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BRIEF NOTE

Health and human rights of children affected by HIV/AIDS in urban Boston and rural Uganda

A cross-cultural partnership

● Timothy P. Williams, Martha Vibbert, Laura Mitchell and Rosette Serwanga

Recent studies in *International Social Work* have highlighted the fact that HIV/AIDS continues to dramatically affect the lives of millions of children around the world (Chama, 2008; Demmer and Burghart, 2008; Mweru, 2008; Strydom and Raath, 2005). Social and biological factors associated with HIV/AIDS have placed children at increased risk for experiencing parental loss, poverty, school dropout, increased workload, social isolation, discrimination, loss of life opportunities and early death (Foster et al., 1997; Strydom and Raath, 2005). Social work practitioners, researchers and advocates must continue to develop innovative and evidence-based approaches for assessment, intervention and ongoing advocacy efforts (Chama, 2008). In this light, we present the case of a promising cross-cultural partnership between two community-based organizations serving young people affected by HIV/AIDS in urban Boston (USA) and rural Uganda, who have come together in order to leverage support, improve advocacy efforts and meet the needs of children and families.

Cross-cultural partnership

The SPARK Center started up over 20 years ago in response to Boston's paediatric HIV crisis. It now serves as a therapeutic child-care facility and after-school program for children with emotional and behavioral challenges, developmental delays and complex medical needs, including HIV/AIDS. Comprised of social workers, educators, nurses and mental health professionals, SPARK and its hospital affiliates provide comprehensive and integrated services to children, including mental health interventions, medical supports and educational services.

Located in the Wakiso District of rural Uganda, the Namugongo Fund for Special Children (NFSC) offers a community-based response to reach orphans and vulnerable children affected by HIV/AIDS. The program is led by a small staff and team of volunteers and reaches hundreds of children each day through multi-site breakfast centres and after-school programming. Medical care, including voluntary HIV counseling, testing and treatment, is available to a growing number of NFSC's beneficiaries, which include children and their care-givers (Musiime et al., 2007).

While at different stages of organizational development and resource availability, both SPARK and NFSC are grounded in a shared belief of promoting the health and human rights of children affected by HIV/AIDS around the world – be it in urban Boston or rural Uganda. Both programs subscribe to a community-based approach to care consistent with the social work ethic of building solidarity with clients in a way that promotes each individual's dignity and sense of self-worth, while maintaining their right to self-determine to the greatest extent possible (NASW, 1999).

Recognizing these mutual goals, SPARK and NFSC have engaged in a growing collaborative effort to develop a sustainable 'twinning relationship' (Einterz et al., 2007) intent on enriching client care, enhancing staff skills and staff retention, sharing knowledge and resources, and connecting HIV/AIDS-affected youth across different cultures.

Using the SPARK–NFSC partnership to strengthen evaluation and assessment

One example of this collaborative effort arose because both organizations felt they should assess current program functions and needs in order to develop appropriate advocacy and programming efforts. Having received a small seed grant dedicated to the development of cross-cultural partnerships, SPARK and NFSC shared an evaluation

consultant (the first author of this article) to develop and implement assessments for each program.

Assessment strategies to promote social justice and reduce health inequalities

As social work and mental health professionals, we are all too aware that health inequalities related to psychosocial well-being are often misunderstood and inadequately addressed in the lives of the vulnerable populations whom we serve (Foster, 2006; Patel et al., 2007). As we considered strategies for each program assessment, we committed ourselves to an approach that would best elicit an understanding of the daily realities facing the children and families as well as empower clients to describe their emotional and social experiences of living with HIV/AIDS. While empirical evidence as well as our own professional experience helped to shape the nature of our enquiry, our chosen qualitative methodology was driven by the need to pursue topics of sensitivity and emotional depth, capture the lived experience from those who live it, merge activism with research, and provide an opportunity for populations who are typically marginalized to have a voice in matters of importance to them (Chama, 2008; Padgett, 1998; UN, 1989).

SPARK assessment

SPARK's self-assessment focused on improvement and accountability in its daily after-school programming for school-aged children and adolescents affected by HIV/AIDS. Through interviews, focus groups and ethnographic observations, key findings from the SPARK evaluation suggested that children experience an array of complex social ecological stressors related to living with HIV/AIDS, necessitating, in turn, a holistic and multi-pronged approach to intervention and treatment. Beneficiaries supported the notion that many of SPARK's interventions provided essential psychosocial support in the face of adverse circumstances. Specifically, children and families reported that the program promoted enduring, therapeutic relationships with staff that were perceived by beneficiaries as facilitating growth, learning, security and well-being. Focus group data articulated how long-term attachment relationships provided a pathway to psychological healing, particularly for children who have experienced parental loss and other early disruptions.

