of mobile oxygen cylinders they had to carry to school and the lack of awareness by the principal and teachers with regard to assisting the children in an emergency situation. Also, News 24 published a relatable story of a six-year-old child with chronic lung disease, who was on mobile oxygen (Health24, 2018). In an attempt to highlight the plight of this state of affair, the child's mother highlighted the lack of a supportive environment in schools surrounding their area as a reason for not sending her child to school (Health24, 2018). As a result, the mother had been searching for a special school for her child to gain access to basic education.

Schools prevent children living with this condition from having access to the schools because they have to be under the care of teachers, headmasters and School Management Teams (SMTs) once they are within the school premises. If the teachers, headmasters and SMTs lack the knowledge of how to deal with children living with such conditions especially in a state of an emergency, they will not accept the children into school and take responsibility for them. Regardless of this, the question of whether or not it is fair for these children not to attend school because there are no systems in place for them remains. This question is pertinent for the children who are mentally competent to attend mainstream school. The challenge is not only unique to the three children mentioned above, but to other children who are not able to attend schools for the same reasons, as indicated by some of my colleagues. This is particularly evident in children from rural areas (Hall, 2018).

The main function of the lungs is for gas exchange. This means that oxygen enters the blood, and carbon dioxide leaves the blood through the lungs. This function is compromised in children who have chronic lung disease. This results in a state of decreased amount of oxygen in body tissues, called hypoxia. Children with chronic hypoxia end up with suboptimal growth, impaired cognitive and behavioural function, and reduced quality of life among other things (Field et al., 2009). Depending on the severity of the disease, some children may need oxygen therapy continuously and others may only need it when they sleep (Field et al., 2009). Those who need continuous oxygen therapy, have to carry mobile oxygen cylinders everywhere in order to continue with their normal daily activities. This is an effort to counteract the effects of the poor supply of oxygen on the children, for example, poor growth (Field et al., 2009).

According to the World Health Organization (WHO, 2018), chronic lung diseases are defined as ‘a group of chronic diseases affecting the airways and the other structures of the lung’. This means the patient has a disease or illness that affects the lungs and causes damage to the structure of the lungs. As a result, the lungs are unable to perform their function, resulting in difficulty breathing. Causes of chronic lung diseases in children include: respiratory disorders experienced by a new-born infant, most commonly those born prematurely (Abman et al., 2017); children born and living with HIV (Zar, 2008); disease like Tuberculosis (TB); Bronchiectasis and Lymphocytic

Interstitial Pneumonitis (Zar, 2008); and genetic causes like Cystic Fibrosis (SATC, 2017).

South Africa (SA) has children living with chronic diseases, which include diabetes, chronic lung diseases, and congenital heart diseases. According to unpublished data, a pulmonology clinic audit in one of the tertiary hospitals in SA revealed that 15% of children on mobile oxygen were of school going age, between six and eighteen years. However, it is unknown how many of these children are attending school.

While there is some literature on children with physical and mental disabilities, there is a dearth of information on children with chronic medical conditions. Furthermore, there is minimal literature on children who are oxygen dependent. In a study of more than a thousand children, only one child was on mobile oxygen amongst the children that had chronic conditions with disabilities and were accessing specialist health and special educational services in the Western health sub-district of Cape Town (Redfern, Westwood and Donald,2016).

Children with chronic lung diseases carrying mobile oxygen have two main challenges. First, health related issues due to the primary disease making them require mobile oxygen. Second, the ability to go to school while carrying oxygen. The United Kingdom (UK) and Scotland (BTS Guidelines, 2009; NHS, 2010) have clear school guidelines that cater for children who carry mobile oxygen. The guidelines accommodate children from when the decision is made for them to use mobile oxygen, and includes what needs to be done at home and in schools. The aim of the guidelines is for the child to maintain mobility and independence. However, in SA, available guidelines are on the implementation of Inclusive Education (Department of Education, 2010). The integrated school health policy (ISHP) only gives guidelines on how to have a health policy in schools but not guidelines on the actual policies themselves (Department of Health and Department of Basic Education, 2012), while the Department of Basic Education (DBE) goes further to give guidelines to teachers on most childhood chronic illnesses, such as asthma, epilepsy, and allergies (Education, 2009). Regrettably, all these guidelines do not address children with chronic lung disease carrying mobile oxygen.

The lack of inclusivity of children on mobile oxygen in the ISHPs by the DBE is the reason children living with this condition fail to go to school. This lack of inclusivity in the DBE guidelines results in the failure of headmasters, SMTs and teachers to accommodate these children because they lack the capacity and awareness to cater for the children with chronic lung diseases. Regardless of this, it cannot be ignored that this goes against the human rights of these children. Children with chronic lung diseases have the right to basic education, as outlined in section 29 (1)(a) of the Constitution of the Republic of SA (RSA, 1996a). Section 9(3) of the Bill of Rights (BOR) also prohibits the discrimination of anyone on any grounds, including disability and social origin (RSA, 1996a). Furthermore, Section 5(1) of the Schools Act of (1996b) states ‘a public school must admit learners and serve their educational requirements without unfairly discriminating in any way’.

It is clear that children who are living with chronic lung diseases and carry mobile oxygen, are discriminated against and denied their right to basic education which is against the law. These acts are in contrast with the concept of IE implemented in 2001. Section 3(1) of the Schools Act (1996b), makes it the parents’ responsibility to make sure their children compulsory attend school from the first day of starting school until they reach fifteen years or grade nine. Section 5 (a) and (b) of the same Act compels ‘the Head of the Department (HOD) to investigate the circumstances and remedy the situation, if the learner who is subject to compulsory attendance is not enrolled at or fails to attend school’ (RSA, 1996b).

In every decision made that concerns a child, the best interest of the child must always be of paramount importance, according to both Section 9 of the Children’s Act (RSA, 2005) and Section 28 (2) of the Constitution (RSA, 1996a). By law, it is the responsibility of the state to ensure children get their basic education, as it is also in the child’s best interest. The state has a legal obligation, to follow the law and make it possible for children carrying mobile oxygen to be in school. There is also a moral obligation on the state to enforce these laws, otherwise, it is against the principle of non-maleficence and justice for these children (Beauchamp & Childress, 2013).

My report focused on IE for children living with chronic lung diseases, that are stable and not acutely ill, and carry mobile oxygen. The report demonstrated that these

children are excluded in guidelines for IE and showed the effect this has on them and the society as a whole.

1.2 Research Question

Is it ethically justifiable to exclude children carrying mobile oxygen in public schools?

1.3 Rationale for the Study

The implementation of IE allowed the state to set guidelines for inclusivity in schools (Department of Education, 2010). For example, using real objects and pictures for learners who are struggling with learning Mathematics; and multilevel teaching, whereby different methods of learning and teaching are used in one lesson, so that all children understand the lesson (Department of Education, 2010). Additionally, there are school guidelines for children with physical disabilities, such as building ramps for children on wheelchairs and guidelines for children with chronic medical conditions (Department of Education, 2009).

Furthermore, guidelines help teachers recognise important danger signs in some chronic medical conditions like diabetes mellitus and HIV infection, and the actions to take should the need arise. Nonetheless, there are no specific guidelines for children carrying mobile oxygen and hardly any ethical or legal inquiry in SA, which attempts to tackle the issue of school going children carrying and using mobile oxygen on school premises. In my opinion, health care extends beyond health care facilities and thus should be accommodated in non-health environments.

The rationale for my study was to advocate for the inclusion of policies consistent with ethical and legal regulatory framework to ensure these groups of children are catered for in schools. This is in light of Section 9 of the Constitution which commits the state to achieve the right to equality (RSA, 1996a).

