

Chapter 10

A Social Entrepreneurship Framework for Mental Health Equity: The Program Model of the Canadian Centre for Victims of Torture

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Abstract Social entrepreneurs, generating unique and highly leveraged responses to major social problems, forming strong connections within communities and creating social capital, are increasingly sources of solutions to complex problems in under-resourced settings. This chapter uses a social entrepreneurship lens to examine the work of an internationally recognized organization serving victims of torture and political oppression. Key components of social entrepreneurship promote an effective response in fragmented and under-resourced health service contexts characterized by narrow, individualistic conceptualizations of mental illness and treatment. The social entrepreneurship framework can be useful in guiding individuals and services early in their development and in providing decision makers with criteria against which they can identify services to have the greatest impact on immigrant and refugee health.

Keywords Refugee · Torture · Service · Intervention · PTSD · Social entrepreneur

10.1 Mental Health Services for Immigrants and Refugees—Questions of Access and Adequacy

In contrast with the increasing recognition of the importance of addressing mental health as a public health concern there remain numerous fundamental shortcomings in the solutions generated. Specifically, while we have a better understanding of the social and economic costs of mental illness and have developed a range of effective interventions, access to adequate treatment and services remains a major problem.

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In high-income countries, fewer than half of individuals with mental illness receive adequate treatment- 41 % in the United States (Wang et al. 2005) and in many low-income countries a ratio of one psychiatrist to 1 million people is common (Saxena et al. 2007).

This problem of providing effective and accessible services to individuals struggling with mental health concerns is further compounded for newcomers. It is not a problem of heightened rates of illness, as there is every indication that immigrants do not on average suffer from poorer mental health than non-immigrants (Tiwari and Wang 2008). This is a consistent finding across many developed countries though there are some exceptions, such as indications of higher rates of psychosis among individuals of African-Caribbean descent in the UK (Cantor-Graae and Selton 2005). Where the challenge lies, in terms of the provision of adequate care to immigrant populations, is in service access. Most immigrants, particularly racialized immigrants, are not accessing mental health care when it is needed (Alegria et al. 2008; Tiwari and Wang 2008). In this area, immigrants have much in common with other marginalized groups that do not have adequate access to care (e.g., sexual and gender minorities or homeless persons). While the overall rates of mental illness for many immigrant groups is on average lower, when illness is experienced they are far less likely to receive care. It is around this issue of access that the disparities in mental health emerge, and in which the impacts of mental illness are exacerbated.

The question of the origin of this disparity in service access and the associated worsened course of illness would seem to lie both in barriers to accessing care (such as a lack of awareness of the available services; lengthy waitlists for available services; lack of health insurance; language barriers) and the lack of appropriate models of care (Wu et al. 2005). It is this latter problem in the delivery of services to immigrants that is the focus of this chapter. Specifically, we will be focusing on services for newcomers who have fled countries in which they have suffered from political oppression, violence and torture.

Fundamentally, the difficulty in developing effective mental health services and service networks for immigrants and refugees lies both in difficulty defining the problem and the associated conceptualization of solutions. The shortcoming of problem definition that is present in most western contexts is one of service systems not employing a social determinants framework (WHO 2008). Mental illness is understood as a circumscribed problem of an individual that is framed in the form of the decontextualized presence or absence of a certain number of symptoms (e.g., criteria of the Diagnostic and Statistical Manual of Mental Disorders; DSM-IV). Flowing from this definition of mental illness are treatments that are illness-focused and typically applied as individual-level interventions. Ideally, these interventions are “evidence-based”, with evidence defined as demonstrated effectiveness in randomized trials which are optimized when interventions are circumscribed and amenable to being manualized. This approach is reified by siloed and poorly integrated funding streams that provide little encouragement, if not active discouragement, of the development of services or integrated systems that address the social determinants of health. From a cultural perspective, the problem of having such narrow definitions of illness and treatment is compounded by the fact that many persons immigrating to western contexts do not understand mental illness within such a framework.

