



Recreational Programs for HIV-Affected Children and Families

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Introduction

For children with chronic illness, recreational programs promoting outdoor activity, positive peer relationships, and respite for parents have existed for some time. Over the past decade, recreational programs designed specifically for HIV-infected and -affected children and families have proliferated throughout the country. Although these programs are primarily found in the form of camps, recreation-based programs also include a wide variety of events and activities: picnics, sports-based activities at recreational centers, one-day hikes and adventure trips, holiday parties and trips to the local zoo or museum. Whereas the majority of recreational programs have catered exclusively to chronically ill children and youth, there is a growing trend toward creating programs that target entire families as participants.

Goals and Purpose of Recreational Programs

Recreational programs for children with chronic illness—including HIV—have myriad goals for the children, their caregivers, and the entire family. They provide caregivers with much needed respite; help youth feel “normal” by experiencing activities with other children who are impacted by the same illness; promote children’s social growth and mastery in their peer relationships; help children regard their condition in a more positive and adaptive light; and combat the isolation that many families feel when one or more family members suffers from a debilitating illness (Swensen, 1988; Silvers, Holbreich, Go, Morrison, Dennis, Marostica & Buckley, 1992; Smith, Gotlieb, Gurwitch & Blotcky, 1987). Recreational programs also are intended to increase children’s self-confidence by giving them an opportunity to share their feelings with their peers, and allowing them to express themselves creatively. Programs utilizing peer mentors provide an opportunity for youth to offer guidance and support to children and adolescents who are experiencing similar challenges (Itin & Taylor-Brown, 2000).

Recognizing the benefits of treating the entire family unit, many recreational programs for HIV-infected children and youth provide services for caregivers and siblings as well. Programs that target entire families seek to promote

friendships and support networks among parents who face similar trials and tribulations, and they give children and parents an opportunity to relate to each other in a more neutral, less stressful environment—one in which both parents and children are buffered from many of the stressors they face at home. These programs make many services (e.g., educational sessions about proper self-care, and round-the-clock medical and psychosocial care) available to all family members.

Programmatic Approaches

Three primary approaches to recreational programming for children and families with HIV/AIDS have evolved: community activities, camps for children, and camps for families. Some programs only employ one of these approaches, while others may use two or more. Following are brief descriptions of each.

Community Activities

Some agencies that serve families affected by HIV/AIDS offer community-based recreational activities such as holiday parties, a day at the zoo or another local attraction, or a picnic. For example, on an average of once a week, the Children’s Hope Foundation in New York City uses hundreds of volunteers to coordinate activities that “bring joy to the children’s lives” and “make life better for kids with AIDS” (Leach, 1996). TEAM (described below) also provides similar community activities in addition to a family retreat. Group discounts, or donations in the form of entrance fees or food, as well as the use of volunteers, can make these activities affordable for agencies with limited resources.

Camps for Children

One of the most common and frequently studied models of recreational programs for children and families with chronic illness is the short-term camp experience. The philosophy that guided the creation of these camps is that chronically ill children need a place where they can learn about their illness and how to manage the daily tasks required for proper care, while having the opportunity to play and feel normal in a supportive and accepting environment (Miller & Bortner, 1996). In most short-term camping experiences, the ill or illness-affected child leaves the household for a short period of time (i.e., a few

days to two weeks) to attend camp where they are encouraged to engage in healthy, age-appropriate activities (Smith, et. al., 1987). The absence of the child provides the remaining family members with time to spend with each other, and an opportunity to tend to other neglected activities (Miller & Bortner, 1996).

Camps for HIV-infected and -affected children and youth as young as five years old exist throughout the country. Although Imani Village in Boston is a 5-week summer day camp for children with HIV, most programs are one week long in the summer and combine the activities of typical sleep-away camps with the educational, medical, and emotional support critical to children impacted by HIV/AIDS. They typically provide age-appropriate activities, often separating camps by age. Some are specifically for infected children, others are for affected children, and some combine them. Examples of camps for children include Camp Courage/TLC in New York, Camp Dreamcatcher in Pennsylvania, Camp Heartland in Minnesota, Camp Heart to Heart in Kentucky, Camp Hope in Texas, Camp Kindle in Nebraska, Camp Laurel in California, Camp Meechimuk in Connecticut, Camp Safe Haven in Massachusetts, and Camp Starlight in Oregon.

