Prioritizing psychosocial support for people affected by Ebola in Sierra Leone

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This paper provides recommendations for the Ebola Recovery Pledging Conference, July 10th in New York City, in building resilience and mitigating conflict risk in the national recovery strategy through the delivery of effective ***Psychosocial Support*** *to Ebola affected families, communities and national systems in Sierra Leone. In summary our recommendations are:*

1. ***The Government of Sierra Leone:***

- *As psychosocial wellbeing is essential to both individual recovery and community development and promotes long-term resilience at community and national levels, it should be integrated into each sector of the recovery strategy for effective coordination and implementation.*
- *Mental health services should be complemented with community-based psychosocial support interventions. These interventions are evidence-based and cost-effective, prevent escalation of psychosocial difficulties and contribute to long-term resilience.*
- *People have a right to truth, information and acknowledgement in cases of failures made during the response. Information retrieval and investigations are required in cases of children who were taken for treatment and have not been accounted for and also in determining the location of burial sites of patients buried early in the response. Acknowledgement of harm, apology and symbolic reparation may be required.*

2. ***The International Donor Community:***

- *Long-term funding commitments are needed to support and replicate ongoing programs delivered by local, trained and supervised staff, rather than short-term project-based and externally driven one-off trainings.*
- *Funding through bilateral aid allocations and support to international aid agencies and local civil society organizations can serve as channels for the development of long-term psychosocial interventions.*

3. ***INGOs/UN Agencies:***

- *Psychosocial programming should be inclusive and provided on the basis of need. Crude targeting of assumed categories of need such as 'survivors' can cause resentment and impede social integration. Programming should take into account the particular needs in schools and peer group settings.*
- *Ongoing family-focused support is necessary, emphasizing guardians and orphans.*
- *Further research should be carried out on: 1) short-term evaluations of specific psychosocial interventions, and 2) longitudinal studies with children and adults affected by Ebola to examine culturally embedded resiliency.*

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I. Introduction

The ongoing Ebola crisis has impacted the psychosocial health of the population of Sierra Leone. Research highlights that women, men, girls and boys who have been directly affected by EVD (survivors, multiply bereaved, orphans, unaccompanied and separated children) experience multiple barriers to social integration, including relational difficulties, complex grief and stress. Affected people adapt to adversity and bring about resilience through a wide range of coping mechanisms, resources and strategies in a culturally meaningful way. The provision of psychosocial support will facilitate this resilience by addressing their psychosocial needs.

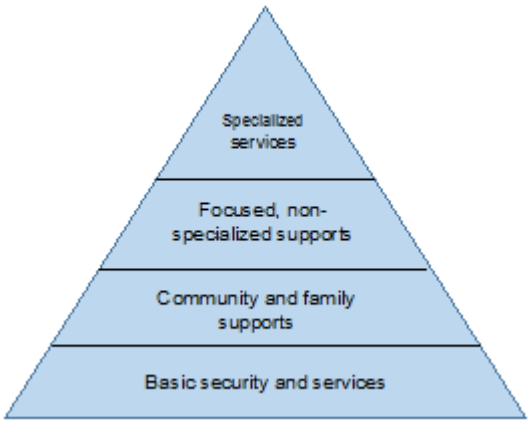

Figure 1. IASC Intervention Pyramid

The provision of psychosocial support involves the development of a layered system of complementary supports that meets the needs of different groups, as illustrated in the intervention pyramid[1]. The first layer, **basic security and services**, represents the emergency response required to protect the psychosocial health of the entire population.

A smaller number of people affected by crises or emergencies will be able to maintain their psychosocial wellbeing if they receive help in accessing **community and family supports**, the pyramid's second layer, which are often disrupted by crises or emergencies.

Focused, non-specialized supports, such as Psychosocial First Aid (PFA) and basic mental health care by primary health workers, comprise the pyramid's third layer and are necessary for the still smaller number of people who require additional and more focused individual, family or group interventions by trained and supervised workers.

Global evidence indicates that 10% – 15% of affected people will require **specialized services**, the pyramid's final layer, such as professional psychological or psychiatric support.

II. Why is psychosocial support needed in a post-Ebola context?

As of July 6, 2015, there are a total of 4,029 EVD survivors in Sierra Leone[2]. 3,574 people have died leaving bereaved families, many of whom experienced multiple bereavements. Epidemiological calculations estimate that in Sierra Leone there are 3,300 orphans as a result of Ebola, with over 100 orphans having lost both parents.

