IHRP Final Report: SECTION27 – Taking rights from paper to practice

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An introduction to SECTION27

This summer, the International Human Rights Program brought me to Johannesburg, South Africa, where I had the opportunity to work with a number of incredibly talented and passionate individuals at an organization called SECTION27. SECTION27 is a public interest law center that is named after section 27 of the South African Constitution. Section 27 of the constitution guarantees the right to health care, sufficient food and water, and social security. As an organization, SECTION27 uses the codified rights in the constitution to protect South Africans from injustices. SECTION27 focuses primarily on issues relating to access to health care, but also works heavily on issues relating to access to education. The organization uses a variety of methods to promote and protect constitutionally entrenched rights in South Africa including litigation, policy work, advocacy, and workshops. I was fortunate enough in my time as a legal intern to be involved in all facets of this work.

The South African Constitution

The South African Constitution is exceptionally comprehensive. It includes not only fundamental rights such as the rights to life, expression, religion, and democratic rights; but also socio-economic rights such as the rights to social security and education. Furthermore, unlike the Canadian *Charter of Rights and Freedoms*, South Africa's Constitution applies both vertically (to government action) and horizontally (between private actors, including corporations). Given that the South African Constitution is extremely young - only 21 years old - there are still many issues with regard to the implementation and balancing of these complex rights. For many issues, it is still unsettled what the codified right means in practice for government action, and for the actions of private actors. This means that many of the issues I was involved with at SECTION27 had the potential to result in big strides forward for the protection and promotion of rights in South Africa.

Race in South Africa and the Legacy of Apartheid

While completing my work at SECTION27, I had to be keenly aware of and sensitive to the deep racial divide in the country. These racial tensions stem mainly from the country's painful history with apartheid law. The decades of racial segregation and oppression of the black population caused generational inequality, leaving today's generation to try it's best to remedy the issue. Although apartheid law had been abolished, inequalities caused by the old laws still exist. Racial tensions are still a very real issue in the country, and much of the infrastructure that existed (such as schools, housing, and hospitals) is still being used today.

In South Africa, people are classified into one of five categories: "white", "black", "coloured" (partial white heritage and partial black heritage), "Asian/Indian" (yes, they are lumped together), and "other." From the moment I stepped foot in the SECTION27 office, people spoke openly and frankly about the issue of race, and in fact used those discussions as a learning opportunity and a tool to better engage with the populations the organization was

aiming to empower. I have never learned more about the complexities of racial dynamics than during my time at SECTION27. Many conversations were also had about my race, and where I fit in. Some regarded me as white, some regarded anyone other than someone from white European descent as "Black", and others regarded me as too racially ambiguous to fit into any category except "other". During my work, my racial ambiguity was sometimes an asset, and sometimes made things more difficult. As a foreigner I found it was extremely important to be aware of what my race latently added to the conversations I was having with clients, in meetings, and in my research. I was also sometimes hindered in my work by language barriers. Although many people in South African can speak English and are multilingual, there were times when I had difficulty understanding people's accents, or it was better suited for a colleague of mine who could speak that person's native language to step in. These obstacles were most definitely a learning experience for me.

My work in Private Health

The Market Inquiry into the Private Health Sector

During my time at SECTION27 I worked primarily with the private health team. One of my main work areas was the Market Inquiry into the Private Health Sector ("the market inquiry"). On January 6th 2014, the South African Competition Commission ("the Commission") officially launched an inquiry into the state of the private health care system, due to the increasing cost of access to private health care. These increased costs have been a serious barrier to access to health care across the country, specifically in rural areas.

The market inquiry has a variety of objectives such as determining what factors have led to the increase in private health care prices, evaluating how patients access and interact with information regarding health care, finding out how prices are determined within the sector (for example how a doctor decides how much to charge for an x-ray), and assessing how existing laws and practices impact the private health sector. All parties affected and interested in the private health sector - patients, doctors, medical schemes, private hospitals, and civil society organizations - are entitled to participate in the market inquiry process. Through the market inquiry, the Commission has the ability to make recommendations to the government regarding existing legislation or regulations. The recommendations that come from this investigation may have an effect on regulations that determine how the health care market operates.

SECTION27 made submissions to the Commission to represent the patient voice in the process, and to emphasize the constitutional obligations at play. Markets work well when companies compete to win business by having the best product for the lowest price. Competitive markets can benefit the consumer when they work well as they encourage innovation (better products) and provide consumers with more choices. However, health care markets are unlike any other market where consumers are buying goods for luxury or pleasure. Health care is not an ordinary good or service, but rather a fundamental human right. In a health care market the consumers – the patients – are extremely vulnerable. They are sick, upset, and have imperfect information. They need the health care professional to tell them what is wrong, and to give them a remedy to their illness. In health care markets, patients do not have the luxury of shopping around for the best price.

