Rehabilitation for survivors of the 1994 genocide in Rwanda: What are the lessons learned?

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The Author wishes to acknowledge the helpful comments and suggestions made by the reviewers and information received from Professor Mary Seeman and Dr Michael Gopfert.

Abstract

Rehabilitation remains a significant concern among survivors of the 1994 genocide in Rwanda. Rehabilitation falls under tertiary prevention, which is a core function of public health. Despite efforts to introduce various rehabilitation programmes for genocide survivors in Rwanda, these initiatives have often proved inadequate in meeting their long-term needs. The failure of the Rwandan Government, international community, United Nations, and other Non-Government Organisations (NGOs) calls into serious question their commitment to international human rights laws. Rehabilitation should be regarded as a free-standing human right for genocide survivors and a human rights-based approach to the rehabilitative process should incorporate measurable outcomes based on an agreed ethical framework. The author calls upon the international community to reiterate its concerns about genocide survivors and reaffirm its commitments to human rights. The main issues discussed in this paper are: the long-term needs of survivors of the 1994 genocide; what is already provided, and the gaps; how Stucki's Rehabilitation Cycle framework (a problem-solving tool) can help improve current provision; the role of the international community, NGOs, and genocide survivors'

organisations in advancing rehabilitation; and the need for a human rights-based approach to rehabilitation. A strong recognition of the right to rehabilitation is crucial. An ethical framework related to the human rights-based approach should also assist in setting outcomes that can be measured against agreed standards, ensuring: rights that have been violated are identified; the accountability of each service provider in promoting rehabilitation; rehabilitation which is inclusive and non-discriminatory; participation by encouraging collaboration with survivors rather than doing things for them; and empowerment by enabling survivors to understand their rights and have the confidence to challenge or question when their rights have been violated.

Keywords: Rwanda, Rehabilitation, Survivors of the 1994 genocide, Human rights laws, United Nations, Non-Government Organisations, Survivors' organisations, Rehabilitation Cycle, Life Cycle Framework.

Introduction

The methodological considerations within this paper are framed by the Foucauldian tradition of discourse analysis specifically focusing on knowledge and power within the context of a human rights-based approach to rehabilitation. (Foucault, 1982; Hewitt, 2009)

Rehabilitation remains a significant concern among survivors of the 1994 genocide in Rwanda. Rehabilitation falls under tertiary prevention, which is a core function of public health that aims to meet longer term needs. It is widely recognised that survivors of genocide suffer physical and psychological effects, which may last for a long time after the traumatic events (Danieli, et al. 1996; Danieli, et al. 2001; Schein et al. 2006; Letschert et al. 2011). Amir and Wielsel (2003) compared the impact on survivors of the Nazi genocide with that of an atom bomb that disperses radiation for a long time after the actual explosion; such is the reality in Rwanda where psychological distress still runs deep. A Rwandan census of genocide survivors (National Institute of Statistics of Rwanda, 2008) estimates the survivors still living in Rwanda to number 309,368 – 180,593 females and 128,775 males, including 43,048 children and young adults aged between 13 and 20 years. The census noted that: 8,000 survivors had no access to higher education; 15,000 children had no access to primary school; 27,500 were disabled due to injuries and torture suffered during the genocide; and 40,000 survivors were without shelter. In 2010, at least 11,256 students sought, but only 1,653 received, assistance (Ibuka 2011-2015) The Rwandan Government and NGOs acknowledge that those survivors who were children during the genocide are the most vulnerable group, due to their exposure to horrific violence at such a young age – witnessing instances of murder, torture, and rape of their close relatives (parents, brothers, sisters, etc.). Human Rights Watch (1996) reported that rape and torture were a significant part of the genocide strategy in Rwanda and estimated that there were between 100,000 and 250,000 cases of rape during the period 1 October 1990–31 December 1994. The victims were aged as young as 2 years old, with a pattern of individual or gang rape that included sexual torture using objects such as gun barrels and sharpened sticks. The most common gynaecological complications reported by the survivors included fistula, pain, incontinence, and regular infections, and around 200 disfigured or disabled survivors still await corrective surgeries (Sandner, 2013).