1.4 Thesis

I argued that children carrying mobile oxygen have a right to basic education without being discriminated against, and therefore IE should include children carrying mobile oxygen.

1.5 Research Aim

The aim of my study was to advocate for the inclusion of specific guidelines for children caring mobile oxygen in schools.

1.6 Research Objectives

My main objectives were:

1. To explore the legal framework of integrating special needs children in mainstream schools.
2. To explore the ethical framework of integrating special needs children in mainstream schools
3. To discuss the ethical implication of non-inclusion of children on mobile oxygen in school guidelines.

1.7 Research Design

The research design was normative with a legal component and the study was based on desktop and library-based research. There was no empirical component to the study. I employed typical research methods and standards applicable to philosophical research. Literature sources used included International and National Guidelines on education of children, research articles and other academic search engines like google scholar. Literature findings were analysed using both international and national framework. Literature findings were also ethically analysed using normative theories and principalism.

1.8 Research Methods

The research question I addressed was 'Is it ethically justifiable to exclude children carrying mobile oxygen in public schools?' and the most important premise of my argument was that children have a right to education.

I reviewed the school guidelines available. I then reviewed what the constitution says, with regard to children's right to education and the right to health (RSA, 1996a). I also evaluated other legal frameworks related to this topic, such as the Children's Act (RSA, 2005) and the School Act (RSA, 1996b).

I used some moral theories to support the claim that it is unethical to exclude children on mobile oxygen in public mainstream schools. I defended my research by using deontology, with a focus on human rights and drawing from Kant's Categorical Imperative. The categorical imperative is expressed as: 'Act only according to that maxim by which you can at the same time will that it should become a universal law' (Rachels & Rachels, 2019: p137). I used this theory to show that excluding these children would affect their personal autonomy.

I also used Principlism, to argue my research (Beauchamp & Childress, 2013). The exclusion of children on mobile oxygen in the school guidelines, will ultimately cause harm to them. This exclusion goes against the principle of justice and the principle of non-maleficence, which says 'one ought not to inflict harm' (Beauchamp & Childress, 2013: p152).

1.9 Ethics

I applied for an ethics waiver as the study was purely a normative study. There were no participants involved in this study.

1.10 Research Outcomes

I revealed that there was lack of school guidelines that support learners on mobile oxygen. Also, I advocated for the state to have clear written guidelines for the caring of learners on mobile oxygen in schools.

1.11 Limitations

Lack of prior research studies on the topic, showing the need for further research on the topic.

CHAPTER 2 - SCHOOL GUIDELINES FOR CHILDREN ON MOBILE OXYGEN

2.1 Introduction

The main function of the lungs is gas exchange. This function is compromised in children who have chronic lung disease and results in a state of decreased amount of oxygen in body tissues, called hypoxia. Depending on the severity of their disease, some children may need supplemental oxygen therapy continuously (Field et al., 2009). The children who need continuous supplemental oxygen, need to carry mobile oxygen while performing their normal daily activities. This is done in an effort to counteract the effects of poor oxygen supply, for example, poor growth (Field et al.,

2009).

2.2 Portable Oxygen Delivery Systems for Ambulatory and Cognitively Competent Children

In an acute setting, there are signs that show that a child has hypoxia and needs oxygen. It is important for the caregivers, the child and the teachers in school to recognise these signs. The signs include cyanosis, a bluish discoularation of the lips and sometimes hands, fast breathing, shortness of breath, fast heart rate and sweating (WebMD). The caregiver or teacher must be able to realise that the child needs assistance when they notice the above mentioned signs in a child.

There are three different sources of oxygen delivery systems that have portable versions. These systems for ambulatory use are oxygen concentrator, portable oxygen cylinder and liquid oxygen. The oxygen concentrator concentrates the oxygen content of normal room air and it uses electricity (Adde F.V. et al, 2013). Also, there is a portable system that is battery operated and is easy to carry around, weighing about 2.3kg or less (Healthcare Afrox). The child can carry this system in a backpack. However, guardians need to make sure the battery is fully charged before the child goes to school.

The portable oxygen cylinder device does not use electricity, nor need a battery (Adde F.V. et al, 2013). It is lightweight, weighing less than 2kg (Healthcare Afrox). It is easy to carry around and can be carried in a backpack. Lastly, liquid oxygen, it can be stored in a device that has the capacity to hold many litres of oxygen. All these portable oxygen delivery devices can deliver oxygen via nasal cannula or face mask.

A nasal cannula device is commonly used. It is made up of lightweight tube with a set of two prongs that rest on a patient's nostrils at one end (Walsh & Smallwood, 2017). The prongs deliver the oxygen. They are secured by hooking the tube around the ears of the user and connect to the portable oxygen device. The face mask device is shaped to fit over the user's nose and mouth. It has a narrow plastic tubing fixed to the bottom of the mask and connects the mask to the portable oxygen device to deliver oxygen (Encyclopedia.com). The mask is held in place by adjustable elastic bands connected to each side and slides over the head and above the ears.

Oxygen is safe if used appropriately and the guidelines given followed correctly. It is important to note that oxygen itself, is not flammable, but it does accelerate a fire source. Smoking inside homes or anywhere near the child is prohibited. The child must not be in contact with fire sources, such as candles, stove burners, and cigarettes (Adde F.V. et al, 2013). The oxygen tubing for all portable oxygen devices is of various lengths. Thus, it is important to take care that the child or other children in class do not trip over the tubing.

Any child who is cognitively competent should be able to use mobile oxygen on their own. While using these mobile oxygen devices, the children can be independent and live an unrestricted life. As such, children carrying mobile oxygen should be allowed to attend schools.

2.3 School Policies and Guidelines

As outlined earlier in the report, IE is:

'Transforming the education system to effectively respond to and support learners, parents and communities by promoting the removal of barriers to learning and

participation in that education system in an incremental manner' (Department of Education, 2015: p7).

This means placing educational support systems in ordinary schools in place, so that learners with barriers to learning are able to attend mainstream schools. Barriers to learning refer to 'any difficulty that arises within the educational system that might prevent learners' access to learning and development' (Department of Education, 2010: p6). Barriers include, no ramps for children on wheelchairs, and teachers not knowing that a child with diabetes might need frequent breaks to get a snack.

The focus of inclusivity is on the educational system as a whole and not on the learner to fit into the system. It focuses on adapting and supporting the system to overcome barriers (Department of Education, 2001). Also, the emphasis is on the 'development of good teaching strategies that would benefit all learners', including those with special needs (Department of Education, 2001). Different types and levels of support in schools would be offered to both teachers and learners.

To tackle barriers to learning, different government departments are involved (Department of Education, 2001). Among them are:

- Department of Public works, for ramp access for learners using wheelchairs.
- Department of Health, to implement integrated nutrition strategies for learners from poor background.
- Department of Social development, to provide social development services and child support grants.

Common barriers identified in IE are, 'language and communication, lack of parental recognition, visual loss, intellectual disabilities, physical disabilities, psychological disorders, and neurological disorders' (Department of Education, 2010).

To implement the IE system, specific school guidelines were put in place to achieve this. Other school guidelines for IE, focused on learners with medical chronic conditions (Department of Education, 2009). Medical conditions included are asthma, epilepsy, diabetes, HIV and AIDS. Teachers are equipped with information to

understand these illnesses, and the impact they may have on learners. The teachers then have an idea of how to assist the learner should the need arise.

The National Policy Act (RSA, 1996c) focuses on HIV and AIDS, and educators and learners must be educated on the condition. Guidelines have been put in place on how to assist learners should the need arise. They include having a fully equipped first aid kit in schools and having protective barriers like latex gloves in classrooms. They also guide on the prevention of transmission during play.