A significant effort has been carried out over the past year to respond to Ebola with the goal of eradicating the disease. Psychosocial support is essential for the efforts to reach zero and helps ensure that the response is as effective as possible. However, while getting to zero, **it is necessary for the Government of Sierra Leone, international donor community, INGOs/NGOs and medical practitioners to address the long-term health needs of those who have been impacted by Ebola, including distress, anxiety, loss, grief, shame and suffering.**

The Ebola outbreak has resulted in a wide range of psychosocial protection concerns experienced at the individual, family, community and societal levels. Over the course of the outbreak, normally protective supports such as school, work, basic preventative health, community groups and daily routines have been disrupted while pre-existing problems of social injustice and inequality have been amplified.

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[1] *Inter-Agency Standing Committee, 2007. IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings. IASC, Geneva.*

[2] *NERC. EVD Daily MoHS Update. Available at: http://www.nerc.sl/.*

Recently conducted research[3] has identified the following barriers to social integration:

Pre-existing (pre-emergency) psychosocial difficulties:

Individuals or groups that are marginalized or experience extreme poverty often find these social problems are exacerbated by a crisis. People who are already socially marginalized are more susceptible to discrimination in times of economic and social stress. For example, when families experience extreme economic pressures, teenage girls are more likely to be expected to engage in transactional sex to support themselves and their families than '*men pikin'* (boys). Children in informal foster care may be less likely to have their school fees paid than other children in the family. Underlying discrimination on the basis of gender, age, disability or social location can be heightened in the emergency context. As would be expected, well-developed social capital and social networks prior to the emergency operate as protective factors.

Emergency induced psychosocial difficulties:

Many of the people interviewed reported experiences of complex grief associated with multiple losses. The specific context of Ebola and the problems that come with it (such as the fear of infection, being unable to care for loved ones, the shock caused by transportation to treatment centers and witnessing deaths and culturally inappropriate burial practices) complicated and, in some cases, heightened people's experiences of bereavement and loss.

Stigma and discrimination affecting adult survivors and bereaved family members varies. Rather than widespread stigma, most people reported complex relational difficulties in one or two relationships. Interpersonal conflicts tended to be rooted in distrust and blame associated with specific events during the emergency rather than a person's general status as a 'survivor.' In a number of cases, a person or family may blame a friend or neighbor for bringing Ebola to the community, infecting a loved one or calling 117 to report a suspected Ebola case. This breakdown in relationships is more complex than the concept of 'stigma' would suggest and requires a different kind of response. **Rather than community level sensitization on Ebola, more focused approaches are needed based on conflict resolution and mediation so that trust and relationships can be rebuilt.**

While adults tended to report that children did not experience discrimination, children confirmed that they did. A considerable proportion of children who survived Ebola or lost parents felt isolated in their peer groups and tended to socialize with other children who had been affected by Ebola. In a number of communities children reported deterioration in their relationships once school started, which highlights **the need for continued interventions in schools and peer group settings.**

Orphaned children and their guardians also reported challenges in adapting to new family structures. As many of the interviewed people came from Ebola hotspot communities, many had been multiply bereaved. Guardians, 79% of whom were women, had often lost a number of family members to Ebola and were caring for between one and ten additional children. Some children and their guardians reported shortages of food, bedding and funds for school fees. Some orphaned children felt they were treated differently compared to biological children (for example, by receiving excessive house and farm work or not returning for school). Guardians expressed difficulties in providing for children economically and emotionally, particularly as children were grieving and in some cases were distressed, withdrawn or exhibiting mood or emotional difficulties. **Ongoing family-focused support is necessary, emphasizing guardians and orphans to support the development of health-sustaining relationships and improved psychosocial wellbeing.**

> The day they bring these children to me I was thinking how will I be able to provide food and shelter for them but I pray to God to give the strength to provide the basic amenities for these children and as time goes by I have [gotten] used to these new responsibilities.
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> *Fatmata, Guardian caring for 10 EVD affected children (AJLC/K/R/ FC).*

Relational difficulties vary over time. Some participants reported that their friends and

[3] *Shanahan, Trócaire, Access to Justice Law Centre, Justice and Peace Commission and Centre for Democracy and Human Rights (2015). Psychosocial wellbeing and protection in Ebola affected communities: Emerging Findings, Mental Health and Psychosocial Support Working Group, Ministry of Social Welfare, Gender and Children's Affairs, Freetown, Sierra Leone, May 25, 2015.*

neighbors were initially distant but that relationships gradually improved, while others felt they were welcomed warmly but experienced difficulties in some relationships as time went on. Needs change over time and even initially supportive environments can experience significant stress and tension when external support and attention decreases in the post-emergency phase. **This supports the need for long-term relational support, including family-focused community-based interventions.**

Psychosocial difficulties associated with humanitarian aid and Ebola response:

Distress induced as a result of the humanitarian response itself is a problem and must be prevented.