During my time at SECTION27, I had the chance to represent the organization at meetings with the Commission to further discuss and clarify our submissions, and to emphasize how

important it is that the patient does not get lost in the process. A summary of SECTION27's recommendations to the Commission are attached as an Appendix A.

Media Workshop

In order to emphasize the importance of the Market Inquiry and to engage the public and other potential stakeholders in the process, SECTION27 held a media workshop about the market inquiry. I was able to play a role to help prepare and execute this workshop. During the media workshop a variety of speakers, including my colleagues from SECTION27, economists, member from the market inquiry panel at the Competition Commission, and other industry professionals gave presentations to journalists from a variety of news outlets about what the market inquiry is and why it is important to the general public. Through this workshop, SECTION27 was able to garner media support for its campaign to engage the patient voice. Patient stories came flooding in after news outlets wrote pieces about the market inquiry, and directed any patients with grievances to SECTION27.

The Patient Stories Handbook

SECTION27's main goal in our submissions to the market inquiry was to represent the patient voice that was in danger of being lost in the legal and economic analyses of the market inquiry. As a result, one of my main projects this summer was compiling a booklet about the state of the Private Health Care market in South Africa, with a specific focus on bringing forward the patient voice.

My role was to research and compile a booklet that was initially meant to be approximately 8 pages long. In order to adequately represent the patient voice I researched patient stories and spoke with patients about their experiences in the private health sector. After gathering information from the patients about what had happened to them, how they felt about it, and what their financial and emotional outcome was at the end of the process, I synthesized the information and provided a legal analysis of their situation to include in the booklet. The patient stories that came flooding in after the media workshop made finding stories a non-issue, as it became apparent that hundreds of people wished to share their experience with us.

After travelling to the province of Mpumalanga to visit the very first patient I interviewed with my colleague, we realized an 8-page booklet was not going to be enough to convey the emotional and financial hardship experienced by patients in the private health sector. The variety of issues these patients were facing, their vulnerability, and the reckless abandon demonstrated by some of the medical schemes, made it clear that this booklet should be a resource and tool not only for the Commission to complete their inquiry while keeping the patient in mind, but also a resource and tool for the thousands and thousands of people being wronged by the private health care system and a weak regulatory framework.

The booklet grew into a 50+ page book, encompassing explanations of patients' rights; a dozen patient stories with an in-depth explanation of the patient's situation and the legal issues with it; editorials by experts in the field such as a Constitutional Court judge, an economist, and the heads of organizations such as Patients Living With Cancer; infographics about the state of health in South Africa; a flow chart explaining the private health system and how exactly it works; and many other resources. After hearing these stories and

researching into a deeply problematic system, I have become incredibly invested in South Africa and its patients. I have continued to work on the book even after my return to Canada.

The patient stories book will be published strategically before the public hearings held by the market inquiry panel. The public hearings will be one of the first chances that patients will have to truly engage with the market inquiry process, and make sure their voices are directly heard. I am extremely excited and anxious to see what effect the patient stories handbook has, and if the Commission uses it as a resource to inform the process and effect change in the healthcare system. I tried my best to ensure the book was written in the clearest terms possible, so as to be accessible to patients who have no previous knowledge of the law or economics. The explanations in the book about how the health care system works, and what rights patients are entitled to are there to empower patients with knowledge that will protect them from a broken system.

The Genesis Case

One of the main issues addressed in the patient stories booklet is the disregard by medical schemes of Prescribed Minimum Benefits (PMBs). To ensure users of the private health system are protected, the Medical Schemes Act ("the Act")¹ provides for PMBs. PMBs are a defined list of minimum benefits that all medical scheme members must have access to regardless of the benefit option they selected. The PMB list contains 270 illnesses and 25 chronic conditions. These include conditions such as tuberculosis, diabetes, HIV, and certain curable cancer and mental health conditions. As it stands, medical schemes are required to pay in full for the diagnosis, treatment, and care of PMB conditions. This means that members cannot be required to make a co-payment for the costs associated of any of the listed illnesses.

PMBs are an important mechanism for ensuring access to adequate health care in South Africa. Although the regulation is in place, many medical schemes attempt to circumvent paying for PMBs, and look for loopholes to avoid covering procedures. Each year, most complaints submitted to the Council for Medical Schemes ("CMS"), are related to non-payment or co-payment for a PMB condition. In 2014, 2736 out of 5008 complaints to the CMS were related to non-payment or co-payment of PMB conditions. These complaints only come from people who are aware that PMBs exist as a regulation. Many patients are not even aware that they are entitled to this minimum level of benefits, meaning that the number of claims would likely be much higher if patients were well informed.