By giving clients opportunities to contribute their unique perspectives, the assessment clarified SPARK's inputs, activities and interventions and demonstrated that while the physical implications of HIV/AIDS for children (e.g. chronic illness and medical adherence)

were pronounced, the social and emotional ramifications (e.g. pervasive feelings of stigma, loneliness and loss) were profound. Yet this comes as little surprise given the mounting evidence concerning the psychosocial implications of HIV/AIDS in the lives of children in the USA (Brown et al., 2000; Dee, 2005; Kang et al., 2008; Rotheram-Borus et al., 2001, 2006). Data from this self-evaluation have functioned practically and effectively to improve current programming quality, enhance client advocacy strategies and inform future evaluation efforts.

NFSC assessment

A secondary purpose of the SPARK assessment was to examine the potential for translating key themes and lessons learned from SPARK's program to its Ugandan partner, NFSC. To ensure that our proposed assessment methodology was designed in a way that was consistent with the local culture, we drew from the expertise and knowledge of our Ugandan social work colleagues to design our study protocol. For instance, they provided assistance in designing a culturally competent and dignity-preserving strategy for obtaining informed consent in a population where a large percentage of potential participants are likely to be illiterate.

The purpose of the NFSC assessment was to identify the pressing challenges facing children and their care-givers as well as to gain a better understanding of the current programmatic capacity and functioning of NFSC. Conducted over a six-week period during the summer of 2007, the methodology largely mirrored that of the SPARK assessment by utilizing ethnographic means of enquiry, including focus groups with children and care-givers, interviews with staff and volunteers, as well as observations. Local Ugandan research assistants were recruited to administer all focus groups and interviews in the local language, in culturally appropriate settings with careful safeguards to support any children or adults who might become distressed by the sensitive nature of the topics discussed.

Assessment findings elicited ways in which NFSC was currently meeting the needs of its beneficiaries, particularly through providing food as well as improving access to schooling, health care and other material resources. Key findings from focus groups with children suggested that in a community deeply affected by HIV/AIDS, the psychosocial impact of the disease weighs heavily on children, alongside the economic implications of overburdened households. Children were profoundly concerned about their access to education, reported anxieties about personal safety (sickness, diseases, abuse, rape, etc.) and expressed worries about family integrity (fears that their care-givers

would become sick and/or die). Of particular note was that many of the children's anxieties and worries about safety and potential death were not identified in concurrent focus groups conducted with children's care-givers.

Mental health: a global concern

It was predictable that in the context of urban low-income communities or an impoverished Ugandan village, material needs such as food, clothing, school, shelter and medical care would undoubtedly be a prominent concern. That said, it is much harder to accurately predict a child's hopes and dreams, most pressing concerns and how these may affect their futures. While addressing children's physical needs is of critical importance, traumatic and life-altering events are no less significant. In the absence of adequate coping skills and social supports, children's current and future mental health is highly susceptible to clinically significant levels of psychosocial distress, including depression, anxiety, withdrawal, increased feelings of stigma and suicidal thoughts (Atwine et al., 2005; Cluver and Gardner, 2007; Landry et al., 2007; Makame et al., 2002). These problems can undermine children's developmental trajectories and potentially hinder their ability to become fully functioning, healthy and contributing members of their communities. The assessment findings undertaken by SPARK and NFSC support the notion that a holistic approach intent on reducing health disparities among marginalized children and families affected by HIV/AIDS should provide integrated mental health services if they are to be truly comprehensive.

Cross-cultural partnerships for programming and research

The rich data collected from the qualitative assessments provided critical information with which to translate current programming at SPARK to its Ugandan counterpart, particularly concerning mental health services.

SPARK and NFSC are in the formative stages of an innovative cross-cultural partnership rarely seen between two organizations operating in such diverse contexts. Given the realities of resources and cultural differences between SPARK and NFSC, a mutually beneficial partnership may seem inherently impossible. Striving for what Einertz et al. (2007) described as 'equity, not equality' (p. 812), a dynamic process of mutuality has emerged between these two organizations serving similar clientele in seemingly different worlds. The SPARK–NFSC partnership was founded on the principles of building relationships, leveraging

resources, informing programs, diversifying our traditional approaches to care, and creating research opportunities set on enhancing the health and livelihoods of marginalized children and families. For these reasons, we posit that the benefits SPARK and NFSC have experienced through collaboration extend well beyond the field of HIV/AIDS.

It has been encouraging to discover that our programs and clients have more similarities than we could have ever predicted. Through sharing our hopes and fears, strengths and challenges, we believe such partnerships can offer a promising strategy for innovative programming, evidence-based research and advocacy.

