

## **Rehabilitation: A World of Opportunities**

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*Mary was a widow and mother to six children the oldest of which was thirteen years old and 7 months pregnant. Mary was also in the end stage of the disease and had full blown AIDS. Even with her health failing she wanted the dignity to be able to receive her guests in the living room and had her co-wife (in Kenya the practice of polygamy is still prevalent in the rural areas) help her out of bed and into a chair. My presence there was not going to change the inevitable passing of Mary but I was able to teach her how to splint her stomach while she coughed which had a large painful tumor inside of it. Her inability to move around complicated her situation as she had developed pneumonia. Through talking with Mary for that brief period that day and making handling suggestions to her co-wife I was able to provide some source of comfort to a painful process and make her journey a little easier. I realized that there truly is a role for physiotherapy within the context of this environment and it is an area that needs to be developed further for the sake of people like Mary.*

Today we recognize twenty years of rehabilitation at McMaster University. I am deeply honoured to be named this year's Helen Saarinen lecturer because much of the reason that we are able to be here today is thanks to the innovation and visioning of Helen Saarinen and the staff and faculty that worked along side of her. The McMaster Rehabilitation Sciences programme was founded in 1989. Since that time, McMaster pioneered the first problem-based learning curriculum in Occupational and Physiotherapy that has been the model for health care education around the world.

In the spirit of this global impact, I chose the title of this lecture "World of Opportunities" for two reasons. First, because it is a shameless play on words to promote the International Health Division of the Canadian Physiotherapy Association of which I am the Chair. Second, and more importantly, it is my belief that the possibilities within the rehabilitation sector are endless and thus a world of opportunity.

This is the basic premise for my talk today which I hope will inspire and motivate you to be able to use your own areas of expertise to be innovative and effect change where it is needed and to allow me to do what I love and that is share the stories from my journey as a physiotherapist so far.

I wish I had had the chance to meet Helen Saarinen. In speaking to those who knew her, her love of her profession was quite evident.

Helen was described as having the ability to recognize the state of the big picture and to have the commitment to challenge the systems that are in place to be able to effect change. Those who knew her said that Helen had the ability to see the potential in people and found ways to nourish that potential. She was innovative, wanted to try new things and was willing to take chances that would turn the world of physiotherapy on its head. Her philosophy was that it was better to take

chances, try something and fail than to not try something new at all. Innovation and change is essential because as Jane Hudson wrote in the Journal of the CPA in December 1960:

*“Neither we nor the profession we represent is standing still. Therefore, let us study, analyze our situation and be a part of a vital program of progress...” Jane Hudson*

In thinking about Helen’s attributes, I started evaluating and reflecting upon my own experiences and what it means to be innovative and to effect change. I’d like to share with you six key points relating to my experience and insights on innovation and change potential within rehabilitation.

## **Have an Awareness of the “Big Picture”**

Firstly, in order for there to be innovation, an awareness of the big-picture and the issues of disconnect must be recognized.

*“Restlessness and discontent are the first necessities of progress.” Thomas Edison*



Prior to entering the Physiotherapy Programme at McMaster in 2001, I had the opportunity to volunteer in an orphanage in Zimbabwe in 1999. At the time, I was working as a kinesiologist in an outpatient orthopaedic clinic and was thinking about next steps in applying to physiotherapy programs in order to work with athletes in sports injuries. I was pretty set in my mind on a career path.

The trip to Zimbabwe completely redirected my career objectives by opening my eyes to a broader community and an emerging health need. At the time, there were a growing number of children admitted to the orphanage as a result of HIV to the point where the orphanage was at its capacity and there were no treatments available.

In my short volunteer experience I provided basic childcare for 3 babies in particular who came to the orphanage sick and the uncertainty about what their life would be like continually entered my thoughts once I resumed work in Canada. I didn’t apply to return to university for advanced training because I couldn’t conceive what my role would be in my predefined understanding of what physiotherapy was and I put my life on hold until I returned to Zimbabwe a year later because I couldn’t stand not knowing how these children were doing.

I returned to Zimbabwe a year later and found the three infants healthy, plump and playful. But there were other children who weren’t so fortunate and had died that year from HIV and other unnamed illnesses at the orphanage. Returning to see the changes I knew if I was going to let



the situation permeate my thoughts, that it was going to do so in a positive way and that it was time that I needed to develop my own skills and to start doing something about it.

I started thinking about the skills that I had and my initial goal to become a physiotherapist. I recognized that a number of the children had developmental delay and that there had to be some kind of role for rehabilitation in this scenario. I entered the physiotherapy program at McMaster in 2001 with the notion that there might be a role for physiotherapy within the global community in the treatment of HIV/AIDS.