While some of these programs try to address the physical, emotional, and psychosocial well-being of every child, others simply aim to “allow kids to be kids.” These divergent program philosophies stem from different interpretations of the needs of illness-affected children. Some program administrators seem to believe that because chronic illness creates many emotional and interpersonal challenges for ill youth, it is impossible and unethical to ignore these issues in a camp environment. Others believe that children impacted by illness have a tremendous need to enjoy themselves and participate in a normalizing and relaxing experience that, for a short period of time, gives them relief from the demands of the disease (Smith, Gotlieb, Gurwitch & Blotcky, 1987).

Camps for Families

Increasingly, camps are being developed for whole families affected by HIV/AIDS. In this type of camping experience, the entire family is identified as the target population—bringing together uninfected and infected family members, children, caregivers and any other essential family members. These family-centered camps exist in various forms and structures and last anywhere from a 3-day weekend to 8 days. Some programs provide the family camp experience one component of open-ended, year-round services that are available to clients (e.g., see SMHYLL and TEAM below). A more traditional and common approach is to offer the camp as a stand-alone program, offering respite, support groups, and educational sessions during a single camping session

(e.g., Red Ribbon Trails). In another variation, the camping experience serves as one component of a structured and time-limited therapeutic program (e.g., Family Pride).

Organizers of family-centered camps believe that parents and children alike can benefit from the relaxing and therapeutic environment that camp offers, often providing parents with an opportunity to meet and receive support from other families who are facing similar emotional and financial challenges (Itin, McFeaters, & Taylor-Brown, in press). Although parents and children attend camp together, they often have separate programs. For instance, support groups and educational sessions may be conducted separately, while some recreational activities involve the entire family. Recognizing the value of a kids-only camping experience, some camp organizers combine the best of both worlds, e.g., they hold weeklong summer sessions for children, and then host a camp or retreat for the entire family on weekends during the fall.

Examples of family-centered HIV camps include Camp Benedict in Minnesota, Camp Hakuna Matata in Arizona, Camp Hope in Missouri, Camp H.U.G. and Jennifer’s Camp in Texas, Camp Sunburst in California, Camp Totokett in Connecticut, and Camp Sunrise in Ohio.

Shared Features of Child- and Family-Focused Camps

Most camps for HIV-affected children, youth, and families involve a collaborative effort between medical and mental health professionals. Often volunteers, these professionals are available around-the-clock to provide medical care and psychological and educational counseling. Educational sessions for adults and children often focus on health promotion activities and address factors that may complicate living with HIV/AIDS, e.g., stress, HIV prevention, relationship issues, lack of information about medications and HIV/AIDS resources, and life coping mechanisms. By providing age-appropriate education about the disease, and a unique and supportive space in which family members can discuss their feelings related to the disease, these camps fill a critical gap in the services that families and children regularly receive.

Educational groups for youth cover such topics as drugs/alcohol, relationships, depression, body image, and issues related to puberty and peer pressure. Younger children often participate in therapeutic groups such as music therapy, movement therapy, guided imagery, yoga, and massage. Sessions designed specifically for caregivers often include advances in treating AIDS, death and dying, sibling dynamics, reducing stress through exercise and meditation, and nutritious cooking and menu planning.

Because those affected by HIV/AIDS are disproportionately poor, camp administrators seek to eliminate any barriers to attending camp. For example, most camps (and other recreational programs) for HIV/AIDS-affected children and families are free for participants and provide free transportation. Funding for these programs usually comes from private and corporate donations, foundation grants, the United Way, and various fundraising events.

Often camp staff attempt to stay in touch with participating youth and families after camp, either by providing services to these families year-round, or through mailings, newsletters, or reunions. However, staying in touch is often a challenging proposition—particularly for programs that do not provide ongoing services outside of the camp. Recognizing the important relationships that youth and caregivers develop during camp, some programs also try to facilitate families staying in touch with each other throughout the year. *TEAM Experiential and Recreational Services* has successfully done this by creating a year-round recreational support program serving HIV-affected youth and their families. Other camps invite campers back at various points during the year so they can renew the connections they previously made at camp and, once again, get energized by being with peers who are similarly affected by the disease. *Red Ribbon Trails (RRT)* provides participants with a \$25 phone card so they can call each other during the year. Currently, *RRT* is also attempting to create an interactive website in which families will be able to communicate with each other in a secure chat room.