2.4 Gaps in Policies and Guidelines, and Where We Are Now

School policies and guidelines cover a range of different barriers like learners with physical disabilities, hearing and speech problems, chronic medical conditions (diabetes, asthma and HIV), and poverty with food insecurities (Department of Education, 2001; Department of Education 2009; Department of Health and Department of Basic Education, 2012). However, there are gaps in the policies. The guidelines do not include children carrying mobile oxygen. These are mentally competent children whose only barrier is the need to carry mobile oxygen. IE is supposed to provide support for both teachers and learners in order for learners to be accommodated in schools. The case of a six-year-old child carrying mobile oxygen who could not access school (Health24, 2018), and the child I encountered at my clinic, are examples of lack of support and inclusion in the guidelines. Non-inclusivity raises issues such as discrimination, violation of the right to education and autonomy on these learners.

The government must ensure children with chronic lung diseases are included in all guidelines using IE system principles, taking reference from countries like the UK and Scotland (BTS Guidelines, 2009; NHS, 2010). They include protocols on what needs to be done at home and in schools for the children. These children are then able to maintain mobility and independence. In the case of SA, the departments of Health and Basic Education should collaborate on this matter.

There is poor progress in the implementation and address of barriers expressed in policies and guidelines. After the IE system was implemented in 2001, a report in 2010 indicated that there was progress made, but the system was far from reaching its set

target (Department of Education, 2010). Lake and Pendlebury (2007) noted that disability accounted for nearly 10 percent of children who are not going to school in South Africa (SA Child Gauge, 2008). They also showed that children with disabilities who attend school, have lower attendance rate than other children, (SA Gauge, 2008). Another study by Hall (2018) showed that 16 percent of children who dropped out of school was due to disability.

Themane and Thobejane (2019) conducted a study in some selected rural schools and found barriers, such as school yards being big, dusty, with no ramps, and with very high stairs. This made it difficult for some learners to access the schools. These findings were present despite existing school guidelines for learners with physical disability. The set goals are not being achieved, despite the presence of guidelines to reach them. This creates a major gap on a need for school guidelines, especially that addresses children with chronic lung disease carrying mobile oxygen. The non-inclusion of children carrying mobile oxygen in the school guidelines makes it difficult for the children to access to schools, thereby interfering with their right to education. All in all, the government has not been clear on steps taken to remove any of the mentioned barriers.

When specific guidelines are put in place, other learners and teachers will be aware of the special precautions to be taken when interacting with the child using mobile oxygen. The school then becomes a positive and safe learning environment for the children carrying mobile oxygen. This will build good self-esteem and decrease the risk of being isolated. As a result, the safe and supportive environment will make them succeed and thrive in schools.

2.5 Conclusion

Literature sources and school guidelines indicate that there are guidelines on most chronic medical conditions, but they make no mention of any available guidelines for children on mobile oxygen. Clearly the continued presence of barriers to learning although there are guidelines in place, presents little to no hope for children carrying mobile oxygen.

CHAPTER 3 - LEGAL OBLIGATION OF THE STATE TO CHILDREN WITH SPECIAL NEEDS

3.1 Introduction

Education is a human right. Human rights are ‘inherent to all human beings, regardless of nationality, sex, national or ethnic origin, colour, religion, language, or any other status’ (UDHR, 1948). Human rights are universal, and all human rights are equal as rights-holders. The right to basic education is a fundamental right, as both individuals and society benefit from the right. It is ‘a powerful tool in developing the full potential of everyone and ensuring human dignity, and in promoting individual and collective wellbeing’ (UNESCO, 2019).

3.2 The Right to Education for Children with Special Needs: International Laws

Article 13 of International Covenant on Economic, Social and Cultural Rights (ICESCR) recognises the right to education for everyone. To achieve full realization of the right, primary education should be compulsory and free to all. The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines disability as including ‘those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’. Article 24 of the Convention obliges the state parties to IE system. Paragraph one of the article states that ‘State parties to recognise the right of persons with disabilities to education’ and to ensure IE system will realise the right (UNCRPD). The article gives guidance on how to establish the right to education to persons with disability, and furthermore, on how to realise the IE system. Some of the guidance include: not to exclude persons with disability from the general education system based on their disability; for people with disabilities to gain access to inclusive, quality and free education, just like other non-disabled children; provision of individualised support consistent with the goal of full inclusion. Basically, the guidelines offer guidance on how not to discriminate against children

with disability. This is also echoed in Article seven of the convention, which prohibits discrimination of children with disabilities.

The United Nation Conventions of the Right of a Child (UNCRC), Article 23, also looks at the rights of children with disabilities. It recognises the provision of special needs of a child with disabilities free of charge, taking into account available resources, and to ensure the child has access to education and training in order to achieve possible social integration and individual development. The UNCRPD discourages the discrimination or segregation of children with disabilities or special needs, and encourages the inclusion and integration into the community and school, as one would with children without disabilities. It goes as far as giving guidance on how to achieve inclusive education for these children.

The above principles on the right to education of children with disabilities should be applied to children with other special needs. Learners carrying mobile oxygen are regarded as having special needs, as they require special attention from educators. They must be treated the same as their peers with other chronic medical conditions like diabetes mellitus, asthma, epilepsy and HIV, and be included in the IE system like them.

The problem of inclusion and the right to education is seen in a landmark case of *Cedar Rapids Community School District v Garret F* (1999) 119 US 992. In this case, a high school student, Garret, sustained spinal cord injury due to a motorcycle accident at four years of age. Garret got paralysed from the neck down from the injury but remained mentally competent. This resulted in him requiring tracheostomy tube suctioning, continuous ventilator monitoring, and intermittent urinary tract catheterization. Initially, Garret attended school with his family making sure he had the care he needed in school. Later, the parents asked for the school to pay for the cost of the care he needed in school. During court proceedings, the court had to determine if the care needed by Garret in school was a medical procedure or related service. Medical procedures are the procedures needed to be performed by a trained health care professional only, while related services are procedures that can be performed by anyone, including lay persons. The court ruled the care needed by Garret to be related services. According to the courts, Garret would not be able to attend school and

exercise his right to education if the care needed was not provided in school. As a result, the school district was responsible for paying for the costs of providing the services. The school had to remove Garret's barriers to education, so he can be included in the school.

The principles in the UNCRC were used in the ruling of Garret's case. Garret had the right to education, which must be compulsory to all. UNCRPD obliges the states to the IE system. It prohibits the exclusion of people with disability from the general education system purely due to their disability. The law encourages the inclusion and integration of children with disabilities in schools and the community. The law also allows for provision of individualised support consistent with the goal of full inclusion. In Garret's case, individualised support means providing the services he needs in school, in order to be able to attend school and realise his right. This is also in conjunction with the 4As of education, developed by UN Special Rapporteur, that were adopted by the Committee on Economic, Social and Cultural Rights (CESCR). The right to education is meaningful when it is 'available, accessible, acceptable and adaptable' (CESCR).

The principles used in the ruling of Garret's case can also be applied in children carrying mobile oxygen. These learners must be included in the IE system so that systems can be put in place for them to be accommodated. This means learners would be provided with individualised support in schools so that they can attend school. Further support can be in the form of teachers understanding their condition and being comfortable with learners in school.