A second difficulty that impedes effective efforts to address mental health disparities for immigrant and refugee groups is what appears to be a poorly coordinated approach to generating solutions. Looking to the research, it is immediately evident that there is a preponderance of research documenting risk factors and rates of illness that is greatly out of proportion with the study of the effectiveness of culturally appropriate interventions. Outcome studies are scarce and even more rare are randomized trials examining culturally grounded interventions (Aisenberg 2008; La Roche and Christopher 2009). In most Western service settings, the most common effort to address mental health equity has been the provision of “cultural competence” trainings. In these trainings providers are given general instruction regarding ways of adapting their practice to be more appropriate to the range of communities accessing their services. The problem with this strategy is that such trainings are highly variable in content and quality and there is no definitive indication that they actually impact the services received (Bhui et al. 2007).

10.2 Survivors of Torture and Political Oppression

While there is a general agreement that it is difficult to generate accurate estimates as to the number of refugees who have experienced torture, due to both variability in context and questions about rates of disclosure, it is agreed that the numbers are substantial. It is estimated that between 5 and 35 % of refugees have been tortured (Campbell 2007), with the numbers of those having experienced prolonged periods of political oppression likely much higher. It is suspected that these numbers are increasing given that the number of nations engaging in systematic torture increased from 93 in 1992 to 132 in 2004 (Amnesty International 2004). The generally agreed upon definition of torture is that of the United Nations (1987; pp. 197–198), which views torture as “. . . any act by which severe pain or suffering, whether physical or mental, is intentionally inflicted on a person for such purposes as obtaining from him or a third person information or a confession, punishing him for an act he committed, or intimidating or coercing him or a third person, or for any reason based on discrimination of any kind, when such pain or suffering is inflicted by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity.”

The long term impacts of torture are, for many, profound in physical and mental health domains with the harm carried forward from individuals, to family, community, and cultural levels of impact (Abai 2011). The most common psychological problem identified is posttraumatic stress disorder, with rates of PTSD ranging from 25–65 % of those tortured (Kinzie 2011). Rates of PTSD are predicted by the cumulative exposure to traumatizing events, the time since the traumatic circumstances took place, and the level of political terror experienced (Steel et al. 2009). While PTSD is the predominant focus of much of the torture research, many other impacts are equally if not more prevalent. Somatic problems typically emerge first, with other difficulties emerging over time including high rates of anxiety and depressive disorders and psychosis, and a range of other long term impacts such as irritability,

suspiciousness, guilt, insomnia, and memory impairments (Abai and Sawicki 1997; Campbell 2007; Kinzie 2009, 2011). Furthermore, the effects of torture on an individual have been found to differ as a function of cultural background with, for example, East Asian persons more often experiencing depression (Campbell 2007). Other effects of torture, beyond the individual level, include higher rates of divorce (Gordon 2001) and higher rates of psychosomatic problems and depression among the children of torture survivors (Kira 2002). Overall, poorer outcomes are associated with prolonged displacement and better outcomes linked to permanent placement (Steel et al. 2009).

Generally speaking, torture victims and their families struggle with a broad constellation of physical and mental health concerns (Domovich et al. 1984). They face contexts of tremendous adversity escaping the countries and contexts in which torture took place and face numerous financial and legal challenges in developing safe and stable living circumstances (Gray 1998). All of these challenges are occurring, at least in Canadian and U.S. contexts, in social and legal environments that increasingly see refugees as frauds and in which there is an increasing risk of categorization as illegal, with the associated break up of families, confinement, and deportation (Macklin 2005).