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References

- Atwine, B., E. Cantor-Graae and F. Bajunirwe (2005) 'Psychological Distress among AIDS Orphans in Rural Uganda', *Social Science and Medicine* 61(3): 555–64.
- Brown, L.K., K.J. Lourie and M. Pao (2000) 'Children and Adolescents Living with HIV and AIDS: A Review', *Journal of Child Psychology and Psychiatry and Allied Disciplines* 41(1): 81–96.
- Chama, S.B. (2008) 'Brief Note: The Problem of African Orphans and Street Children Affected by HIV/AIDS: Making Choices between Community-based and Institutional Care Practices', *International Social Work* 51(3): 410–15.
- Cluver, L. and F. Gardner (2007) 'Risk and Protective Factors for Psychological Well-being of Children Orphaned by AIDS in Cape Town: A Qualitative Study of Children's and Caregivers' Perspectives', *AIDS Care* 19(3): 318–25.
- Dee, J. (2005) 'Their Unexpected Adolescence', *New York Times Magazine* (26 June).
- Demmer, C. and G. Burghart (2008) 'Experiences of AIDS-related Bereavement in the USA and South Africa: A Comparative Study', *International Social Work* 51(3): 360–70.
- Einterz, R.M., S. Kimaiyo, H.N. Mengech, B.O. Khwa-Otsyula, F. Esamai, F. Quigley and J.J. Mamlin (2007) 'Responding to the HIV Pandemic: The Power of an Academic Medical Partnership', *Academic Medicine* 82(8): 812–18.
- Foster, G. (2006) 'Children Who Live in Communities Affected by AIDS', *The Lancet* 367(9511): 700–1.
- Foster, G., C. Makufa, R. Drew, S. Mashumba and S. Kambeu (1997) 'Perceptions of Children and Community Members Concerning the Circumstances of Orphans in Rural Zimbabwe', *AIDS Care* 9(4): 391–405.
- Kang, E., C.A. Mellins, W.Y.K. Ng, L.G. Robinson and E.A. Abrams (2008) 'Standing between Two Worlds in Harlem: A Developmental Psychopathology Perspective of Perinatally Acquired Human Immunodeficiency Virus and Adolescence', *Journal of Applied Developmental Psychology* 29: 227–37.
- Landry, T., I. Luginaah, E. Maticka-Tyndale and D. Elkins (2007) 'Orphans in Nyanza, Kenya: Coping with the Struggles of Everyday Life in the Context of the HIV/AIDS Pandemic', *Journal of HIV/AIDS Prevention in Children & Youth* 9(1): 75–98.

- Makame, V., C. Ani and S. Grantham-McGregor (2002) 'Psychological Well-being of Orphans in Dar es Salaam, Tanzania', *Acta Paediatrica* 91(4): 459–65.
- Musiime, V., F. Sali, H. Kizito, A. Bukuru, E. Kizito, C. Kityo and P. Mugenyim (2007) 'A Successful Joint Clinical Research Centre (JCRC) Outreach Programme for Increasing Voluntary Counselling and Testing (VCT), HIV Care and Treatment in a Kampala (Uganda) Suburb', paper presented at International AIDS Society Conference, Sydney, Australia.
- Mweru, M. (2008) 'Women, Migration and HIV/AIDS in Kenya', *International Social Work* 51(3): 337–47.
- National Association of Social Workers (NASW) (1999) 'Code of ethics'. Available online at: <http://www.socialworkers.org/pubs/code/code.asp> (accessed 1 March 2009).
- Padgett, D.K. (1998) *Qualitative Methods in Social Work Research*. Thousand Oaks, CA: Sage.
- Patel, V., A.J. Flisher, S. Hetrick and P. McGorry (2007) 'Mental Health of Young People: A Global Public-Health Challenge', *The Lancet* 369 (9569): 1302–13.
- Rotheram-Borus, M.J., J.A. Stein and P. Lester (2006) 'Adolescent Adjustment over Six Years in HIV-affected Families', *Journal of Adolescent Health* 39(2): 174–82.
- Rotheram-Borus, M.J., J.A. Stein and Y.Y. Lin (2001) 'Impact of Parent Death and an Intervention on the Adjustment of Adolescents Whose Parents have HIV/AIDS', *Journal of Consulting and Clinical Psychology* 69(5): 763–73.
- Strydom, H. and H. Raath (2005) 'The Psychosocial Needs of Adolescents Affected by HIV/AIDS: A South African Study', *International Social Work* 48(5): 569–80.
- United Nations (UN) (1989) 'Convention on the Rights of the Child'. UN General Assembly Res. 44/25. Treaty Series, vol. 1577, p. 3. Available online at: <http://www.unhcr.org/refworld/docid/3ae6b38f0.html> (accessed 1 March 2009).

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