

Beneath the Mask: Program Evaluation of Leading the Way,

A support Group by the Teresa Group for Children Affected and Infected by HIV and AIDS. Toronto, Canada, 2007

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Executive Summary

Leading the Way (LTW) is one of the programs delivered by The Teresa Group, a community-based organization dedicated to providing practical assistance and emotional support to children, youth and families living with and affected by HIV and AIDS. In February 2007, Spire Consulting was contracted to examine the data that had been collected over the years at LTW.

The questions used to guide the evaluation were:

- What is the impact of LTW on the participating children and youth?
- Is there a difference in the psychosocial functioning of children who are aware of the HIV infection in themselves or their family versus those who have not been told?
- To what extent do children in LTW experience heightened levels of anxiety and depression?
- How can the program be strengthened to better meet the needs of LTW participants?
- What best practices can be identified from the LTW program?

Both quantitative and qualitative data were used to gain answers to the research questions. Quantitative data included the participants' completion of the Children's Depression Inventory, the Revised Children's Manifest Anxiety Scale and an evaluation scale designed at LTW. Program retention rates were also calculated. The qualitative data included reports completed by the facilitators on the groups and individual children, and participating children's artwork, songs and answers to open-ended evaluation questions. Analysis of the quantitative data revealed a number of interesting findings about the children and youth who participate in LTW. Using simple cut-off scores it was estimated that 15% of the children were depressed and 11% were anxious. Children in the undisclosed group were significantly more likely to be over the 50th percentile for depression than children in the disclosed group. The majority of children demonstrated lower scores on both the anxiety and depression scales after participation in LTW, although caution must be used with these results due to the lack of a control group.

Many children attend LTW for multiple sessions and almost 70% of the children returned for at least a second session. They also rated the groups and the facilitators very highly.

Qualitative analysis of the documents showed how the facilitators used many activities to help the children explore themes relevant to HIV and AIDS. Children in turn used these activities to explore the impact that HIV and AIDS has on their lives. Over time, the facilitators noted the participants' increased ability to cope with their emotions and to manage their behaviours, as well as an increase in knowledge about HIV and AIDS.

A number of themes emerged in the qualitative analysis. The first theme centred on children's fears about the future, including the loss of parents and caregivers and concern about what would happen to themselves and their siblings. For children who had been disclosed to, facts about HIV and AIDS helped allay some of these fears.

The second theme dealt with the children's fears of rejection related to HIV and AIDS, which kept the children from talking openly about it in their communities. This led the participants to feel strongly about having LTW as a safe place to express their emotions especially those triggered by illness and death in their families.

A third theme examined the effects of HIV and AIDS on families. Families experience stress as parents struggle to cope with living with HIV or AIDS. Families' structures and roles are changed due to the illness, separation and death of family members.

Another major theme was the factors affecting the children's ability to cope since HIV and AIDS do not occur in isolation from other life events, especially poverty, racism, community violence and family conflict. Coping with HIV or AIDS is particularly difficult for children, since their concerns, understanding of HIV and AIDS, and coping mechanisms are influenced by their stage of development. There are a number of important implications based on the findings of this evaluation. Data gathered for this evaluation provided important insight into the challenges facing children affected by or infected with HIV or AIDS. Since these children experience isolation due to the stigma around HIV and AIDS they need long-term support from a consistent source to cope with the issues that they face.

This evaluation indicates that the success of LTW stemmed largely from its adaptability and flexibility. Furthermore, the activity-centered approach successfully allowed children to nonverbally express complex and difficult emotions.

It is recommended that LTW continue to strengthen its program through ongoing monitoring and evaluation. They should also continue to find activities that develop the participants' sense of accomplishment, and keep incorporating time for frank discussions about HIV and AIDS-related issues. Continuing to provide opportunities for the children to challenge negative representations of people whose lives have been touched by HIV and AIDS was also thought to be important.

Thirdly, it was recommended that LTW continue to identify opportunities to promote leadership among LTW participants. A literature search to gather concrete information on empowering youth for leadership and decision-making could be undertaken.

Finally it is recommended that LTW seek opportunities to educate and sensitize key stakeholders, including schools, school boards, faith communities and the media, about discrimination and other HIV and AIDS related issues.