10.3 Models of Care and Support for Victims of Torture: The Evidence

The challenges in developing effective service models for torture survivors are significant and complex. Treatments and services need to address more frequent and severe physical and mental illness symptoms (Domovich et al. 1984), fewer available social resources (Mollica et al. 1998), and more severe consequences associated with deportation. Just as there is little guidance in treatment literatures for all marginalized populations, literature on effective treatments for torture victims is likewise very sparse (Campbell 2007). There have been some case studies, with several completed by Basoglu and colleagues, indicating that cognitive behavioural therapy for PTSD is promising (Basoglu and Aker 1996; Basoglu 1998; Basoglu et al. 2004). There is an emphasis on multidisciplinary models of care which include attention to psychological and physical health (Campbell 2007; Fabri 2011) along with attention to legal (Germain and Velez 2011) and spiritual needs (McKinney 2011), family-level intervention (Weine et al. 2008) and involvement in political advocacy (Gray 1998).

Case studies of services for torture survivors describe services that are grounded in community participation (see McKinney 2007; Ramaliu and Thurston 2003). This includes support for micro-enterprises, self-help groups, and the use of volunteers as “culture brokers” who help refugees negotiate dominant cultures in their new environment. These elements are present in services that provide some components of traditional case management and access to medical services along with support for political advocacy activities. It has been cautioned, however, that a drift towards services in which political advocacy is the predominant or sole emphasis are less effective (Basoglu 2006).

General themes running across the torture survivor service literature involve the need to rebuild the identity of persons affected by torture, with one of the most damaging impacts of torture involving its impact upon individual and community identities (Abai 2011; Ramaliu and Thurston 2003). Interventions, grounded in attention to the social determinants of health, must help individuals and communities rebuild a sense of control and agency, rebuild the capacity for having trusting relationships, and help people move past crippling levels of fear (Basoglu 2006; Gray 1998; McKinney 2011; Winter 2011). Furthermore, there is a general agreement that to have a meaningful impact such services need to provide support for a substantial amount of time given the extent and chronicity of the problems faced (Abai and Sawicki 1997; Campbell 2007).

There are two challenges to the comprehensiveness and depth of the intervention literature as described above. First, is the much-referenced lack of randomized trials (e.g., Campbell 2007; Fabri 2011; Kinzie 2011). There is a risk, however, in this criticism in that it can tend to conflate interventions with services. These authors are correct in noting a need to extend the extensive number of controlled trials of psychotherapeutic and pharmacotherapy interventions to torture survivor populations. It is indeed not clear that existing literature generalizes to this group. The conflation problem arises, however, in that the holistic service approaches that are generally understood to be effective are not amenable to randomized trial designs. This problem is further compounded by the tremendous diversity of the clients of such organizations. What is needed, and what is the second challenge, is a framework or model that can be used to help understand how effective services for torture survivors operate. Some components of these services might be evaluated through randomized trials but many, and certainly the impacts of the services as a whole, cannot.

10.4 Social Entrepreneurship: A Promising Framework

One way of considering the attributes of non-profit organizations that have succeeded in delivering services to marginalized groups such as survivors of torture and political oppression, despite limited resources, is to use the lens of social entrepreneurship. The concept of social entrepreneurship (SE) emerged in the 1980s, growing largely out of Bill Drayton's work in identifying and supporting individuals who were effectively addressing major social problems in developing countries (Bornstein 2007). He and others sought to identify persons who had developed innovative and effective ways of unraveling highly complex systems of oppression, apathy, and dependency to mobilize communities and effect change. These were persons and services which employed highly leveraged approaches—having identified targets for intervention that might yield large systemic change.

While there is some contention as to the meaning of the SE construct, it is generally taken to be defined as individuals and groups who (i) identify and develop a solution that address unmet needs, (ii) are “relentless” in their effort to create social value, (iii) are continuously engaged in innovation and act despite adversity and resource

limitations, (iv) are highly embedded in the communities and networks related to their work, (v) generate social capital and, (v) have developed sustainable and transferable solutions (Paredo and McLean 2006; Myers and Nelson 2011; Shaw and Carter 2007).