AIA Recreational Services for Children Affected by HIV/AIDS

Since 2000, the Children's Bureau of the U.S. Department of Health and Human Services has allocated a small portion of Abandoned Infants Assistance (AIA) funds to support recreational programs for children and families affected by HIV/AIDS. Although dozens of family-centered camps for HIV-affected families now exist throughout the country, the four AIA-funded programs discussed below illustrate some of the different programmatic approaches that are used.

The goals of the *Support & Mentoring for Haitian Youth Living with Loss Program (SMHYLL)*, which is located near Boston, Massachusetts, are to provide quality, culturally competent recreational services to HIV/AIDS-affected youth, and their families, and to help clients create a balance with regard to their emotional and physical well-being. Additionally, the program seeks to increase the self-esteem of children and families through mentoring and recreational activities, and to provide respite for the caregivers. Support, mentoring and

recreational services are provided to families year-round, and the camp, located in Mattapan, MA, serves as one aspect of the SMHYLL program. On average, 30-39 families attend camp two or three times per year for a weekend or a week. There, children are assigned to mentors who are typically college students and church members. Educational sessions on parenting skills and nutrition are held for caregivers. Because this program mixes everyone together—family members who are HIV positive and negative—HIV-positive participants do not fear being stigmatized, and all participants are able to partake in camp activities and enjoy each other.

Red Ribbon Trails (RRT) is a four-day summer camping program in Illinois for approximately 20 HIV-affected families recruited from AIDS organizations throughout Illinois. The intent of the program is to provide families with respite (in the form of a camping vacation), recreation, and therapy (children and parents attend separate support groups). Because HIV-affected families from rural areas fear disclosure and subsequent stigmatization, many of these families experience acute feelings of isolation. RRT provides an opportunity for parents to connect with and support each other while the children enjoy a traditional camping experience.

Together Everyone Achieves More (TEAM) Experiential and Recreational Services offers a community-based response to the needs of HIV-affected children and adolescents in the Greater Rochester, New York area through its provision of therapeutic and recreational services. Similar to SMHYLL, TEAM provides year-round services to HIV-affected youth, primarily in the form of skill-building training sessions (e.g., anger management sessions, peer mentor training) and recreational activities (e.g., skating parties, picnics, ropes courses, pool parties). The objectives of TEAM are to enhance young people's assets and strengths through community service and leadership opportunities, and to bolster peer, family and community support through recreational activities (Itin & Taylor-Brown, 2002). The program seeks to increase the coping skills of HIV-affected children and youth through relationship-building with family and community members, and through risk reduction (e.g., reducing drug/alcohol use and sexual activity).

As part of TEAM, youth leaders (who have in some way been affected by HIV/AIDS) serve as facilitators in some of the TEAM programs, including a young boys' recreational group, a young girls' recreational group, the "Verbally Correct" recreational group for adolescents, Peer Mentors, and the Family Unity retreat (Itin & Taylor-Brown, 2002). The first three groups focus on normalizing experiences for HIV-affected youth. Peer mentors are graduates of Verbally Correct, and are

selected for participation based on their leadership potential. They receive skill-building training focusing on HIV prevention, providing support to other youth whose lives are touched by HIV, and providing adventure-based programming and support for younger participants at the Family Unity retreat. The Family Unity retreat is a four-day program in the Adirondacks for HIV/AIDS-affected families. It provides respite for parents, traditional camp activities for kids (e.g., ropes course, hiking), and informal conversations among kids and families covering grief and loss. In addition, various family events, including rafting, photography, memory books, and positive remembrance rituals memorializing family members and friends that have been lost to AIDS, are integrated into the experience.

Family Pride in New York City is a structured, eight-week psychotherapeutic and recreational program for families affected by HIV and other terminal illnesses. The overarching goals of the program are to increase and deepen communication between family members, and reduce the isolation among the six families that participate in each eight-week session. In this approach, participating family members take part in a weekend of camping approximately six weeks into the program. The camping component is viewed as a critical part of the program, in which families are able to interact in a relaxing and supportive environment. Family Pride staff have found that participating families “underestimate their strengths; parents in particular are surprised by how much their children know and understand about them.” The program is offered four times per year, with different families participating in each session.