*This is where I must confess...* I sat in the lecture hall in the basement of the Institute for Applied Health Science during the whirlwind week of my first week of physiotherapy school, uncertain that I was really in the right programme until Dr. Patty Solomon entered and introduced herself and added in a one off comment that she was doing research in the area of HIV. At that point, I lit up as my suspicions that there is a role for rehab in HIV care were validated and I thought to myself, "I knew it!!" so I decided to stay.

In this sense, the awareness of the big picture of an emerging issue of HIV and my personal feeling of disconnect in how the issues was being addressed in Zimbabwe acted as a catalyst for innovation and self-discovery for the opportunities available for rehabilitation.

### **Be Flexible when Working Towards a Goal**

This leads to the second insight related to innovation. Often we can set a course and make a plan however there needs to be some forgiveness and flexibility in the process of working towards the goals that are set for oneself.

*"The most successful people are those who are good at Plan B." James Yorke*

Towards the end of the physiotherapy academic program I discovered that rehabilitation research was taking place in Canada. The Canadian Working Group on HIV and Rehabilitation was established to help understand our role in prevention, care, treatment and support of people living with HIV, with the ultimate goal to improve quality of life for people living with HIV. That Canadians were taking charge in becoming the leaders of HIV and rehabilitation should not have been a surprise to me.

What was a surprise to me was how HIV and rehabilitation was not on the radar in sub-Saharan Africa where the pandemic was reaching peak incidence in several countries. I wanted to return to Zimbabwe but I couldn't find a clinical supervisor for a number of reasons: health care professionals were in short supply, many were also dying themselves from viral infection, drugs were not available in the area so clinicians who were infected and could afford it were leaving the country for treatment and those who remained were too over-worked to be in a position to take on a student.

Aside from the fact that the political environment was not favorable for foreigners and I'm pretty sure that the university would have put a kibosh on my idea anyway, I had to question my

motivations and think about whether my presence was something that would assist or create more issues in an already complicated and fragile situation. *I had to have a plan B.*



Fortunate for me, I was placed in contact with a Kenyan Physiotherapist who coordinated a disability programme in rural Kenya who was willing to supervise me in my final student placement and who very simply replied to my long-winded explanations, justifications and request for a placement with an email that read: “*Just come.*”

I completed my final clinical placement as a physiotherapy student in rural Kenya in a disabled children’s program and within a separate community based rehabilitation programme for people with HIV and AIDS. My goal was still to understand the clinical role for rehabilitation in HIV however; I needed to be open to a different approach, which allowed me to explore the opportunities in rural Kenya, which proved to be an enriching and extremely educational experience beyond what intended goal. I had embraced “Plan B”.

For context, I’d briefly like to tell you a little about the placement: I stayed with my supervisor Mr. Okidi and his family who subsequently gave me my own Luo name “i luo angi Julie Akinyi” as was quickly adopted into the large African family.

Every day was host to new learning experiences. Mr. Okidi’s community based rehabilitation program services the entire province where an estimated 140 000 people with disabilities are living. There are other therapists within the hospitals however many people in the rural areas are too poor to access hospital services. This responsibility for a large geographical area meant that we would travel to different locations every day and only once a week were we predictably in the clinic.



On clinic days, people with disabilities would be seen hiking up the rural road and through the fields from all around either walking on crutches, hitching on the backs of bicycles (boda-bodas) or being carried piggy-back or transported by family members by whatever means that could be found. All people with disabilities were invited to attend the clinics and so I learned first hand about a wide variety of conditions.

Many of the clients presented with issues relating to polio, for which I had only seen in older adults in Canada as post-polio syndrome. Although vaccination programmes have eradicated polio in Kenya, there are large numbers of children who have been affected and who have not been adequately managed as a result of poverty and rural living.

I saw children with cerebral palsy, congenital malformations, amputations and burns. Cooking over open fires leads to a lot of burns especially in young children who play close to the fires. People who were blind, deaf or had other communication disorders would come to the clinic. I treated people with tuberculosis whose infection had traveled throughout their body and into the spine and the brain to leading to serious orthopaedic and neurological complications.



We would travel to homes often in areas where we couldn't drive because the mud was so thick. It was during one of these home visits that I met Mary whom I introduced you to at the beginning of this presentation. We would show up at people's homes unannounced so as to get a true picture of how children with disabilities were being cared for by their families. In this sense the scope of practice expanded to include being the eyes of the children's protection society in the area. Much of my responsibilities in addition to assessing needs and providing hands on therapy included, measuring and fitting people for calipers, crutches, splints, wheelchairs and orthopaedic footwear that we would then need to make out of metal and leather.