Although inclusion and integration of children with disabilities in the community is important, it is paramount that decisions are made in the child's best interest. Inclusion should not be forced, if it will be of no benefit to the child. This is shown in the case of *Eaton v Brant Country Board of Education* (1997) 1 S.C.R. 241 in the Supreme Court of Canada. Eaton was a 12-year-old girl with cerebral palsy. She was unable to communicate through any means, severely visually impaired, mobility impaired, and was wheelchair-bound. She was initially in a regular mainstream class set up. After three years, teachers were of the opinion that Eaton must be placed in a special school. They felt that the education environment would harm her and that it was not in her best interest to be in the mainstream school environment. The parents appealed the

decision up to the Supreme Court. Unfortunately, the court ruled that placing Eaton in a setting for learners with special education needs was in her best interest. The judge was of the opinion that introducing the learner with special educational needs in the mainstream school by disregarding their ability to cope amounted to hurting the child. As such, the decision was not of discriminatory nature, but was based on what was in Eaton's best interest. In this case, the risk of integrating Eaton in the mainstream school posed more risks and no benefits.

The principles used in the above case do not apply to mentally competent children carrying mobile oxygen. These children can attend mainstream school, as they are mentally competent. Their only barrier is carrying oxygen to school which can be resolved when teachers have an awareness of the condition.

3.3 The Right to Education for Children with Special Needs: National Laws and Regulations

The Constitution of the Republic of South Africa (1996) is the highest law in the country. Chapter two of the Constitution is the Bill of Rights (BOR) and section 39 of the Constitution states that "the courts and other legal bodies must consider international law when interpreting the BOR". section 231 says that 'a treaty binds SA after approval by the National Assembly and the National Council of Provinces, unless it is self-executing, or of a technical, administrative, executive nature'. Since SA has signed and ratified most of these international treaties and all the above treaties, they are regarded as laws in the country and should be followed.

Section 29(1)(a) of the BOR presents the right to basic education for everyone, irrespective of gender, race, disability, or ethnic group, including adult education. s 7(1) of the BOR states 'the state must respect, protect, promote and fulfil the rights in the Bill of Rights'. The state in this case refers to anyone from Member of executive council (MEC) of Education, Head of Department (HOD) of Education, to school principals and teachers.

The right to basic education is presented in s 5(1) of the School Act (RSA, 1996b) which states that 'learners can be admitted in public schools and serve their educational requirements without being unfairly discriminated in any way'. In this

regard, learners with special needs should be able to attend mainstream schools like learners with no special needs. s 5(6) of the School Act (RSA, 1996b) allows for the rights and wishes of the parents of learners with special needs to be considered by the HOD and the principal when placing the learners in school.

In the Children's Act (RSA, 2005), s 11 makes provision not to discriminate children with disabilities and chronic illnesses, while at the same time providing them with the support they need. s 11(1)(b) considers *'making it possible for the child to participate in activities, while at the same time recognizing the special needs that the child may have'*. For children with chronic illness, paragraph 2(b) states 'due consideration must be given to provide the child with conditions that ensures dignity, promote self-reliance and facilitate active participation in the community'.

The main aim for IE is to include children with special needs in mainstream schools. Educational support systems in ordinary schools are meant to be put in place so that learners with barriers to learning can attend mainstream schools. Barriers to learning refer to 'any difficulty that arises within the educational system that might prevent a learner's access to learning and development' (Department of Education, 2010). Barriers include, no ramps for children on wheelchairs, teachers not knowing a child with diabetes might need frequent breaks to get a snack, or a child from a poor socio-economic background is unable to come to school because they do not have school supplies.

The focus of inclusion is not on the learner to fit into the system, but on the educational system as whole. It focuses on adapting and supporting the system to overcome barriers (Department of Education, 2001). The emphasis is on 'the development of good teaching strategies that will benefit all learners', including those with special needs (Department of Education, 2001).

It is the duty of the state to make sure that support systems are put in place, so that children with special needs can attend school. This is recognised by s 29 of the Constitution. s 29(1)(b) further states 'everyone has the right to further education, which the state, through reasonable measures, must make progressively available and accessible'. Both the SA Constitution and the ICESR recognize that the fulfilment of

economic and social rights can only be achieved over time and calls for the progressive realisation of the rights. Deliberate steps must be taken by the government immediately and in future it must be towards the full realization of the right (ESCR.Net).

Although the goal of IE system is to integrate children with special needs in mainstream schools, special schools have a role in the IE system. They provide important education services to learners who require intense levels of support, for example, children with a severe visual disability or profound mental disability. Special schools also accommodate learners who require much less support who should be in mainstream schools (Department of Education, 2001). Lack of this is depicted in the case of *Western Cape Forum for intellectual Disability v Government of the Republic of South Africa* (2011). The applicant was the Western Cape Forum for intellectual disability, a non-government organisation, taking care of children with severe and profound intellectual disabilities in the Western Cape Province. They argued that the state makes no provision of education for children that the forum represented.

In the Western Cape Province, the only form of education available for these children is in special care centres run by non-government organisations. These centres are insufficient and children who are unable to gain access to them receive no education at all. As a result, children are prevented from their right to education. The court ruled in favour of the forum and against the state. The Western Cape Province did not take reasonable measures to make sure children exercised their right to education. The province had to ensure every severely and profoundly intellectually disabled child in the Western Cape had affordable access to basic education of adequate quality. This case highlights the right to education for everyone, without discrimination.

The Discrimination Act (RSA, 2000) makes provision for the state to provide for the elimination of obstacles that unfairly limit people with disabilities from enjoying equal opportunities. Necessary steps need to be taken to reasonably accommodate the needs of children with special needs in schools. s 24 of the act further states ‘all ministers must implement measures within the available resources which are aimed at the achievement of equality in their areas of responsibility’. The provision is also made by s 3 of the School Act (RSA, 1996b). s 1 states:

‘every parent must cause every learner for whom he or she is responsible to attend a school from the first school day of the year in which such learner reaches the age of seven years until the last school day of the year in which such learner reaches the age of fifteen years or the ninth grade, whichever occurs first’.

According to s 5(b) it is the responsibility of the HOD ‘to investigate the circumstances of the learner’s absence from school’ and ‘take appropriate measures to remedy the situation’ when a learner subject to compulsory school attendance fails to attend school.

Even though the state must ensure the learners receive their right to education, the parents have responsibility to their children’s education and safety as well. They are responsible for the children’s school attendance. It is their responsibility to make sure their child will not run out oxygen while in school. Parents are also responsible for making sure that the child is adequately skilled to handle the equipment independently or with assistance. They also need to make sure their child is stable and not acutely ill when they send them to school. They must be involved and support their children by helping with homework for example. Parental involvement will help build their children’s self-esteem.

Even though it is in the best interest of the children carrying mobile oxygen to get the education, their rights to education should not overshadow the rights of other learners. Other learners must still be able to exercise their right to education fully, despite resources being used for learners carrying mobile oxygen. The other learners can also be trained to understand their peers’ condition so they are aware of special precautions to take while interacting with them.

South African Council for Educators (SACE) code of professional ethics makes it the teacher’s responsibility to take reasonable steps to ensure the safety of the learner (SACE, 2016). The teacher can only be able to ensure safety if they understand the condition of the learner. For them to be able to attend to these learners, they have the right to be educated on their conditions. There should be well-designed training programme in place, that will enable them to operate effectively within the challenging environment. Teachers are not health care professionals. They should not be expected

to play the role of nurses. They should be trained to recognise danger signs and the actions to take should the need arise.

3.4 Progressive Realisation

3.4.1. Definition

SA ratified ICESR on the 12th of January 2015. By ratifying the ICESR, the SA government is obligated to give progressive effect to the right to education (Article 13(2)(a)). The SA Constitution and the ICESR recognise that the fulfilment of economic and social rights can only be achieved over time. They recognize that lack of resources can obstruct the full realisation of the rights and therefore call for the progressive realization of the rights. Progressive realisation of ESCR does not mean the government has to wait until a certain level of economic development is reached before it fulfils these human rights.