Health and social workers noted that explicitly targeting survivors for support causes resentment and can hinder reintegration. **Publically identified survivor specific services (i.e. "Survivors' centers" or clinics) are not recommended.** Global evidence (see for example, IASC, 2007) supports **service provision on the basis of identified need rather than crude categories** such as "Ebola survivors" or "Ebola orphans." **Specialized support should be provided for workers,** who can experience distress as a result of aiding people who have been affected by Ebola.

Severe distress has been experienced by families who remain unaware of the status or whereabouts of their loved ones. In a number of cases (over twenty in the Northern Region alone) parents have not received information regarding the whereabouts of their children who were taken by ambulance for treatment. Many of these cases originate in October, November and December 2014. Parents have in some cases received conflicting information from different service providers and do not know whether their children are still alive or have died.

Another difficulty that has contributed to increased spiritual distress and harm is the fact that burials of Ebola victims did not follow culturally appropriate burial practices. This was particularly true during the first six months when people were buried in unmarked graves. **Appropriate memorials and remembrance ceremonies should be developed with individuals, families and communities in a way that is meaningful to them. Information retrieval regarding the location of appropriately marked burial is essential and should not be delayed any further. The Government of Sierra Leone should ensure that support is made available to families to design meaningful commemoration and remembrance ceremonies for their loved ones.**

Resources and Strategies people use to build resilience:

Children and adults talked about ways that they bring about a sense of safety, calming, self and community efficacy, connectedness and hope in their own lives. These five elements have been identified as keys to effective emergency psychosocial programming.[4] **It is important for all stakeholders to learn how individuals, families and communities engage in these coping mechanisms so psychosocial interventions can be constructed based on the local context.**

Adults and children attempted to bring about a sense of safety during the outbreak by practicing infection control measures, sharing stories, parables and songs about Ebola and listening to news about Ebola on the radio. Many participants made sense of the outbreak in spiritual terms, although they also accepted the medical and biological basis of EVD. Telling stories about the origin of the outbreak (for example, a curse, a witch plane crash and a prophecy) helped participants feel safe in some cases. However, the excessive focus on Ebola can lead to rumination and feeling worse about problems. **A psychosocial lens should be used to design public information and social mobilization campaigns during EVD outbreaks, ensuring that governments, UN and**

> I started to feel discouraged. I tried all my best by using my aunt's mobile phone and called some of my friends and told them if they left me alone I will pass away like my father and mother. When they heard that message they decided to join me and console me.
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> *Osu, 18 years old, (AJLC/K/M/AK)*

[4] *Hobfoll, S. E.,Watson, P, Bell, C. C., Bryant, R. A., Brymer, M. J., Friedman, M. J., Friedman, M., Gersons, B. P. R., de Jong, J. T. V. M., Layne, C. M., Maguen, S., Neria, Y., Norwood, A. E., Pynoos, R. S., Reissman, D., Ruzek, J. I., Shalev, A. Y., Solomon, Z., Steinberg, A. M., & Ursano, R. J. (2007). Five Essential Elements of Immediate and Mid-Term Mass Distress Intervention: Empirical Evidence. Psychiatry: Biological and Interpersonal Issues, 70, 283- 315.*

humanitarian actors engage in dignified and open dialogue with affected communities. Confused, frightening and contradictory messages must be avoided.

Children and adults used a range of methods to try to calm themselves, including pills. There is clearly a locally expressed need for calming and relaxing that is not currently being adequately met. **Resources are required to fund programs, incorporating relaxation techniques (breathing exercises, traditional dance, music), sleep hygiene, practical skills and stress management for dealing with acute anxiety and stress. More targeted approaches such as grief and bereavement counseling or economic support will also be necessary in some cases.**

Participants promoted connectedness within their relationships, families and communities. There are numerous stories of people reaching out to support each other during quarantine, when family members were in treatment or when survivors returned to communities. Participants reached out to others to promote their own connectedness when they needed it.

While orphaned children and their guardians experienced difficulties negotiating new family structures, children also experienced problems in peer relationships. Safiatu[5], an 18 year old woman who lost her husband, three children, mother and father to Ebola, described how she attempts to provide a safe base for the children in her care.