Although patient protection in the private health sector is already lacking, Genesis medical scheme - a prominent South African medical aid provider - is involved in litigation with the Minister of Health to set aside regulation 8. The removal of regulation 8 would effectively remove any obligation on medical schemes to pay for PMB conditions in full. If Genesis is successful, it will cause serious financial hardship for patients. Many South Africans suffer from chronic conditions such as HIV and tuberculosis, and cannot afford to be forced to

¹ Medical Schemes Act 131 of 1998: http://www1.chr.up.ac.za/undp/domestic/docs/legislation 52.pdf.

² Council for Medical Schemes Annual Report 2013/14 at 50-3.

make co-payments for these chronic conditions, especially when they are already paying premiums for private medical aid.

Furthermore, Genesis' success would also cause a huge strain on South Africa's public health care sector, which is already struggling to accommodate the volume of patients who are not on private medical aid. The public health sector struggles with public sector dumping. This is the phenomenon of patients who are paying for private health being forced to access health care in the public sector because of their medical scheme's rules. Public sector dumping further saturates the public health care sector, and drains it of its already limited resources.

During my internship, SECTION27 applied to intervene as *amicus curiae* in the case between Genesis and the Minister of Health. SECTION27's application was accepted near the end of my internship. It is SECTION27's hope that the Genesis case will clarify and strengthen the constitutional obligations of private corporations, especially when their business is in the public service, such as health care.

Public Health

Communicable Diseases Regulation

During my time at SECTION27 I was also given a chance to do some work with the public health team. One of my first tasks was helping to write and edit submissions to the National Department of Health on the Draft Regulations for Communicable Diseases. The National Department of Health is publishing regulations about how to deal with patients who have communicable diseases in terms of enforcing quarantines, forcing them to take medications, and dealing with loss of job due to absence from work. SECTION27 was one of the main legal resources that the National Department of Health consulted when drafting the new regulations. This process has been ongoing for nearly a decade. I had the opportunity to research and write my recommendations for the final draft of SECTION27's submission to the National Department of Health. For example, I researched international best practices when dealing with patients who have contagious diseases and are concerned with losing their income when being forced into quarantine. I am excited to see what the final regulations look like, in the hopes that our recommendations will have been implemented, and the rights of people with communicable diseases will be protected.

The Silicosis Case

The public health team was also working on a number of cases during my time at SECTION27. One such case was regarding the health of miners who had contracted silicosis during their time working. SECTION27 has applied to intervene in the case as *amicus curiae* on behalf of two civil society groups. The silicosis case is a class action lawsuit against 32 gold mining companies that are operating in South Africa. There are two classes in the case: one comprising current gold mine workers, and another comprising former gold mine workers who contracted silicosis on the job and their dependents where the mine worker died as a result of the silicosis. The case is set to be heard in October.

Education work

Also during my time at SECTION27, I had the opportunity to participate in class presentations regarding sexual abuse in schools. SECTION27 created a handbook for student who are sexually abused in school by teachers. This handbook had the aim of helping empower students and educating them on what to do if they or a friend are sexually assaulted at school. The workshops were extremely helpful to student in letting them know step by step what to do in the event they are sexually abused, (which forms to fill out, where to go first, etc.), and also educated them on their rights as learners when it comes to abuse by authorities. The sexual abuse workshops were so well received and so helpful that many school requested that the handbook also include information for students who are abused at home, by their peers, or by strangers. Unfortunately due to the volume of cases the education team was inundated with, the sexual abuse workshops were delayed until the casework is done later this year.

I also had the opportunity to help edit a report on the state of blind schools in the country. This meticulously researched report documented the atrocious state of schools for disabled children, specifically blind children in the country. Many of the teachers in these school were unable to read braille, and many of the schools were completely unequipped to be safe environments for visually impaired leaners.

During my time at SECTION27 the education team was also working on litigation for a case regarding the absence of textbooks in many rural schools, and another case regarding the unsafe conditions of many schools, which led to the death of a young boy. Although I received some exposure to these cases, I did not work directly on them.

Conclusion

My experience as an intern at SECTION27 gave me a completely renewed sense of why I wanted to pursue a legal career. Through my time at SECTION27 I was exposed to advocacy work, legal research and writing, casework, and policy work. My IHRP experience was an invaluable one, and I learned many skills and was exposed to truths that I would not have been able to learn in a classroom. It was refreshing to be around such passionate and talented individuals, and I hope to continue to be involved with the great work that is being done at SECTION27.