Deliberate steps must be taken by the government 'immediately and in the future towards the full realisation of the right' (ESCR.Net). CESCR have identified steps that can be taken immediately for any level of resource availability. The law institutes minimum core obligations. These are obligations considered to be of immediate effect to meet minimum essential levels of each right. These must be achieved, irrespective of resources available. The state is obligated to respect, protect and promote these rights immediately.

Immediate obligations include, eliminating discrimination, and providing free and compulsory education for all. Efforts to remove barriers for children carrying mobile oxygen in school to promote school attendance and rights to education would be a minimum core obligation. If the state fails to meet a minimum core obligation due to limited resources, it must prove that it had made effort to achieve the right, and show it is instituting steps to achieve the goal. These steps must be taken within a reasonably short time.

3.4.2. Where is South Africa now?

Twenty years after the implementation of IE, some children continue to experience barriers to their right to education. According to Themane and Thobejane (2019), most schools still have insufficient physical resources to support inclusive practices. They found that school yards were big, dusty, with no ramps, and with very high steps (Themane & Thobejane, 2019). Classes with large number of learners were one of the barriers still being encountered in some schools (Materechera, 2018). However, the main barrier was the teachers' capacity to teach the learners (Themane & Thobejane, 2019). The teachers felt that they did not have enough knowledge to be able to support learners with some disabilities. As a result, they preferred to refer learners to professionals who they believed were better equipped to support the learners (Nel, Engelbrecht & Tlale, 2014).

Despite the barriers, the teachers had a positive attitude towards IE, although the knowledge acquired from workshops was described as theoretical (Themane & Thobejane, 2019). Teachers need practical solutions to support learners who experience barriers to learning (Nel et al., 2016), not only theoretical suggestions. With HIV, teachers believed with enough support and ongoing training, they would be able to successfully include HIV-positive learners in an inclusive classroom (Beyers & Hay, 2011). HIV is among medical conditions included in guidelines on IE, and HIV positive children are able to attend schools, without feeling discriminated against. This shows that enough time was spent on the topic, educating and training the teachers.

Teachers in schools have been trained on conditions like HIV, TB, asthma and diabetes among others. Training offered involves understanding and awareness of these conditions, and guidelines have also been put in place (Department of Education, 2009). The guidelines include what the teacher should look out for in a child with a particular medical condition, and what to do should a need arise. The same principles must be used for learners carrying mobile oxygen. Teachers must be trained to understand conditions of learners carrying mobile oxygen, and what to do should a need arise.

Despite ISHP giving guidelines on how to have a health policy in schools (Department of Health and Department of Basic Education, 2012), the school guidelines for teachers on chronic illnesses of childhood, does not include children carrying mobile oxygen and the state has not shown why these children's rights are being violated, nor the steps to be taken to remedy this.

3.5 Support of children on mobile oxygen in schools

Children carrying mobile oxygen also have a right to basic education. Education must be 'available, accessible, adaptable, and acceptable in all its forms and at all levels, for the right to education to be meaningful' (CESCR). It includes provision of adequate and safe environment as seen in the case of *Komape and Others v Minister of Basic Education (2015).*

The 4As of education must also be applied to competent children carrying mobile oxygen. These are the children with improvement in the health care systems, as they live beyond what was previously expected, and now have medical sequel. Advance in medical care has proven that children on continuous oxygen do not need to be in institutions like hospitals. They can live normal independent lives like their peers who are not on mobile oxygen.

There are no specific guidelines for children on mobile oxygen in schools, and the same principle for children with other medical conditions should be applied. Both international laws and SA national laws are clear on the right to education and discrimination. International documents like the Limburg Principles, and CESCR have identified steps that can be taken immediately for any level of resource availability.

The goal of IE system is to bring services to learners in schools rather than placing them in specialised settings. The success of the IE system will enable learners carrying mobile oxygen realise the 4As. There are no exact numbers of children carrying mobile oxygen in schools, however it is estimated to be low. Although the numbers of children carrying mobile oxygen of school going age are low, they are expected to increase, partly due to improvement in health care services in general.

In the case of *Cedar Rapids Community School District v Garret F* (1999), the Limburg principles were applied. The court ruled for the school district to pay for the cost of the procedures Garret needed for him to be able to attend school and exercise his right to education. In the case of children on mobile oxygen, the barrier is that principals, teachers and other children in school do not have knowledge about their condition and the ability to support these learners. The principles used in Garret's case can also be applied in children on mobile oxygen.

While removing barriers to learning, it is important to take into account what is in the best interest of the child. In the case of *Eaton v Brant Country Board of Education* (1997), it was in the best interest of Eaton to be in a specialised school setting, due to the severity of her disability. Equally so, in the case of *Western Cape Forum for intellectual Disability v Government of the Republic of South Africa* (2011), the court also ruled for the state to provide basic education of adequate quality to learners with severe intellectual impairment. Even though the children in the two cases remain in specialised school settings, the states are still obliged to provide education that is appropriate for the children.

The two cases above refer to learners with severe mental impairment, and do not have the mental capacity to grasp concepts that mentally competent learners can grasp. One may argue that learners carrying mobile oxygen should be placed in specialised settings. However, these are mentally competent learners who carry mobile oxygen. Nonattendance of school or being placed in secluded special schools may cause psychological harm. The condition of learners carrying mobile oxygen needs to be included in the school guidelines like other chronic medical conditions.

While IE advocates for the inclusion of these children in schools, their physical limitations should be taken to account. Positively stated, learning in terms of grasping concepts is not different from children not carrying mobile oxygen because they are mentally competent. Their physical limitations may be apparent in school playgrounds, where they may not be able to run around like their peers. This limitation should not be a problem as physical fitness or activity is different even in children without any physical or medical disability. Other alternate nondemanding physical activities like playing musical instruments or chess should be considered for them.

According to the Constitution, it is the state's responsibility to make sure education for all is realised. The state should provide a safe environment for all learners, and safe care that meets all their special health care needs. Learners carrying mobile oxygen do not need medical care while in school for most part. However, they need their carers to understand their condition. The state in the form of DOE, in partnership with the DOH, should equip teachers and other learners with necessary knowledge so that they understand the condition. By understanding the condition, they are able to give needed support to the learners, which will result in a safe school environment for the learners. Education for learners on mobile oxygen should be available, acceptable, accessible, and adaptable.

3.6 Conclusion

Both International and National laws dictate the State to ensure that the right to basic education is realised. For those with barriers to learning, it is the responsibility of the state to take steps and make means to ensure that the barriers are removed so that the right to basic education is realised. Failure of the state to make sure basic education for all is realised, and exclude children carrying mobile oxygen in the school guidelines is unlawful.

CHAPTER 4 - ETHICS ON THE RIGHT TO EDUCATION OF CHILDREN CARRYING MOBILE OXYGEN

4.1 Introduction

Mentally competent children carrying mobile oxygen should have access to main stream public schools. These children are vulnerable as they face many challenges. A vulnerable person is “a person whose survival, care, protection or development may be compromised, due to a particular condition, situation or circumstance and which prevents the fulfilment of his or her rights” (Policy 12399A, 2013). This includes people with chronic medical conditions (Vulnerable Populations: Who Are They? 2006). Due to the vulnerability of children carrying mobile oxygen, their rights should be protected and prioritised by the state.