Evaluation of Recreational Programs

Although many people advocate for the creation and continuation of recreational programs for HIV/AIDS-affected children and their families, there is a dearth of research evaluating the effectiveness of these camps, as well as the effectiveness of community activities, for this population. Currently, most evaluation of HIV camps is based upon campers’ satisfaction with their camping experience and suggestions for improvements. Although this feedback may be informative for those running the camps, more rigorous evaluations should be conducted in order to assess whether these camps are meeting their stated objectives. As part of new funding requirements (and in the hopes of soliciting new funding), recreational programs are increasingly required to collect outcome data: conducting pre-/post-evaluations with their campers, hiring professional evaluators to conduct in-depth qualitative interviews or observational research based on ethnographic theory; or using existing, validated scales that measure health knowledge, self-efficacy, and attitudes toward illness (Briery & Rabian, 1999). For example, preliminary data from the TEAM program

suggest that the program is having a positive impact on participants: participating youth have shown improvement in their communication and leadership skills, team cohesiveness, and willingness to help others (Itin and Taylor-Brown, 2002).

Although evaluations of therapeutic camps for HIV/AIDS-affected families are few and far between, several studies have been conducted on the effectiveness of camps for children suffering from other illnesses. In a pre- and post-study of ninety campers attending three different one-week pediatric camps for asthma, spina bifida, and epilepsy, Briery and Rabian (1999) used the Child Attitude Toward Illness Scale (CATIS) and State-Trait Anxiety Inventory for Children (STAIC) to evaluate whether campers’ attitudes and anxiety changed from the beginning to the end of camp. The authors found that across all three illness groups, children’s attitudes toward their illness improved, while their anxiety levels decreased. Although they were unable to assess which aspect of the camping experience caused the improvement, the authors concluded, “summer camping programs are associated with beneficial outcomes for children with disabilities and illnesses, and that these benefits may be reflected across a number of psychosocial indicators and across illness groups” (p. 189).

In another study of pediatric oncology patients who attended a one-week summer camp, Smith, Gotlieb, Gurwitsch and Blotcky (1987) found that, based on maternal report, children spent substantially more time socializing after attending camp. The objective of the camp in the study was to make children feel as normal as possible, so no formal cancer-related discussions or educational sessions were conducted. According to the authors, the camp experience seemed to have a normalizing effect on the campers: campers spent more time engaged in social and physical activities after attending camp, and these changes were still present one month later. The camp appeared to have a beneficial impact on families, as well as the children; mothers reported spending more time outside the family and with their other children. The authors believe that the positive change recorded in the campers was a “natural consequence of engaging these children in a fun, week-long experience” (p. 540).

In camps whose primary goal is to educate youth about their illness and about self-care, studies have shown more equivocal findings. At a therapeutic camp for diabetic youth, one study found that the more dysfunctional the family system of a camper, the more adjustment to the illness (as measured by competence in self-injection, blood glucose monitoring) he or she experienced from the beginning to the end of camp (Holden, Friend, Gault, Kager, Foltz, & White, 1991). However, with time, these

changes “may deteriorate back to pre-camp levels due to the inability of less functional families to maintain adaptive changes” (p. 274). Indeed, campers from more functional families displayed greater maintenance of change than campers from less functional families. The authors concluded that the qualities of a balanced family system most likely provide more support for maintaining adaptive change. This study illustrates the impact of contextual factors (e.g., family functioning) on a child’s ability to make changes in his or her behavior, or self-care regimen. It also emphasizes the need for ongoing support services to supplement camp experiences.

In another study evaluating the effectiveness of educational sessions offered to youth at camp, Harkavy and her colleagues (1983) found that age was an important predictor of how much a youngster knew at the beginning and end of camp. Older children (campers 12-15 years of age) showed significant improvements in diabetes-related knowledge areas, while younger children (10-11-year olds) showed no change in any of their test scores during their stay at camp (Harkavy, Johnson, Silverstein, Spillar, McCallum & Rosenbloom, 1983). This study reveals the importance of a camper’s age in how much new knowledge he or she can acquire during a short-term camping experience. The authors concluded that adolescents may be better equipped to acquire new knowledge and to process educational material than younger children.