Holistic rehabilitation should encompass justice, practical support, and social, economic, physical, and psychological healing. Siegert et al. (2010) argued that rehabilitation demands the consideration of human rights and Freeden (1991) similarly believed that human rights laws were the cornerstones of rehabilitation. Therefore, a combination of well-targeted rehabilitation programmes within an overall human rights approach could significantly reduce survivors' suffering and promote healing and recovery. Human rights laws include: Universal Declaration of Human Rights (1948); United Nations International Covenant on Economic, Social and Cultural Rights (1966); UN Convention on the Rights of the Child (1989); The Right to Health under International Law (2000); The Right to Reparation under International Law (2005); The Right to Rehabilitation - United Nations Convention against Torture (2005); United Nation Convention on the Rights of Persons with Disabilities (2006). In practice, human rights laws are powerful instruments in the fight to mitigate the impact of genocide, setting the standards that should be applied to promote and advance the rehabilitation rights of survivors. Successful implementation and effective use of these laws, however, depend on the government's goodwill and cooperation between national, international, and survivors' organisations. Moreover, the involvement of survivors is crucial to ensure that rehabilitation programmes meet their individual needs. Survivors' organisations, therefore, should make an effort to understand these human rights laws and what to do when survivors' rights are infringed.

Survivor Needs

Survivors of the 1994 genocide present complex needs. Maslow's Hierarchy of Needs (Maslow, 2007) can assist survivors in gaining an insight into those areas of their lives that may require attention in order to achieve meaningful rehabilitation. Maslow's Hierarchy consists of five categories: physiological needs and safety needs are classed as the basic needs that must be met first before the higher level needs of Social, Esteem, and Self-actualisation. This framework is useful in assessing long-term needs, the most compelling of which for survivors of genocide are as follows:

1. Physiological needs: These needs are essential to keeping any human being alive, and include water, sanitation, food, and sleep. One of the challenges facing survivors, or any other vulnerable population, living in a rural area is access to clean water. In rural areas, people may travel quite a distance to fetch water, adding pressure on survivors who already feel vulnerable due to health problems, or fear being killed by those perpetrators trying to avoid justice. Rwanda is making good progress in improving access to clean water; however, it may take another three years to reach all rural areas. In fact, the Rwandan government has set a target of 100% access to clean water by 2020 (Republic of Rwanda, 2012).
2. Safety/justice needs: These needs incorporate important things such as accommodation, living in a safe community that provides access to health care, education, and employment or income-generating activities. Also, survivors who are still trying to locate the remains of their loved ones are unable to achieve this if they feel unsafe.
3. Social needs: Fulfilment of these plays a very important part in the higher level needs. There is a large volume of published studies discussing the challenges for survivors of genocide in relation to social needs. Some studies including Rieder et al. (2013) and Rombouts (2006) highlight that they encompass the need to give and receive love, for friends, and for belonging; they also highlight that some survivors who are victims of sexual violence have been rejected by significant others. In addition, while some survivors continue to seek the opportunity to speak out or testify, others wish to move on by not speaking out. Therefore, any discussions are discouraged to minimise trauma reminders, as genocide is such a sensitive topic, yet it has to be acknowledged that survivors have the right to be listened to and treated with respect. Meeting these social needs relies heavily on the interaction between people living in the same community.
4. Esteem needs: Survivors need to be taught how to respect themselves and recognise when others disrespect them. Many survivors feel guilty for surviving seeing their survival as insignificant. Roberta (2001-2008) highlights that survivors' guilt often leads first to disrespect for oneself, which then influences others to show the same disrespect.
5. Self-actualisation needs: Maslow argues that self-actualisation is the highest need and not easily achieved, and so has to develop gradually. The achievement of self-actualisation extends to justice, truth, and meaning, the research to date tends to focus on the narrower aspects of these needs, such as HIV treatment, counselling, and peace and reconciliation Furthermore, most studies conducted in Rwanda fail to acknowledge the significance of this long-term need for survivors of genocide.