I used Normative ethical theories and Principalism to argue my claim that the state is morally obligated to include children carrying mobile oxygen in IE guidelines, thereby making it possible for the children to access main stream schools, without any discrimination.

4.2 Normative Theories

Two major approaches to normative ethics were used. Deontological approach focusing on Kant’s Categorical Imperative, and the Utilitarian approach, which emphasizes the consequences of actions.

4.2.1 Kant’s Categorical Imperative

Immanuel Kant (1724-1804), was a German philosopher who used deontological approach in his work. His approach put emphasis on duties and rules. Kant focused on how people acted, their emotions and intent. He did not focus on producing some societal good. He argued ethical reasoning is based on people living by principles that can take the form of rules or laws.

Kant expressed moral laws in the form of Categorical Imperatives. Categorical imperatives are absolute commands with no concern of practical benefit or pleasure.

They state ‘act only according to that maxim by which you can at the same time will that it should become a universal law’, (Rachels & Rachels, 2015: 130). For any action that one takes, one needs to ask whether they will be willing for the rule of that action to be applied at all times. If that is the case, then the action is morally correct and should be a universal law.

All the school guidelines, including guidelines on IE do not include learners carrying mobile oxygen. This has resulted in schools not being equipped with necessary resources to enable easy access to schools for these learners. In these guidelines, it would be questionable to not include learners with other barriers to learning for example, not including children with physical disability, learners who are HIV positive, or learners who have asthma. Learners with these barriers are included in all the school guidelines and resources are provided for them. However, it is questionable that leaners carrying mobile oxygen are not included in the guidelines.

According to Kant’s Categorical Imperative, if learners with other barriers to learning are included in the guidelines, learners carrying mobile oxygen should be included as well. The reverse should also be true. If learners carrying mobile oxygen are not included in the school guidelines, arguably, learners with other barriers could be excluded. Interpretively, there will be no guidelines, if children with other barriers to learning are not included. If the state draws up school guidelines on children with barriers to learning, all barriers to learning must be included in the guidelines. Lack of total inclusivity is morally unacceptable, and it equates to discrimination, which is also morally unacceptable.

Kant also gave the principle of Categorical Imperative a different formulation, which states: ‘Act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only’ (Rachels & Rachels, 2015:139). Treating people ‘as an end’ means respecting people’s rights, avoiding to harm people, and treating people well. Treating people ‘as an end’, also means respecting people to make their own decisions. Children carrying mobile oxygen are unable to access schools if they are not included in the guidelines. Unknowingly, the state is making decisions for the children, of not going to school. The decision that interferes with their

right to education and the right to make their own decisions. Including all the children in the guidelines will give them their autonomy, respect and freedom to choose.

4.2.2 Utilitarian approach

Utilitarian is a form of Consequentialism, where morality of an action depends on the outcome or the consequences of that action. An individual's happiness gets equal consideration. No one's well-being matters more because one is powerful or rich. There is no discrimination in terms of the consequences. It is an ethical theory that says 'an action is right if it produces the greatest overall balance of happiness over unhappiness' (Rachels & Rachels, 2015: 111). Beauchamp and Childress (2013: 355) also formulated the theory as 'a requirement to do the greatest good for the greatest number'.

Omitting children carrying mobile oxygen in IE guidelines, means barriers to learning for this group of children are present. Their basic rights are violated; they are being discriminated against; and they cannot have their autonomy. All this will result in great unhappiness to the children themselves. Not being able to access the schools will result in them not getting basic education. Lack of basic education can result in no empowerment, which ultimately results in total dependence to others, becoming a burden to their families, and the whole community.

According to the Utilitarian approach, the omission of these children in the guidelines, is morally wrong and the reverse is true. Including these children in the guidelines will reduce their barriers to learning. As a result, they would be able to retain their autonomy, and excise their basic human right of education. Education brings independence, which provides greatness and overall happiness. This level of independence lessens the burden on the state and the community and bring happiness to all.

Including this group of children in the guidelines and providing them with resources, would be like taking care of their well-being. The well-being of these children matters in the same way as other children with or without barriers to learning and discriminating against them is morally wrong.

The reason for not including this group of children in IE guidelines could be because the state considers it involving the minority, and therefore the state would rather use its resources to the majority instead. In reference with the principle, ‘do the greatest good to the greatest number’, the argument could be that, it is a small group of people that need a lot of resources. The resources include training the teachers on how to take care of learners in schools. Their non-inclusion would mean saving and redirecting resources to the majority, which would bring happiness to the state and the majority of people. This reasoning is not morally correct and it is based on discrimination due to unfair distribution of resources. The Utilitarian approach also takes everyone’s wellbeing into consideration. As mentioned, the consequences of non-inclusion not only affect these learners, but also affects the family, the community and the state. It is for this reason that including them would bring the greatest good to the greatest number.

4.3 Ethical Principles

Beauchamp and Childress (2013) outline four principles to biomedical ethics. To determine an optimum course of action, each of the four principles need to be weighed and balanced. The four principles are autonomy, non-maleficence, beneficence, and justice. They are used as general guidelines to formulate specific rules.

4.3.1 Autonomy

The South African Oxford pocket dictionary defines autonomy as ‘self-government’. Beauchamp and Childress (2013: 101) explain that personal autonomy encompasses ‘self-rule that is free from both controlling interference by others and limitations that prevent meaningful choices’. It means independence or freedom. The principle is based on respect for persons, which requires that ‘individuals should be treated as autonomous agents’ (Belmont report, 1978). It holds the premise that people have the right to make their own choices. For an individual to make an autonomous decision, the choice they make must be voluntary, without any controlling interference, and must be adequately informed and competent to make such decision. In case of minors, the decision is made by caregivers and children together.

All learners, including those carrying mobile oxygen and their caregivers must exercise their autonomy by choosing a school for themselves and their children. This is possible if resources are put in place for them in schools.

Lack of inclusion in IE and other school guidelines, has led to schools not being equipped with necessary resources for learners carrying mobile oxygen. The children are then unable to attend school and exercise their right to education. These children and their caregivers are not given the opportunity to choose to attend mainstream schools or reject the opportunity. The presence of barriers means the decision is made for them and they do not have autonomy to make decisions on their own. The presence of barriers to learning for these children, in my opinion is equivalent to interference by the state. In my opinion, they are coerced into not attending schools because choices would have been taken away from them.

SA School Act (1996) provides for the HOD and the principal of a school to consider the rights and wishes of parents of learners with special needs, in determining the placements of those learners. If the guidelines include these children and resources are put in place, barriers will be removed. Schools will be equipped with necessary resources. Mentally competent children carrying mobile oxygen and their caregivers, would be able to make autonomous decisions, whether to attend mainstream schools or not. This is real autonomy, as they make decisions because they have choices.

Autonomy needs to be weighed and balanced against other principles. If an individual's autonomous action causes harm to other individuals, the principle may be overridden (Varkey, 2020). Allocating resources so that learners carrying mobile oxygen can make autonomous decisions and access mainstream schools to get their right to education, does not harm anyone. Instead, it would bring benefit to the majority of people, and it would not be overridden in this case.

4.3.2 Non-maleficence

This principle obligates people to 'refrain from causing harm to others' (Beauchamp & Childress, 2013: p150). The rule of the principle requires one to intentionally avoid actions that can inflict harm, or risk of harm (Beauchamp & Childress, 2013). Inflicting harm to people does not necessarily mean inflicting physical harm or causing injury. It

can also be an adverse effect on one's interest (Iserson, 2017), causing actions that limit the potential of others, or violating other individual's autonomy (Varkey, 2020). Non-maleficence also supports more specific moral rules, including not depriving others of the goods of life.