There have been several recent calls for the use of the social entrepreneur framework to address health equity (e.g., Drayton et al. 2006; Germak and Singh 2010; Savaya et al. 2008; Wei-Skillern 2010), in large part driven by its applicability to the problems underlying health inequity. Social entrepreneurs are highly effective in connecting multiple sectors and bridging siloed systems (Drayton et al. 2006; Harting et al. 2010). Such an approach is directly relevant to mental health equity which is a function of many health determinants and suffers in most contexts due to fragmented and poorly coordinated service systems. Social entrepreneurs also generate community-based solutions to problems, an approach that is relevant if not necessary to effectively addressing mental illness in many ethnocultural contexts.

10.5 The Example of the Canadian Centre for Victims of Torture

The Canadian Centre for Victims of Torture (CCVT) is an example of a service whose development and operations can be readily understood within a social entrepreneurship model. CCVT, located in Toronto, Ontario, has identified as its mission to provide comprehensive mental health, legal, medical and psychosocial support to survivors of torture and political oppression. CCVT is the second largest organization in the world that works with survivors of torture and war. CCVT has assisted approximately over 14,000 survivors from 136 countries living in Canada. For the past 34 years, CCVT has supported an average of 1,500 clients annually with their clientele including equal proportions of adult men and women and nearly one half of their clients being youth, children, and seniors.

Building from a conceptualization of the impacts of torture and political violence as being systemic, with the primarily impact being that of dissolution of bonds within family and community networks and identities, CCVT conceptualizes intervention as being one of “reconstitution.” This process of reconstitution, of systems, families, networks and communities, is framed as being only possible when driven by the survivors themselves. The role of staff is to create a conducive environment where recovery can take place. It is a process within which survivors are assisted in moving from victims to active community members.

One of the central concepts of the Canadian Centre for Victims of Torture is to see itself as a community. CCVT has a paid core staff of less than fifteen, approximately fifty professionals (lawyers and medical professionals) working voluntarily, and 250 volunteers who assist in every aspect of the organization and acting as a bridge to the community at large. The conceptualization is one of this group regarding itself as a community which can provide a bridge for an individual to move from isolation to contact with others, a place in which network relationships can develop

and in which families can find support in re-establishing themselves. It is also a community which is connected with other communities, both exile communities and the host community.

The care provided includes examination and treatment of abused bodies and inquiry about the experiences of torture that had been suffered. Care also extends through practical help in obtaining accommodation, social assistance payments and, at a later stage, career counselling and assistance in obtaining employment. Psychiatric assessment and treatment, counselling, psychotherapy on individual, family and group basis, child psychotherapy and art therapy are all available. Although clients nominally attend the CCVT on an appointment basis it is not uncommon for them simply to turn up or telephone to talk to whoever is available.

A deliberate attempt is made to create an atmosphere of informality so that clients can regard the CCVT less as a medical facility and more as a safe place, a place in which they can feel a sense of belonging. Some clients have contributed to CCVT by decorating, repairing furniture, providing refreshments at meetings and contributing their own personal and professional expertise to seminars and to publicizing the Centre's work through the media.

In this way, an effort is made to create a setting where survivors can experience themselves as participants making a contribution rather than as victims passively receiving services.

CCVT tries to establish opportunities for clients to establish a common ground with others in which they can experience a common personhood and humanity, and recover and build upon their sense of history and continuity. In this way the traumatic experience is not only approached slowly, but is also set within a larger story of an individual in a family, a network, and a community. The violence and torture are then events within a story, terrible events to be sure, and events which threaten to fracture the story completely, but they are not the whole story or the only story.

We responded with . . . a burning concern with social justice, political action, and the impatience and frustration against a confused world of passive bystanders. (Federico Allodi, CCVT Founder)

CCVT is fundamentally a social entrepreneurial organization. It has a clear social justice framework that assists in (i) bringing focus to their work, (ii) providing a compelling case for support for partners and stakeholders and, (iii) feeding into the a coherent narrative of meaning and agency that is much needed by people who have been tortured (Ramaliu and Thurston 2003). The organization is able to hold this approach of political involvement and activism alongside evidence based interventions such as pharmacotherapy and psychotherapy. In this manner they avoid falling into the problem of some organizations where political advocacy becomes the predominant or sole focus and lessening their overall effectiveness (Basoglu 2006).