Risk Factors

Maslow's Hierarchy of Needs is a widely understood and simple model that can be adapted to assess the holistic rehabilitation needs of survivors. In conjunction, the Life Cycle Framework by Pickin and Leger (1993) can also assist in examining contributory risk factors related to age or biological changes. Pickin and Leger outlined the nine stages of the Life Cycle Framework: Stage 1 - late pregnancy to 1 week after birth; Stage 2 - 1 week to 1 year; Stage 3 - 1–4 years; Stage 4 - 5–14 years; Stage 5 - 15–24 years;

Stage 6 - 25–44 years; Stage 7- 45–64 years; Stage 8 - 65–74 years; Stage 9 - over 74 years. To date, little attention has been paid to the biological changes related to age, even though it can help to identify and support vulnerable survivors in an efficient and effective way since it is necessary to recognise that needs change over time for various reasons and that rehabilitation services need to reflect this. The World Health Organization undertook a systematic review of studies on the long-term health impact of genocide and reaffirmed that disasters caused by mankind have far more serious effects than environmental disasters (World Organisation, 2002) Some survivors reported a series of symptoms that meet the criteria for post-traumatic stress disorder (PTSD), including personality changes, cognitive impairment, poor sleep hygiene, social problems, and somatic complaints. These symptoms were often exacerbated during the *gacaca* trials (a judicial initiative based on a traditional Rwandan mechanism of local conflict resolution) (King, 2011). Musonera et al (2004) expressed concerns about the vulnerability of survivors during these trials: for example, panel members were not trained on how to sensitively question the survivors, who described their experiences of being humiliated and emotionally abused during these trials. Some survivors were re-traumatised while providing details of how their loved ones were killed, tortured, raped, or pushed into toilets or rivers alive; some reported that their involvement had doubled their recovery time or even made it impossible to start on that journey. Redress (a not-for-profit, legal human rights organisation) argued that without true restorative justice, survivors would not be fully rehabilitated. Redress (2012) also acknowledged that each survivor would have their own perception of justice: the following three quotes from survivors shed some light on what justice meant from a survivor's perspective:

- 'Justice was a political initiative born out of a concern to put an end to the culture of impunity. But the struggle against impunity was not going to bring back our loved ones who had died. It is a principle that determines the future without changing anything about the past.' (Etienne, a lawyer in Kigali)
- 'We will always strive to have the courage to testify, despite the serious consequences that entails.' (Prudence, a hospital worker in Butare)
- 'The survivors who continue to fight for justice do so for our loved ones who are not with us anymore, to honour their memory and to show them that we have not abandoned them.' (Agnes, a farmer in Ruhengeri) (Redress, 2008).

These statements imply that something has gone wrong with the *gacaca* trial system, since some survivors are clearly pessimistic about justice but remain strong, courageous, and prepared to take the risk. There is a large volume of published studies describing the role of *gacaca* courts and drawing attention to the concerns raised about their processes and procedures. A common criticism is that it does not fulfil one of the two principal objectives of the genocide convention - punishment of the crime of genocide, instead focusing instead on reconciliation.

The genocide has resulted in material losses: survivors have found themselves homeless and living in poverty. *Gacaca* started out with the objective to ensure that those responsible for destroying or damaging properties would provide compensation/reparation. However, this proved difficult to achieve as there was no additional legislation to establish a compensation fund or any kind of enforcement to support the *gacaca* courts. Currently, recovering payment depends on the perpetrators' willingness to pay, or the survivors' determination to pursue the perpetrators, if they are capable and wish to do so. Consequently, some NGOs have suggested that the Rwandan Government, with contributions from the UN, should establish a national reparation task force, but no progress has been made so far. NGOs recognised the danger when survivors pursued compensation from the perpetrators or the perpetrators' families. A survey conducted by the National Commission Against Genocide (1995-2008) reported that 156 witnesses had been killed, 14 of whom were children, either as a result of the ongoing genocide ideology or perpetrators and their families

wishing to eliminate survivors who may testify against or pursue compensation from them. When the Rwandan Government introduced the *gacaca* courts in 2001, it promised survivors that a law on compensation would be enacted to secure a compensation fund. However, after a six-year campaign, survivors of genocide and the organisations supporting them published Ibuka (2013) a joint declaration on the right to reparation, but this has been ignored for the past 19 years. Survivors' organisations reiterate that in order to comply with the UN Basic Principles and Guidelines on the Right to a Remedy and Reparations for Victims of Gross Violations of International Human Rights Law, reparation must be considered, comprising: restitution, compensation, rehabilitation, satisfaction in ending human rights violations, and guarantees of non-repetition. It is worth noting that the international community should have played a major role in drafting *gacaca* legislation, and training and monitoring the officials; instead, it exerted massive pressure on Rwanda to speed up the trials or temporarily release some prisoners from the overcrowded prisons.