Failure of the DBE to include children carrying mobile oxygen in IE guidelines and equipping schools with resources, means these mentally competent children who have the ability to be in main stream schools, are unable to do so. Their autonomy is being taken away from them. Their basic human rights are infringed upon. They are being deprived of the good in life, in the form of education, and ultimately independence. This despite the state being legally obligated to provide access to education.

Taking away the children's autonomy, and infringing the children's basic human rights, causes harm to the children. The above actions can results in the family and the community having to carry the burden of taking care of them their entire life. This in itself can result in harm to everyone.

The principle of Non-maleficence considers what is in the best interest of the people. It weighs the benefit against the burden, and chooses the best course. In this case, what is in the best interest of these learners is to be included in the guidelines for IE, and remove the barriers to their learning. This will promote the learners to have a better life and flourish. It is also in the best interest of the community at large when learners do not have to depend on them.

4.3.3 Beneficence

Beneficence is defined as 'the doing of good', or 'charity' according to Dictionary.com. The principle refers to the 'moral obligation to act for the benefit of others' (Beauchamp & Childress, 2013: p203). We have a duty to help others to further their legitimate interest. With beneficence, one obeys the principle by positive actions.

The state must take positive steps to make sure the rights of these children are realised. Firstly, DBE must make sure these group of learners are included in IE guidelines and all the other school guidelines, so that their rights are not violated. Secondly, the state must take active measures to make sure resources are available,

and measures are put in place to achieve what is in the guidelines. By actively taking these measures, the department allows learners to exercise their autonomy by attending mainstream schools. This promotes welfare to the learners, which is the hallmark of this principle.

Beauchamp and Childress (2013) also distinguish specific beneficence as obligatory beneficence. This is where one has a duty to people they have special relationships with, for example, a parent to a child, or a state to a community (Beauchamp & Childress, 2013). These learners belong to a special vulnerable group, to which the state has an obligation to, both ethically and legally. Vulnerable groups should be a priority to the state. If the state does not put measures in place so that schools are equipped with resources, the action will cause harm to these children. It is ethically wrong, as the principle of beneficence obligates the state to act to help.

4.3.4 Justice

The principle of justice means treating people fairly, without discrimination. Beauchamp & Childress (2013: p250) refer to justice as 'fair, equitable, and appropriate treatment in light of what is due'. Including learners carrying mobile oxygen in IE, school guidelines and providing schools with resources means the principle of justice is being applied.

Distributive justice refers to 'fair, equitable, and appropriate distribution of benefits and burdens determined by norms that structure the terms of social cooperation' (Beauchamp & Childress, 2013: p250). The principle underlines concern about how social benefits and burdens should be distributed. It is important to maintain balance between burden and benefits. Resources need to be put in place so learners can exercise their right to education. In this instant, lack of resources to cater for learners carrying mobile oxygen in schools creates a burden to teachers as they are unable to handle these children. The responsibility of the state to provide resources to these learners may be a burden to itself. However, treating the learners fairly without any discrimination means having to provide the resources. This will bring benefit to the learners as they can exercise their right. It will also benefit the teachers as they will

know what to do with the learners and the community, and in the long run these learners will gain independence.

Distributive Justice can be presented through some general theories of justice. The theories are not exclusive, but can be used in combination. The Egalitarian theory emphasizes on equal access to the goods in life that every rational person values. The egalitarian theorist would allocate resources to reduce inequality (Cookson & Dolan, 2000). A combination of the goal of inequality with other principles of justice is important, but equality is not their goal (Cookson & Dolan, 2000). Egalitarian's thinking influences the rule of Fair opportunity where they are concerned with equal treatment for all. They ensure the community has access to a range of services. They also make sure the community can access a decent minimum range of services. Applying this theory to learners carrying mobile oxygen, the allocation of resources for these learners gives them a fair opportunity to learn like their peers not carrying mobile oxygen. This will enable them to have access to schools and get their education. Egalitarians focus on the process through which distribution takes place. They evaluate why certain distribution takes place, instead of the outcome of the distribution.

An American philosopher, John Rawls (1921 -2002) used the principle of equality to describe distributive justice. The equality principle comes from fair equality of opportunity. It is also called the fair-opportunity rule. It is on the basis that individuals 'should not be denied benefits on the base of undeserved disadvantageous properties, because they are not responsible for these properties' (Beauchamp & Childress, 2013: p263). Children carrying mobile oxygen have been neglected for too long. Resources needed must be put in place to remove the barriers to learning, so that children receive education that is suitable to their needs. These resources must be supplied, even if they cost more, so that learners get similar opportunities as their peers without barriers to learning.

The egalitarian principle often invokes material criteria of need (Beauchamp & Childress, 2013: p252). With the principle of need, essential social resources should be distributed according to need (Beauchamp & Childress, 2013: p251). This refers to a fundamental need, and if the need is not met, a person will be detrimentally affected. In a health care setting, the need might refer to individuals with a potential to benefit

from treatment (Cookson & Dolan, 2000). Examples include individuals with an immediate threat to life. It can also look at the capacity of the individual to benefit. These mentally competent learners carrying mobile oxygen, are capable of learning in mainstream schools. It is not only learners carrying mobile oxygen that will benefit from the allocation of resources in order to exercise their right to education. Caregivers of these learners will benefit because they will ultimately eliminate the burden of taking care of them. Failure of allocation of resources will have a detrimental effect on everyone.

The Liberty principle puts emphasis on an individual's right to liberty. John Rawls also used this theory to described distributive justice. The theory affirms individual liberty (Beauchamp & Childress, 2013). Every individual has equal liberty right. However, it acknowledges that certain rights and freedoms are more important than others. If there are not enough resources to cater for children carrying mobile oxygen, money can be taken from elsewhere, for example, from entertainment of ministers, and instead be used for education as it is more important than entertainment to ministers.

According to Utilitarianism (Beauchamp & Childress, 2013), maximising theory, maximizes utility or welfare. The theory requires that we seek 'to produce the maximal balance of positive value over disvalue'. The consequence in this theory is not happiness for many as in classical Utilitarian theory (Cookson & Dolan, 2000). The best possible consequence in this distributive justice is maximising well-being. Positive value in this case is basic education for all and the benefit that education brings. All learners must have access to basic education. The theory is applied if there are learners that need more resources distributed to them than other learners, then the resources must be distributed as such.

The principle of justice refers to people being treated fairly without discrimination. All children must be given an opportunity to exercise their right to education. By providing resources to one group of learners and leaving out another group is discrimination and not just. Using all above principles, resources must be distributed such that learners carrying mobile oxygen are provided with education and barriers to learning are removed. Should we not then distribute resources equally to be fair? Is distributing more resources to one group than the other, not a discrimination to the group that

receive less resources? By applying the above theories and principles of distributive justice, it is not discrimination to give more resources to the needy as this provides equal access of opportunities and maximises welfare.

4.4 Conclusion

It is unethical to omit the inclusion of learners carrying mobile oxygen in school guidelines. Resources need to be put in place so that these learners are also included in the guidelines. I used the four principles of ethics to show that resources need to be allocated to enable learners carrying mobile oxygen to exercise their right to education through mainstream schools.

Even though the four principles are independent of one another, in combination they present a strong argument in favour of the learners. Most importantly, there is no principle that can compete with another principle.

CHAPTER 5 - CONCLUSION AND RECOMMENDATIONS

It has been more than 20 years since IE was implemented. It is in line with international laws and the Constitution. According to the Constitution, it is the state's responsibility to make sure education for all is realised. Part of making sure education is realised for all, is providing a safe environment for all learners, and safe care that meets all their special health care needs.