Returning to the second key insight relating to innovation. As you can see, I may have set a course and made a plan to learn about one thing, however, through readjusting the process by which I reached that goal, the innovative process was much more rewarding than my original intention and I learned not only about HIV impacts but also about the prevalence of disabilities in the majority world. There are over 650 million people living with disabilities throughout the world, and 80% of these reside within resource poor communities.

## Take a Risk

This brings me to my third insight into innovation. It is inevitable in that in the pursuit of progress an element of risk taking also transpires. The question is, who is taking the risk and at whose expense? Moreover, how do we decide whether the benefits outweigh the risks?

*"Don't be afraid to go out on a limb. That's where the fruit is." H. Jackson Browne*

When I made my way as the first student to participate in a placement in this part of the world there were a number of stakeholders in this risk assessment.

Although keen on innovation in educational opportunities, McMaster University was taking a risk in allowing a student to participate in a clinical placement in the uncharted territory of a resource poor community. Little was known about the physical and clinical environment that I would be visiting other than the brief email communications that I had received from my supervisor and as you will recall, was not a man of many words.

It was likely there would be minimal contact and much was unknown about the supports available should something go wrong. Was this placement going to offer me the clinical training that I would need to be an excellent therapist in Canada? One thing that we did know was that I was going into an area where malaria was endemic.

As it turns out risk can be minimized if we use our skills of self-directed and problem-based learning. I recognized malaria as a problem and to measures to prevent it. I very quickly learned that a mosquito net although in the movies romantically drapes on the ground does nothing to keep mosquitoes out unless it is tucked in. I also learned that it is difficult to tuck in your own net in the middle of the night in the pitch dark by the light of your Indiglo watch when you are not certain whether the mosquito you are hearing has already found a way in and you are possibly sealing him in.

Clearly, I was taking the physical risk. I laugh now because I suppose I should have been more concerned about my safety however I was too pre-occupied with the concern that if I didn't get to see a certain number of clients that I might not meet my academic requirements and risked potentially not graduating. *Oh the horror!*

The biggest risk in this type of student placement initiative is not born by the student or the institution however; the biggest risk was for the community that received me into their programme.

It was a risk taking on a student from Canada because resources were already limited. Hosting a Canadian meant trying to mobilize resources to accommodate not only my educational requirements, but also accommodating the safety and lifestyle expectations that my hosts knew a North American would expect. (I'll be honest; I was pretty useless where rural Kenyan lifestyle was concerned... milking cows, slaughtering chickens, cooking over a flame in the dark ... I needed all the resource support I could get.)

Not only was it risky in terms of diminishing resources, it was also a risk because of the expectations that my presence would introduce to people in the community. For example, I became acutely aware of the fact that people from the community with disabilities would expect that if I made a recommendation for a piece of equipment that that equipment would also be provided by me because I have the financial means to make it happen. If I provided the equipment it would immediately benefit the client but it also introduced an unsustainable practice that would undermine the community-based programme and the local expertise that often would offer alternative solutions or would negotiate with the client and their family ways around the problem of no equipment or no money for equipment. This active engagement in problem solving is important for the empowerment of the clients we work with.

So far, I have been focusing on the concept of innovation. The goal of innovation is to be able to work towards effective change with the end goal of having a positive impact within our area of influence. Therefore, the next three insights relate to effecting change.

### **Use (and Build Upon) the Tools Available**

In order to be able to effect change, it is wise to use the tools that are available and build upon them.

*“Nobody can go back and start a new beginning, but anyone can start today and make a new ending.”  
Maria Robinson*

There are a couple of quick stories that can illustrate this point:



Samuel was an eight year-old boy with hydrocephaly who I met during my placement. He was a real character with no verbal filter, he would say pretty much whatever was on his mind and so everyone liked him for his candor, or disliked him depending on what was said. His mother Pamela had asked if I could train him to walk and he came to live at the clinic for a week with this goal in mind. During my assessment, I learned that Samuel’s mother had trained him in head control, sitting and standing balance.

Everyday when Pamela needed to go to the garden, she would bring Samuel. She would dig a hole in the ground and bury him in it up to just below his chest. She would then go to work in the garden and keep an eye on him. Soon he began to learn to lift his head to be able to see his mother and what was going on around him. At the end of the day she would unbury him, take him home and clean him up. The next day would be a repeat of the same and little by little she started needing to dig the hole shallower and shallower.