CCVT is fundamentally embedded in the communities that it serves. It is not a model of service delivery by "providers" but, rather, facilitates networks of mutual support, volunteerism, and integration. This characteristic likewise has numerous benefits to the organization that are very salient to both the needs of its clients and the current socioeconomic context. With its contingent of volunteers serving roles

ranging from culture brokers to lawyers and physicians, CCVT does not require a large operating budget relative to the services it provides. Furthermore, CCVT is closely in tune with the needs of the communities it services. This leads to a well-grounded and current understanding of the types of interventions which have a maximum degree of leverage. Finally, through its many social forums, the organization engages people in rebuilding the meaning, interpersonal bonds, and trust that are so profoundly damaged for many in contexts of torture (Basoglu 2006; Gray 1998; McKinney 2011; Winter 2011). This emphasis upon social connectedness also extends beyond the organization. CCVT has cultivated a range of partnerships with policy makers, other service organizations, and academic institutions. Through an adept strategy of building social capital around the organization, its ability to have an impact through advocacy, raise funds, and improve the access to social capital for its clients is greatly enhanced.

The final core characteristic of CCVT that aligns with those of social entrepreneurs is its focus on reflexivity and rapid implementation of programs. As a function of the degree of inclusion that CCVT facilitates for its participants, it has developed into an organization that is very sensitive to the needs of the communities it serves and responds to those needs. This has extended to their taking some risks in programming—providing services that communities ask for that radically depart from what might be considered traditional western models of care. When a community was concerned about their children struggling in school, they set up a homework program for teenagers. When Somali women were concerned for their personal safety as single mothers, they arranged self-defense classes. When Muslim clients would not come to group meetings in a Church basement which was at the time serving as the CCVT offices, they approached a local Imam who agreed to attend a meeting at the church to reassure their clients that attending the group would not compromise their commitment to their faith. In this manner CCVT has nimbly and effectively met the needs of a wide range of cultures. Furthermore, their responsiveness to their clients' needs and requests represents a striking and compelling difference from the contexts they have faced of degradation and powerlessness enacted through threats, violence, and myriad legal and bureaucratic barriers.

10.6 Conclusion

While equitable access to effective mental health services is a problem for all marginalized individuals and communities, the problem is exacerbated for survivors of torture. Along with facing the numerous stressors that form challenges and barriers for most immigrants, torture survivors, as individuals, families, and communities, struggle with many more significant and complex health concerns. These individuals, in western contexts, are then faced with systems of care that regularly confound native residents for whom English is a first language. These systems are based upon models that offer little attention to the social determinants of health that are pivotal for refugee well-being and, even when the interventions offered are evidence-based, the research

upon which they are founded is questionably applicable. In turn, the literature on interventions and models of care for torture survivors is largely fragmented.

In this context, there is a need for a coherent framework into which one might place services that include evidence-based psychotherapy for PTSD, lobbying members of parliament, and homework clubs for teenagers. Social entrepreneurship is a model of understanding those addressing a broad range of major and complex social problems that is readily applicable to organizations such as CCVT. While not articulating specific interventions, it identifies core characteristics such as values grounded in social justice, innovation in generating solutions, community embeddedness and reflexivity. It can provide a tool for policy makers and service providers to better recognize and understand how effective interventions for marginalized groups develop and operate. Furthermore, as western governments increasingly align with a neo-liberal agenda of offloading social responsibility to communities, we are increasingly faced with contexts in which models for understanding community-driven solutions are desperately needed. It would be beneficial if future inquiry was undertaken to refine our understanding of how organizations such as CCVT attain their impacts. This will likely involve integrating rigorous case studies with much called for and arguably over-emphasized randomized trials of the intervention components of service organizations.

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