



Confidence

HIV-positive capacity building: reclaiming our confidence

By James Watson

As many of us understand, HIV can place enormous strain on the mental health of even the most physically healthy PLHIV. It can put dreams out of reach and damage one's ability to formulate future goals.

The "capacity building process" is an essential part of Community-Based Research (CBR)' and can have a profound impact on the well-being and life course of people living with HIV and AIDS (PLHIVs). 'Capacity building' is an approach to personal/professional development that builds independence. One goal of capacity building is to empower people to address their own challenges, particularly those that arise from social inequities and stigma.

However, questions remain about accountability, sustainability and the power dynamics involved in the CBR capacity building process. There is societal value in our lived experiences as PLHIVs. By sharing some of my story I hope to illustrate a few of the joys, pitfalls and limitations involved in CBR capacity building; by doing so I hope to initiate a discussion on the development of best practices for this vital component of CBR.

As many of us understand, HIV can place enormous strain on the mental health of even the most physically healthy PLHIV. It can put dreams out of reach and damage one's ability to formulate future goals. In my case, I became lost and damaged within the very support program that was supposed to help. I was adrift in a provincial disability support program

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in Ontario, Canada, surrounded by endless bureaucracy. The way home to the safety of 'real world' careers and paid vacations seemed fraught with insurmountable obstacles. I had almost given up hope for a job, let alone a career. I was a specialist at leaping from one cash-in-hand job to the next. This enabled me to live with a modicum of dignity, despite being marginalised as a social pariah for attempting to survive.

As one year faded into the next, my self-confidence eroded and I found myself isolated and depressed. I was embarrassed by my situation and bought into the stigma associated with disability, poverty and social housing. I felt incapable of participating in everyday life. These feelings were exacerbated by my confusion of being physically healthy when I was feeling so miserable. The local AIDS service organisations meant well, but at the time seemed incapable of helping a healthy PLHIV reintegrate into the working world. Prevention, outreach and (at times) oversimplified case management took precedence. I felt

that none of the organisations were capable of offering guidance suitable to my situation.

With nowhere to turn, I turned inward, resentful and angry towards myself and others. I instinctively knew what the problem was; I knew that feelings of inadequacy combined with a lack of ability to control my environment where the reasons why I was miserable, but could find no solution. I needed purpose, direction and meaningful achievement.

I was close to giving up hope when the seemingly impossible occurred. I heard of a job opportunity where an HIV-positive diagnosis was a mandatory condition of employment. Distrusting but desperate, I made cursory inquiries into this possible good fortune. The listing was for a position as a Peer Research Assistant (PRA) for a research study entitled "Positive Spaces Healthy places" (PSHP). I was unsure what was involved but couldn't pass up the opportunity to refocus my knowledge of this disease into something positive.

PSHP was the first longitudinal CBR initiative in Canada to examine the relationship between housing status and stability on the physical and mental health of PLHIVs.² The job description said that "no experience was necessary" *except* the experience of (1) living with HIV and (2) a desire to make a difference in the lives of my peers. As I researched CBR and its holistic approach, an awakening of sorts took place. I no longer felt alone in my thinking that there is more to a person's health than clinical data (with its fearful counting of T cells and viral loads). I recognised the *personal* in CBR and discovered that community ownership and actionable information that makes it possible. The opportunity to be part of this field, where social factors were recognised as determinants of one's health, was one I couldn't let pass by.

After the interview, where my sincerity heavily outweighed my work experience, I managed to secure the job. Thankfully, CBR is a field where lived experience and a desire to build your capacity are highly regarded. This form of research strives to evaluate the social determinants that affect the lives of PLHIVs, while building confidence and skills from within the project itself. This capacity building component is essential and needs to be built-in to any quality CBR project. The goal of the research process and resulting data is to make an impact that is relevant and useful to community organisations, researchers, policy makers and PLHIVs. The impact on my life began the moment we started training as Peer Research Assistants.

I entered the first day of training with six other PLHIVs from across

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the province with eyes open and knees shaking. It was an education I embraced and soon became an ardent supporter of CBR principles. I came to understand that as PRAs, we were central to the project's success. The common experience of living with HIV, regardless of race, ethnicity, gender, culture or any other social construct was a shared life experience of profound importance. A cornerstone of PSHP is PLHIVs interviewing PLHIVs, in an environment of safety and understanding. This key component is not only deeply ethical, but the best way to illicit honest responses. It had been a long time since I was central to work of substance; I could feel my self-confidence returning.

However, it was not all sunshine, rainbows and hugs for all. I was unprepared for some of the power dynamics and politics of researchers of various backgrounds. However, at the end of the day, CBR is kept honest by the PLHIVs embedded in its mission and methods. We were the front line workers in this initiative, responsible for the screening, interviewing and administration of the participants, and were promised future involvement in the analysis and presentation of the results. Our input as PLHIVs carried weight, and was paramount to the projects' integrity. When we raised concerns we were listened to with respect as equal partners. After years of having little influence in society, this egalitarian approach to decision-making was exhilarating.

In hindsight, I may have been somewhat naive to believe that such democratic processes could endure beyond the level of the CBR proletariat.

It seems to me now that if capacity building is to prepare you for your future, protecting you from *all* division and disagreement might hinder rather than help your progression.