Resource Availability

Very soon after the genocide, survivors were forced to confront their complex individual and communal needs and losses. On regaining some of their physical strength, they swiftly established an umbrella survivors' organisation in 1995 called 'Ibuka', meaning 'Remember**',** Ibuka (2011-2015) which currently supports 15 member associations nationally. Ibuka's strategic goals include: providing assistance to genocide survivors to overcome the lasting effects; preserving the memory; working for justice; providing a decent burial for exhumed remains of the victims; and preventing any further genocides.

In an effort to support genocide survivors, the Rwandan Government introduced a National Assistance Fund for Needy Survivors of Genocide (FARG), (FARG, 2016), which receives 6% of the national budget every year. The UN has also issued at least three resolutions, so far ineffective, (UN, (2004), UN (2009), UN (2012)), calling for NGOs to provide assistance to the vulnerable survivors of the 1994 genocide in Rwanda, namely orphans, widows, and victims of sexual violence. According to Schimmel (2010) the UN contribution to rehabilitation programmes in Rwanda has been minimal and only benefitted 2,000 survivors. It has to be acknowledged as highlighted in the Ibuka's (2012) recent conference report on assistance for genocide survivors, there have been some achievements over the past 19 years, including: 68,367 students completing secondary education, and 7,511 completing higher education; the construction of 39,723 houses, although over half of these were constructed by NGOs, and some are of poor quality or partially finished; 173,917 genocide survivors receiving medical assistance (funding from the UK Department for International Development enabled the Survivors' Fund (SURF) to establish a care and treatment project to assist 2,500 women who had contracted HIV during the genocide); while a further 28,199 genocide survivors received additional support, and income-generating activities were initiated. However, the intensity, quality, and persistence needed in these efforts are often lacking and difficult to sustain. Moreover, the hard-to-reach survivors are even more vulnerable because of their location, such as those in impoverished rural areas. Unfortunately, there are no figures available for these individuals, thus making efforts to deal with their situation even more difficult.

The recent FARG report (SURF, 2014) and impact assessment report (AERG, 2013) acknowledges that insufficient provision has been made for the rehabilitation programmes. Failures include: the lack of provision of appropriate and secure homes for 8,000 survivors; 180 homes in need of urgent repair; no consideration being given to survivors' dependants when allocating support; and in 2010, at least 11,256 students seeking, but only 1653 students receiving, assistance. An evaluation revealed that there was still a budget of FRW 50 billion to spend, (Ibuka, 2012) which is equivalent to £71,428,571, while nearly two out of three income-generating projects were not making any profit. There are many challenges faced by genocide survivors: health insurance for the

employed ranges from FRW 2,900 (around £3) to FRW 7,000, although the most vulnerable survivors are eligible for free health care, excluding secondary care treatment; according to SURF (SURF, 2013) older women face more challenges in engaging in economic development initiatives due to reasons such as health problems, low self-esteem, and poor self-actualisation; and those living in rural areas cannot afford to travel to the capital for support such as trauma counselling, or other treatments, while most services do not have the capacity or resources to extend their services or provide an outreach service.

Developing memorial sites is also a vital component of the healing process, yet some survivors are struggling to find funding for these. Hence, the recent appeal launched by SURF (2016) to build a memorial site at Kiziguro that will list the 3,000 people who were massacred at the parish church and their bodies dumped in a nearby pit. Only 11 Tutsis survived, and 7 are still alive, living in terrible poverty and painful grief, knowing that the 3,000 victims will be forgotten if no memorial site is built. Other challenges faced by survivors include locating their loved ones' remains; those who are lucky to do so, however, cannot afford a decent burial, and have to rely on government communal burials, which infringe survivors' privacy and compromise the dignity of their relatives. A decent and dignified burial is crucial for a sense of closure, although this may not be a positive thing for all survivors as some can be re-traumatised by the process, which can then last for months or even years.