> *Facilitator: If you knew another child who was in the same situation with you, what would you do to bring him/her closer?*
> Safiatu: Well this is one of them… We console ourselves. At times we sit together and discuss. Because my mother is a sister to her father. Her father and mother are dead as well as her sisters and brothers. At times even if she offends me I will still encourage her. And in the other hand, if I hurt her, she won't feel annoyed.
> *Facilitator: You courage yourselves?*
> Safiatu: Yes we courage ourselves, two of us. There is another child they left me, at times he becomes very much disrespectful. People tell me I have given him a lot of chances. But I just tell them that I don't have anything to do. Because as he is, he don't have a father or a mother. I am the only one he knows. So if he offends me and I react, I will discourage him the more. If he wants to abuse me, let him do it. It won't be written on my body.
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> *Safiatu, 18 years old, (CDHR/PL/PB/SK)*

For young women like Safiatu, short-term economic support is welcome but insufficient, as long-term, family-focused interventions either individually or ideally in a group setting are required. **Family-focused interventions that are supported by the government and/or donors through bilateral aid allocations can bring parents/guardians and children together to promote understanding and positive patterns of relating, reduce conflict and strengthen people's tools and strategies for coping with difficulties.** There are indications that interventions carried out to date to respond to people's psychosocial needs have had positive effects on their wellbeing. They are able to come to terms with the crises while forgiving those that they may have initially blamed.

> There was a time in our village when one women was ill. She told us that she has no Ebola. She went to the hospital and the doctor told her that she has no Ebola so people went and visit her. After sometimes she die and all those who visit her house die also. That was a painful situation in our village. We are all uncomfortable because of these false story that the women told us. It was really painful because most important peoples die.
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> … The way I was feeling the first time and now, everything has change. My stress has gone through the teaching and the games we play and made me happy these times. I am now joyful in everything I do and think positive things for myself and others. I have forgiven this woman for what she has done in our village.
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> *Ramatu, Participant LemonAid Fund WRESL Psychosocial*

[5] *All names of beneficiaries quoted have been changed to protect their privacy.*

III. What is needed for the development of successful psychosocial interventions?

Long-term and appropriately resourced psychosocial service provision is required to respond to locally identified needs. Training, supervision and resourcing of national community-based staff is needed. Short-term project-based funding is not sufficient to meet the psychosocial needs identified. Without adequate support, follow-up and acknowledgment of the impact of the crisis on people's lives, livelihoods and long-term wellbeing will be compromised. Appropriate, community-based programming will prevent escalation of problems and a resulting strain on clinical settings.

Psychosocial interventions should draw on existing familial, social and cultural systems in facilitating psychosocial recovery. Effective interventions will mimic naturally occurring supports and utilize local resources and strategies that foster wellbeing and bring about resilience at family and community levels. This can involve linking to existing family and community support, focused, non-specialized supports and specialized services. Strong referral mechanisms within and between intervention layers are essential. Further, this approach should be intersectoral, making sure healthcare workers, teachers and child protection workers are trained in psychosocial practices.

Currently, an inter-agency working group[6] in Sierra Leone is collaborating on the development of a shared methodology for delivering family-focused community-based supports. This methodology will draw on existing practice (Mindfulness based stress reduction, Acceptance and Commitment Therapy methods, Community Healing Dialogues and Cognitive Behavioral Therapy skills training, among others) to develop a range of culturally grounded methods and activities for working with families and communities to build resilience. There is also **a continued need for research and evaluation to test the effectiveness of these tools and methodologies in the immediate and long-term**, building on past research[7].

The reasons for prioritizing long-term, psychosocial support programs include the following:

- They respond to a need that has not yet been prioritized by the Government of Sierra Leone or international donor community.
- They are cost effective. For instance, with $200,000 it is possible to implement a tailored family-focused intervention with 120 guardians and children in 6 severely affected communities over 18 months.[8]
- This is the ideal time to invest in these types of programs. Appropriate, community-based programming will prevent escalation of problems and strain on clinical settings. As is such, there is a strong case for encouraging international aid agencies and civil society organizations to work in tandem to respond to the psychosocial needs of Ebola-affected communities.

Furthermore, research should be carried out, ideally by a UN agency, to assess the impact of psychosocial interventions in the Sierra Leonean context to measure how children and adults affected by Ebola fare over time and to examine culturally embedded processes of responding to adversity in order to promote resiliency. This research will better prepare the Government of Sierra Leone to respond to the population's psychosocial needs in the event of a future humanitarian crisis.

Funding requests put forward by the Government of Sierra Leone to formalize psychosocial work should be considered affordable, cost-effective and priority areas for support by donors. Finally, governments, donors and aid agencies need to place chief importance on transparency and accountability for all resources to guarantee the effectiveness of the money that is invested in psychosocial interventions. This can involve making public the amount of funds invested in this work and where the investment is being made, as well as careful monitoring of invested funds through local organizations and international aid agencies.

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[6] This working group is comprised of several organizations, including Trócaire, International Medical Corps, Plan International, Concern, Save the Children, International Organization for Migration, Mental Health Coalition and Enabling Access.

[7] For instance, LemonAid Fund has been researching the impact of its tools for over 7 years in the Sierra Leonean context.

[8] This would include the creation of sustainable community systems, training community counselors, individual and group counseling sessions, partner operational costs, communications costs, and a PSS health line. Staff costs, supervision and training are essential.