It is clear that the implementation of the IE system has not been fully implemented. This has resulted in the basic right to education for children with special needs not being met. The state is still struggling to put in place support systems for these children. As such, they are being discriminated, and it is impossible to exercise their basic human right to education. This is not in the best interest of the children.

Learners carrying mobile oxygen do not need medical care while in school for most part, but they need their carers to understand their condition. There must be collaboration between DOE and DOH to plan and implement guidelines for these learners. The task team must be made up of paediatricians and nurses from DOH, as well as SMTs, principals and teachers from DOE.

DOH ought to advice on resources needed by the DOE. Resources needed are mainly education and training on underlying medical conditions of learners carrying mobile oxygen; description on the use and safety of oxygen in a school environment; and how to notice learners when they need assistance. The training must be for school principals, teachers, and other learners. The training can also be from learners themselves, as no one understands what they are going through better than themselves. These learners do not need procedures in school, other than their oxygen. Training will increase confidence in principals and teachers. The learners' families will have confidence in entrusting schools with the care of their children. If teachers are equipped with knowledge, a positive environment for the learners will be created.

There is a dearth of local literature on learners carrying mobile oxygen in schools. Even in first world countries like UK, Scotland and the USA, literature is limited. However,

these countries have guidelines for this group of learners. SA can get guidance from these countries and provide their own school guidelines for this group of learners.

Due to lack of literature on the subject, the following is recommended:

1. Research to determine the prevalence of children of school going age, who carry mobile oxygen.
2. To determine the proportion of these children who have access to mainstream schools, both in the private and public sector.
3. To determine the exact proportion of these children who do not have access to schools.
4. To draw up school guidelines, that include children carrying mobile oxygen, taking guidance from first world countries like UK and Scotland.

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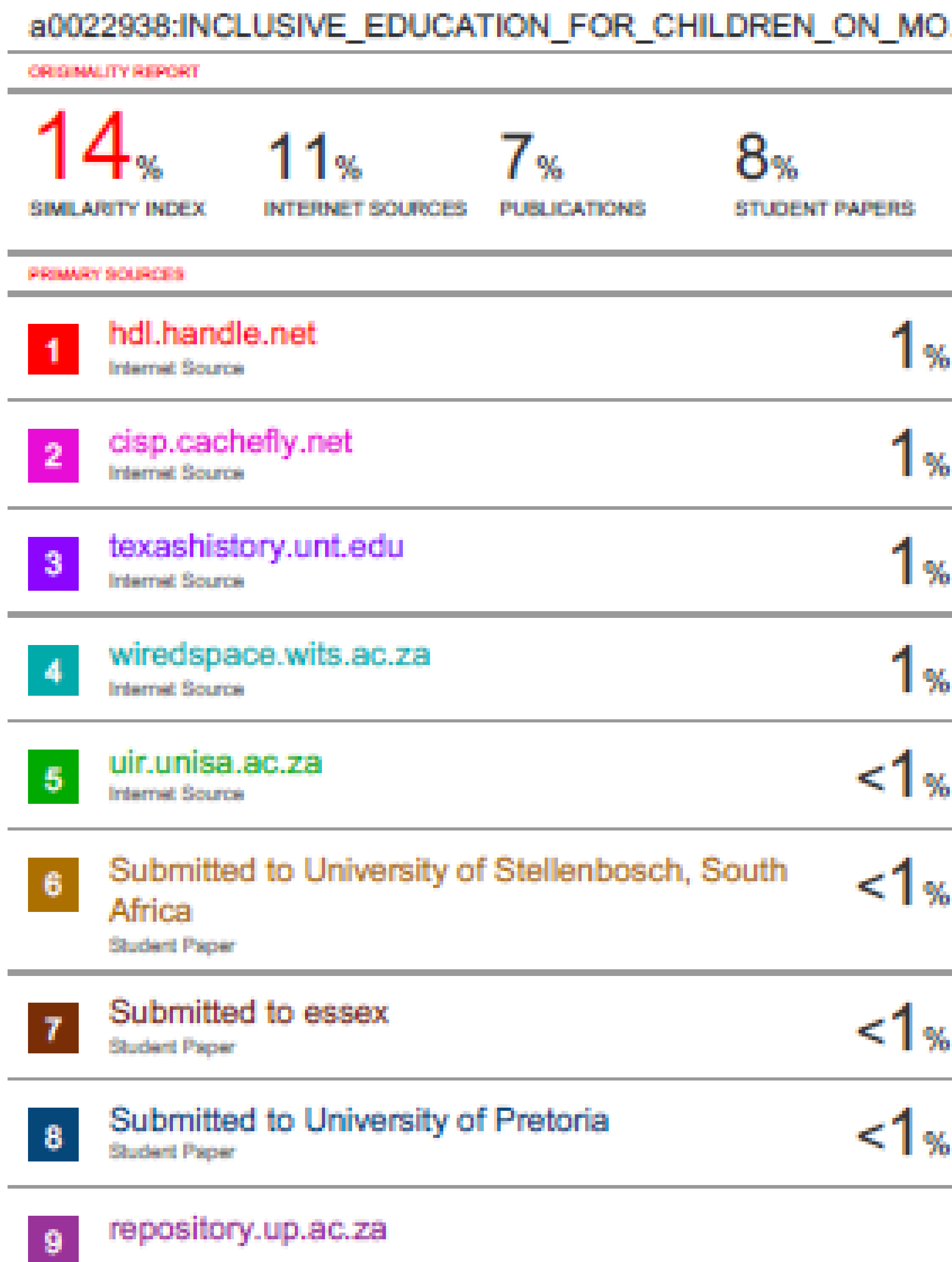
APPENDICES

Appendix a: Turnitin report



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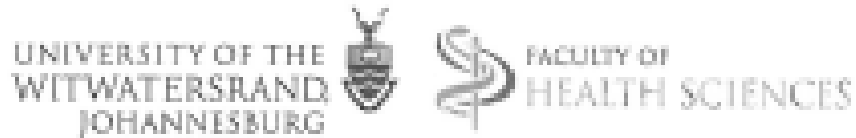
Appendix b: Ethics Waiver



University of the Witwatersrand Student Ethics Declaration Form

(To be completed during the protocol assessor meeting)

Background

All Research conducted by a University of the Witwatersrand student, with human subjects or animals, requires approval by the Wits Human Research Ethics Committee or Animal Research Ethics Committee, respectively.

If research has been undertaken without the necessary ethics approvals, this is considered an ethics violation. This will be reported to the relevant structures, the data will have to be discarded, and in the case of students, they cannot use the data towards their degree.

To prevent any ethics violations, the ethics requirements for the proposed project will be discussed with you at the protocol assessment.

Declaration

Based on the current protocol assessment (and any proposed changes suggested by the assessor committee), we, the undersigned, understand that the proposed research requires:

Item	Yes	No
1. Human Research Ethics clearance certificate	Yes	No (marked)
a. Covered under existing supervisor ethics	Yes	No
b. Requires a new HREC application	Yes	No
2. Animal Research Ethics clearance certificate	Yes	No
3. No Human or Animal Ethics Clearance	Yes (marked)	No
4. Unclear, will seek appropriate guidance from the HREC/AREC committees (whichever relevant)	Yes	No (marked)

Signatures

Supervisor/s: [signature] Student: [signature]

Date: 17/05/2019

11 March 2019/MP

Appendix c: Plagiarism Declaration

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I OMPHILE TSHEGOFATSO MEKGOE, (Student number: 0420060e) am a student registered for the degree of **MSc Med Bioethics & Health Law** in the academic year 2021.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: Date: 15 / 09 / 2021