It has recently come to light that there are 1,462 survivors of the genocide in Rwanda aged over 70 who have no one to care for them (SURF, 2013). In addition to still suffering from psychological stress related to the genocide, they experience the same age-related problems as all older adults, such as deteriorating physical and mental health. A recent Rwandan draft policy set out a framework for harmonising social protection programmes Ministry of Local Government (2011) and outlined substantial changes to the support that the government provides to survivors of genocide. This policy is firmly committed to continuing the support provided to vulnerable survivors and pays particular attention to elderly survivors; but the policy fails to anticipate all the issues/problems within each age group, or to determine how to deal with them. It is worth noting that the degree of vulnerability differs from one individual survivor to another. Updegraff and Taylor (2000) assert their vulnerability depends on each survivor's: physical and psychological health status; active coping style; optimism; perception of their level of control over life events; a strong sense of self; and the nature of ongoing stressful life experiences, support, medical treatment, age, and social status.

Rehabilitation Policy and Program Needs

A general reflection on the existing rehabilitation programmes for genocide survivors in Rwanda reveals wide discrepancies between government/UN intentions and survivors' experiences. In order to render the right to rehabilitation meaningful, there is a need for an articulated national strategy and a clear implementation plan, but sadly, there is no international rehabilitation policy for genocide survivors in order to ensure accountability. In the absence of such a policy, it is impossible to set measurable outcomes based on human rights laws, including the right to rehabilitation. According to Redress (2009), a human rights-based approach to rehabilitation programmes should include: identifying the rights that have been violated; accountability, by allocating specific duties for each service provider in promoting rehabilitation; inclusivity and non-discrimination - listening to survivors and including all survivors regardless of gender, age, etc.; participation by working/collaborating with survivors rather than doing things for them; empowerment through ensuring survivors understand their rights and have the confidence to challenge or ask questions when their rights have been violated.

Public health practitioners, survivors' organisations, advocates, and academics have an important role to play through the use of effective and appropriate measures to facilitate a holistic and integrated rehabilitation needs assessment, which will assist in identifying and tackling some of the complex problems that affect survivors' well-being. A modified version of Stucki's Rehabilitation Cycle in Stucki and Sangha (1998) which is a problem-solving tool provides a potential way forward in which to improve rehabilitation. This framework has proved useful for guiding policymakers and funders in planning and making decisions on resources required for rehabilitation programmes. The World Health Report on Disability, (World Health Organisation, 2011) demonstrates that rehabilitation should not be costly if Stucki's Rehabilitation Cycle framework is used effectively. However, for this to be successful, it should make reference to the core principles of The Right to Rehabilitation, which state that rehabilitation must include medical, psychological, legal, and social needs. The Rehabilitation Cycle follows five steps in addressing survivors' needs:

Step 1- Identifying problems and needs: Every effort should be made to identify the problems and needs of survivors of genocide, which survivors are not always aware of themselves. As previously discussed survivors of genocide do not understand their rights either. Frameworks, such as Maslow's Hierarchy of Needs and the Life Cycle discussed above can be used to ensure that essential needs are not overlooked. Maslow's Hierarchy of Needs is a very useful tool in assessing ongoing long-term needs, while the Life Cycle Framework examines the contributing factors related to age and biological changes.

Step 2 - Relate problems to modifiable and limiting factors: By identifying modifiable and limiting factors, rehabilitation providers need to recognise survivors' strengths. Those providing rehabilitation should try to relate the problems identified to the appropriate stage in the Life Cycle Framework, which will help in understanding particular risk factors or influences on health. Gender and an individual's ability to benefit from rehabilitation should also be taken into consideration, in order to determine the socio-economic, environmental, and resource needs.

Step 3 - Define target problems and target mediators and select appropriate measures: There should be multi-agency discussions to identify the most appropriate organisation to assist a survivor, and then the appropriate measures for implementing and evaluating the interventions. A number of organisations providing rehabilitation services in Rwanda specialise in different areas; for example, FARG assist with education and accommodation, while SURF provides counselling.

Step 4 – Plan, implement, and coordinate interventions: At this stage, the survivor's participation is crucial. It is important that survivors are able to feedback on the positive or negative outcomes of the rehabilitation they receive, so that agencies or organisations can continue to learn more about the best ways to meet survivors' needs. To achieve this, though, the providers of rehabilitation services must establish formal working partnerships. There are over six rehabilitation initiatives in Rwanda, many of whose initiatives overlap, but no effort is made to avoid duplication; FARG and SURF, however, are well established and tend to support other initiatives. Formal partnership working will bring a number of advantages, including: joint training opportunities to develop mutual understanding; access to larger funds; arrangements for sharing information; and sharing or exchanging resources.