As a disclaimer, I’m not recommending this as a therapeutic technique. Can you imagine what Children’s Aide would say to that if someone tried that in Canada? Although, the point may be that tools for innovation can be really low tech, respecting the expertise of Pamela and the resources she had available allowed me the opportunity to begin advancing a plan for Samuel’s rehabilitation.



Along the same lines, sometimes the latest and greatest technologies need not be the starting point for change rather we should start with common sense. Brenda came into the clinic with known brain damage as a result of malaria that had caused prolonged high fever. She did not attend to anything or anyone other than on occasion she would watch and smile at her father. She would continually flap her hands above her head, which greatly distressed her family.

We were so excited to learn that there was a pediatrician and an MRI in the town 30 minutes from where we were, (which was kind of in the middle of nowhere), that could provide advanced insight into what we should do. We thought it would best serve Brenda to take her for conclusive diagnosis and recommendations before commencing a rehabilitation plan.

Brenda needed to be sedated because of the flapping. She could not be still inside the MRI. She then spent two days in hospital recovering after the sedation. Her MRI was read and she and her father returned to the clinic with a note from the physician with the much anticipated results and recommendations. The report read: *“This child needs rehabilitation”*. We used the element of play and worked with her father who was the only focus that she had on activities that required both her hands.



Finally, I discovered the best tool to build upon was the confidence in my own skills and ability as a clinician. The more I worked in a resource poor setting, the more I had to rely upon the skills, knowledge and creative problem solving from my training which the community brought out in me because there really weren't a lot of other options.

My physical assessment skills became stronger because there weren't charts and other diagnostic tests to turn to for a diagnosis. I learned the art of negotiation especially with family members who were hesitant to build parallel bars convincing them that in addition to helping their child with their gait that the bars would also serve as a great place to tie up cows. I braved removing a cast from a child's foot using a rusty saw and by the end of my time with Samuel, the child who was buried daily, I had taught him to take 15 steps with minimal assistance. I realized that I actually knew things upon graduation, helpful things, things that could make change in my client's lives.



All three of these examples illustrate the importance of building upon the tools that are available in order to effect change.

## Recognize the Potential in Others

The fifth insight relating to effecting change is being able to recognize the potential in other people.

*“Never doubt that a small, group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.” Margaret Mead*

I returned to Canada and started talking to the graduating class of 2004 to let them know about the opportunity to engage with an amazing community in Kenya. I figured if I was able to do this, and I am not a super hero, then there is huge potential for other students and trained professionals in rehabilitation to become involved and to also have the same kind of experience.



The Kenya Working Group (KWG) of the International Centre for Disability and Rehabilitation was founded in January 2004 as a volunteer based, grass-roots non-governmental organization to help make it easier for students and rehabilitation professionals to have this international experience and to continue supporting community based rehabilitation through research, education and service provision in Kenya.



From humble beginnings, the group has grown to 79 members connected through our website with an additional number of people who have joined the KWG Facebook group. Recognizing that people have different interests in supporting the work of the KWG, several subcommittees have been set up. There is an academic liaison for student placements, a fundraising group to support initiatives financially, a research subcommittee that has begun looking at our impact and the use of outcome measurement in the community and there is a whole social aspect of connecting with like-minded colleagues who love this work.

Since establishing the Kenya Working Group, 42 Canadian volunteers have traveled to the project area to continue supporting rehabilitation work in the community. When volunteers visit the rural areas, they do so along side local professionals to be able to learn from each other and to help build capacity in the rehabilitation sector within Kenya.

Success in the growth of this group and its programs relate directly to the strength of the skills, knowledge and attitudes of not only the Canadian volunteers but in the potential of our partners in Kenya who support and guide us. In this regard, recognizing the potential in students and colleagues both in Canada and abroad was important to carry on with the continuum of care for clients in the community and as being agents for change.

How do we know that we are making a positive impact in the work that we do? (Being a McMaster graduate I am constantly seeking evidence to support the work that I engage in doing.) As mentioned, we have started to introduce outcome measurement in the program to evaluate quantifiably the fruits of our labor. Although less quantifiable, I'd like to share one more story with you.

Beatrice is a thirteen year-old girl whose father carried her into the clinic because she could not walk. She was from a distant village in a difficult area to get to called "Monkey Bay". She had polio as a child and as result she had weakness in both legs with her left more severely affected. Her father carried her everywhere as a child and now that she was reaching puberty she was

becoming too heavy (He was after all, kind of a scrawny guy).



After some muscle testing I found that she had strength in her hips and gluteal muscles and with a single caliper and a pair of crutches we were able to train her to walk. She went back to the village and got out of the bus on her own and much to the amazement of the community she walked. Her community who had seen her carried everywhere considered it to be a miracle.