It was through the capacity building process that I found a new direction and purpose in my life. Surprisingly, the participant interviews themselves contributed greatly to my personal rehabilitation. Hearing these diverse stories of struggle and survival was difficult, but a profoundly cathartic experience. It was an honour to bear witness to these complex personal tales, and a privilege to be placed in a position of such confidence and trust. At the same time, it is not easy and sometimes exhausting, when parts of your own story are reflected back to you with regularity. This was why, as part of our training as PRAs, we focused on self-care and took the time to debrief as a team. We gained the capacity to keep an appropriate level of distance from participant experiences, in order to prevent losing ourselves in the fog of personal tragedy.

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As the interviews drew to a close the capacity building continued. We were offered opportunities to attend workshops and to present results at research conferences and forums. We added our voices to journal articles, and some were hired to participate as research assistants in other projects. The successes of the study ultimately lead to its extension and the continuation of our involvement in the project.

“Capacity building” had a positive effect on us all. I regained the self-assurance to return to school and the following year was offered a job by the Ontario HIV Treatment Network (OHTN), a partner in the PSHP research project. I was hired as a project coordinator; one of my projects was to help oversee the next phase of the PSHP research study. I was overjoyed with the job offer and couldn't believe what opportunities had opened up for me since being involved in community based research. However, with this first full-time job

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in many years came apprehension and a new set of challenges. Although promised support, I felt out of my depth and unsure of myself. Was this the beginning of another phase of the capacity building process or the end? Was I still under the protective wing of supportive educators or now a “regular” employee with all of the expectations of that role? I was surprised at my level of stress over possible failure.

What I may have needed was mentoring. I brought unique and important skills to my new job, but what I didn't have was the confidence to hit the ground running by myself (or experience with a photocopier!). If a capacity building framework is not built in to an organization's mandate, it may be challenging to offer professional support for the inexperienced. I argue that if capacity building is to succeed in the long run, without inadvertently setting a person up for failure, support and training opportunities need to be in place throughout the transition from

part-time contract work to unfamiliar full-time work. A detailed plan of support needs to be actualised for PLHIVs, so that well-earned feelings of self-efficacy and self-esteem are sustained. I had been instilled with the gentle and more holistic values of CBR capacity building, and my understanding of this process collided with the “real world” structure of corporate hierarchy and employee/ employer expectations.

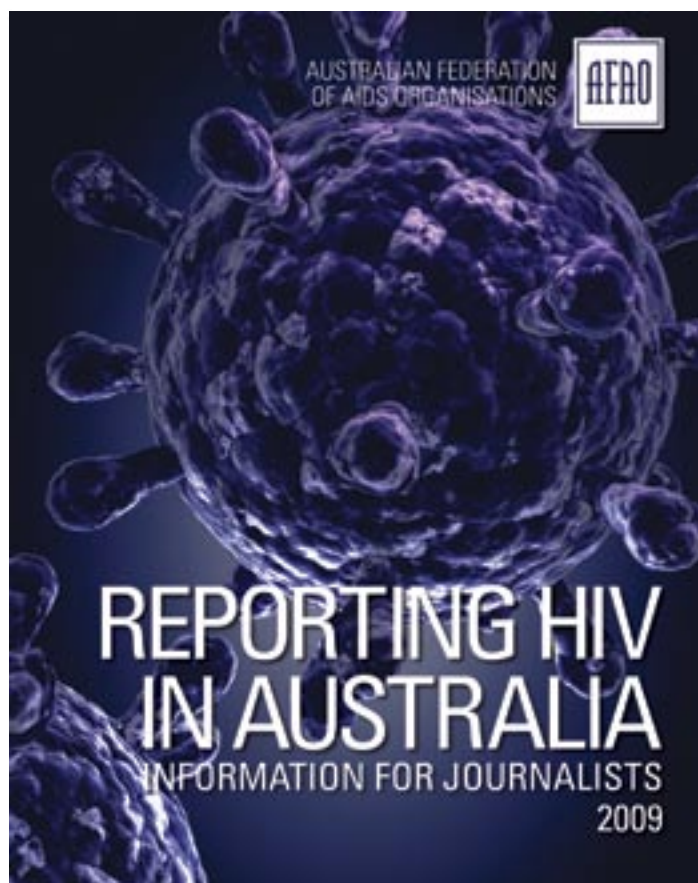
I have had moments of concern about the effectiveness of PLHIV capacity building and its ability to support lasting full-time employment. If CBR capacity building is ultimately to succeed, there needs to be buy-in and coordinated planning from all organisations with a stake in the future health and well being of PLHIVs. It has been a difficult personal progression at times, but I fully support CBR and the capacity building that it can provide. Thankfully, the OHTN, where I am a Research

Coordinator, is taking a leading role in Ontario by initiating the development of a Peer Research Training Institute, where diversity, career support and sustainability are at the forefront of its vision. The future looks bright for capacity building in my province as we progress with PLHIVs not as passive recipients, but as equal partners.

References

- 1 Community-based research (CBR) is a collaborative approach to research. It is based on community involvement in all stages of the research process as equal partners. In CBR, community members work in partnership with academics and scientists to put research into action.
- 2 A longitudinal CBR initiative is a research study designed to follow the same group of people or participants over an extended period of time.

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www.afao.org.au

FOR JOURNALISTS AND OTHERS WRITING ABOUT HIV:
www.afao.org.au/ReportingHIVinAustralia