Step 5 - Assess the effects: Any rehabilitation programme should be subject to ongoing evaluation or research, and also help in reassessing the impact and long-term effects of genocide in general. The information gathered via the Rehabilitation Cycle can be used to inform or influence national and international policymakers and funders when making decisions.

Challenges Ahead

The participation of the international community and NGOs in rehabilitation can be invaluable. However, delivering holistic rehabilitation programmes within a wider multinational and international context can be challenging. Rehabilitation programmes in Rwanda involve collaboration between national and international agencies, but the international community and NGOs have limited experience of working in developing countries and this leads to negative outcomes (Milner, 2005) As previously discussed, survivors of genocide are vulnerable people with multiple needs, and the biggest challenge for most services is to identify or define those needs and address all aspects of survivors' lives or provide appropriate interventions. Therefore, survivors' organisations, or survivors themselves, should be encouraged and supported in informing rehabilitation services about their needs, although it is important to remember that survivors may not actually be aware of their own needs. Maslow's Hierarchy of Needs can be used to enable survivors to recognise their essential needs, such as shelter and subsistence, but also their social and self-actualisation needs. To ensure easy access, quality, consistency, and equity, there is undoubtedly a need for an 'umbrella' agency to coordinate a national rehabilitation programme: a daunting task, especially when it involves national and international organisations.

There is increasing concern regarding the violation of the human rights of survivors of genocide. However, incredibly, there is very little literature related to human rights and rehabilitation for such survivors. It is worth remembering that human rights are moral norms. Ward et al. (2007) state that a 'right' is something we own, the 1948 United Nations Universal Declaration of Human Rights outlines specific human rights, such as the right to an adequate standard of living, life, liberty, and security of the person. The 2006 United Nations Convention on the Rights of Persons with Disabilities is the most relevant to rehabilitation, although it does not argue for extra support for people with disability, but promotes equal rights instead. Other relevant laws that can play an important role in rehabilitation include: the UN Convention on the Rights of the Child (1989), promoting the rights and well-being of the child; the Right to Health under International Law (2000), ensuring access to appropriate health care that meets individual needs; the Right to Reparation under International Law (2005), reinforcing reparation as an important part of justice; and The Right to Rehabilitation - United Nations Convention against Torture (2005), emphasising a holistic rehabilitation which encompasses justice, practical support, and social, economic, physical, and psychological healing.

A question remains over how the many organisations can be informed, or helped to become more aware, of these essential universal ethical principles. The starting point must be to educate everyone involved in rehabilitation programmes about those human rights laws relevant to rehabilitation, since a lack of in-depth knowledge of these laws/conventions hinders the effectiveness and sustainability of any intervention. There is no doubt human rights laws provide the core of an ethical framework necessary for guiding delivery of rehabilitation programmes. Human rights laws contribute, for example, in ensuring: i) equality – treating survivors equally regardless of gender, age, sexual orientation, social status, religion, disability, or pregnancy and maternity; ii) dignity – survivors choosing where to live and having access to health care, privacy, and social contact; iii) international collaboration – rehabilitation providers identifying appropriate partners, encouraging innovation, supporting each other, being flexible, and undertaking and developing programmes at a steady pace; and iv) duty to prevent harm to humankind – rehabilitation providers identifying potential harm or problems and taking action by developing, implementing, promoting and maintaining appropriate policies.

Summary

The authors call upon the international community to make an effort to avert the suffering of survivors and realise that survivors of genocide have the right to rehabilitation. The Rwandan government should make an effort to provide a platform for survivors to speak out on the issues affecting them, ensuring that appropriate support is in place, as this may mean reliving their traumas. Rehabilitation services should take on an additional role of raising awareness of the needs of survivors by using a simple model such as Maslow's Hierarchy of Needs, as well as the Life Cycle Framework to identify risk factors related to age. An ethical framework related to a human rights-based approach would assist in setting outcomes that can be measured against agreed standards. Also, in-depth knowledge of relevant human rights laws/conventions (power and knowledge as a discourse) would help in ensuring: identification of rights that have been violated; accountability of each service providing rehabilitation; inclusive and non-discriminatory rehabilitation; participation of survivors, by services collaborating with, rather than doing things for, survivors; empowerment, by ensuring survivors understand their rights and have the confidence to challenge or question when their rights have been violated.

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