Several weeks later, while in Kenya, my husband and I were invited by the chief of the area in Monkey Bay to attend a "Christmas Party". We were relieved because there had been a lot of work leading up to Christmas so we welcomed the break.

It took almost half a day of travel on local transit, in a shared taxi, on the back of a bicycle and after a long hot, dusty hike to get to this party. When we arrived we found that we had been hoodwinked. There was no party! What we did find is that every person and his cousin with a disability for miles had come to be assessed because news of Beatrice's story had spread and people came looking for some of the same.

## Value the Present Time

The sixth and final insight relates to timing of change. We can't spend too much time seeking the right time for change, or the opportunity to be effective now will be missed.

*"Very few things happen at the right time, and the rest do not happen at all." Herodotus*

Undoubtedly, timing is an important factor in the introduction of change. In preparation for this lecture I was highly ambitious in my estimation of what kind of impact this particular lecture would have and I purchased a CD called "Speeches that Changed the World."

Interestingly I noticed that all of the speeches chosen were highly relevant because of the precipitating environment in which they took place. Churchill in the declaration of world war II, Nelson Mandela upon imprisonment and at his release echoing the dawn of a new era in apartheid history were examples from this CD. What I noticed, is that the speeches weren't so much the factors that created the change, rather the change was happening and the people giving the speeches were able to put a voice to the changes taking place thereby acting upon the opportunity.

*"Change will not come if we wait for some other person or some other time. We are the ones we've been waiting for. We are the change that we seek." Barack Obama*

In 2003 when I proposed to undertake a student clinical placement in Kenya, the environment was right to allow a student to do so and so began the precedence of allowing student clinical placements to Kenya. It was also an interesting time to bridge the concept of rehabilitation in HIV in Kenya where rehabilitation clinicians were not engaged in working with this population.



Last summer the KWG was invited to host a workshop and to speak about the role for rehabilitation in HIV with therapists from across the Nyanza province. Local Kenyan therapists were keen to learn as more clients are knowingly seeking treatment for HIV related illnesses in this area.

It is not an issue of waiting for the time to be right, it is a matter of recognizing what time is the present and how you can use the gifts, skills and knowledge that you are given to make a lasting change.

As rehabilitation professionals we need to continually be seeking active solutions to current problems that affect our own communities in tandem with community issues abroad.

I'd like to now review the six key insights that were inspired by Helen Saarinen's attributes and learned through experiences on my journey as a physiotherapist:

## Relating to Innovation:

- In order for there to be innovation, an awareness of the big-picture and the issues of disconnect must be recognized.
- Often we can set a course and make a plan however there needs to be some forgiveness and flexibility in the process of implementing the plan.
- It is inevitable in that in the pursuit of progress an element of risk taking also transpires.

## Relating to Effecting Change:

- In order to be able to effect change, it is wise to use the tools that are available and build upon them.
- Recognizing the potential in other people will strengthen your efforts.
- We can't spend too much time seeking the right time for change, or the opportunity to be effective now will be missed.

I would propose that the time we are presently facing is a time of global health interdependence and many of the health issues that affect us are echoed throughout the world. We can be leaders in our area of expertise.

Former Minister of Health for Mexico, Dr. Julio Frenk highlighted the international transfer of risks and opportunities as being one of the biggest health challenges affecting our health infrastructures and systems. Globalization in its relationship to international health has removed the fences that separate us from our neighbors.

*“‘Health interdependence’ is a fact of life today across the planet, because it’s not just germs that travel. It’s also ideas and lifestyles.” Julio Frenk, Former Minister of Health (Mexico)*

As rehab professionals, we go beyond treating the joint, acute inflammation or the multitude of impairments we encounter. Through rehabilitation, we provide the tools for quality of life, function, well-being and for many, *hope*. We are trained to think about long-term solutions to problems that arise. We are specialists in looking beyond quick fix solutions and can be effective in bringing about positive changes in the communities in which we work.

The power we have comes from the knowledge and skills that we have trained and developed through our education. Our minds and our hands are the tools we use to put this power into action. The degree received from this institution as well as other academic institutions around this great country all represent an amazing amount of power that will open doors that lead to a world of opportunity.

It is our responsibility to recognize how, where and when to use this power. It is a comfort to know that we have a good solid history behind us. Twenty years at McMaster University alone provides an abundance of lessons learned that can help build and shape other institutions that are still in their infancy. We are a strong profession thanks to visionaries and trail blazers such as Helen Saarinen. It is now our time to recognize the opportunities and responsibilities before us.