Conclusion

The emergence of recreational camps for HIV-affected parents and children represents an important step in understanding and addressing the myriad ways that the disease affects social and family systems. By providing families with the opportunity to build support and stability and temporarily escape the day-to-day struggles of their lives, camps assist children and parents in developing the personal and interpersonal resources they need to confront the demands of the disease. When designing recreational programs for HIV-affected families, program administrators can select from a variety of approaches: a stand-alone camp; part of a structured and time-limited, therapeutic program; or a component of open-ended, year-round services available to HIV-affected youth and families. Despite variations in the structure of recreational programs for HIV-affected children and families, all share the following key elements: the provision of medical and psychosocial services; the aim of improving communication of peers and between parents and children; and the goal of eliminating all barriers (e.g., transportation, fees) to participating.

The importance of rigorous evaluation procedures cannot be underestimated. Such evaluations are critically important at a time when, in order to procure and

maintain funding, program administrators must be armed with data documenting the efficacy of these programs. At a time when recreational programs for HIV-affected families are expanding, the next step must involve the establishment of sound methodological evaluation—thus illuminating the ways in which these services can be improved to best serve their intended audience, and ensuring the continuation of such programs.

References

- Briery, BG, & Rabian, B. (1999). Psychosocial changes associated with participation in a pediatric summer camp. *Journal of Pediatric Psychology*, 24(2), 183-190.
- Harkavy, J; Johnson, SB; Silverstein, J; Spillar, R; McCallum, M; & Rosenbloom, A. (1983). Who learns what at diabetes summer camp. *Journal of Pediatric Psychology*, 8(2), 143-153.
- Holden, EW; Friend, M; Gault, C; Kager, V; Foltz, L; & White, L. (1991). Family functioning and parental coping with chronic childhood illness: Relationships with self-confidence, illness adjustment, and regimen adherence behaviors in children attending diabetes summer camp. In *Advances in Child Health Psychology*, Johnson, JH (Ed.) & Johnson, SB (Ed.); pp. 265-276.
- Itin, C., McFeaters, S., & Taylor-Brown, S. (In press). Family Unity for HIV Affected Families: Creating a Family-Centered and Community Building Context for Interventions that Facilitate Coping with HIV/AIDS Related Losses. In *End of Life Care Textbook for Social Workers*, Berzoff, J (Ed.) & Silverman, P (Ed.); New York: Columbia University Press.
- Itin, C., & Taylor-Brown, S. (2002, Fall). Together everyone achieves more (TEAM): Peer leaders reach out to HIV affected youth. *The Source*, 11(3), 17-18.
- Leach, J. (1996). Providing hope for kids with AIDS. *The Colgate scene on-line*.
www.colgate.edu/scene/nov1996/josephson.html.
- Miller, SL & Bortner, M. (1996). A week in the country: A model respite program. *AIDS Education and Prevention*, 8(2), 176-186.
- Silvers, WS; Holbreich, M; Go, S; Morrison, MR; Dennis, W; Marostica, T; & Buckley, JM. (1992). Champ camp: The Colorado children’s asthma camp experience. *Journal of Asthma*, 29, 121-135.
- Smith, KE; Gotlieb, S; Gurwitch, RH; & Blotcky, AD. (1987). Impact of a summer camp experience on daily activity and family interactions among children with cancer. *Journal of Pediatric Psychology*, 12(4), 533-542.
- Swensen, TG. (1998). A dose of Camp Dost: Meeting the psychosocial needs of children with cancer. *Issues in Comprehensive Pediatric Nursing*, 11, 29-32.

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Related Websites

Children Affected by AIDS Camp Network (CAAF Camp
Network): www.caaf-campnetwork.org
Camp Benedict: www.camp-benedict.org
Camp Courage/TLC:
www.campgooddays.org/CGDPrograms.htm#courage
Camp Dreamcatcher: www.campdreamcatcher.org
Camp Hakuna Matata: www.apaz.org
Camp Heartland: www.campheartland.org
Camp Heart to Heart:
www.geocities.com/camphearttoheart/
Camp Hope:
www.aidshelp.org/programs/progs_servs_peds.html
Camp H.U.G.:
www.aidshelp.org/programs/progsservs_pediatric_camp_HUG.html
Camp Kindle: www.campkindle.org
Camp Laurel: www.camplareel.org
Camp Meechimuk: Email—hunidos@yahoo.com
Camp Safe Haven:
www.charityadvantage.com/safehaven/welcomehome.asp
Camp Starlight: www.wiar-nw.org/campstarlight/campstarlight.shtml
Camp Sunburst: www.sunburstprojects.org
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