

Adventure, Etc.—A Health-Promotion Program for Chronically Ill and Disabled Youth

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Adolescents with a chronic illness or physical disability have a more difficult time separating from parents, achieving a sense of mastery, developing social skills among peers, and achieving a positive body-image than do able-bodied adolescents. To promote attainment of these developmental tasks, Adventure, Etc. was created as a wilderness/urban Outward Bound experience for chronically ill, physically disabled, and able-bodied teens. Pre- and posttesting and interviewing assessed locus of control, self-image, family environment, and family dynamics. Over a two-year period, 37 teens completed the program and were tested; 23 were chronically ill or disabled. The chronically ill/disabled group showed a significant increase in internal locus of control. No change was found in the able-bodied group. Both the able-bodied and the disabled/chronically ill groups showed a significant improvement in body image. Reported family conflict declined, as did family recreational involvement, while individual recreational activities among these adolescents increased. Based on these results, new follow-up activities for the parents and adolescents were initiated to further the gains of program participants.

KEY WORDS:

Adventure, Etc.
Developmental tasks
Locus of control

While health promotion activities have increasingly captured public attention, little has been written re-

garding the needs of youth with chronic, life-limiting, and disabling conditions. The issue becomes increasingly critical due to the expanded life expectancy of many children who heretofore would have been expected to die during the first decade of life (1). For such youth, the achievement of age-appropriate developmental tasks is frequently hampered by a variety of factors that are often beyond the control of the individual adolescent or practitioner. These factors include a generalized social devaluation of those with certain conditions, the reflexive development of a lower self-concept due to negative social attitudes, and the reinforcement of a catastrophized self-concept by oftentimes well-intentioned parents, teachers, health professionals, and even strangers (2,3).

Among rehabilitation researchers, improvement of the quality of life of those with physical limitations is a key goal. Kotke (4) notes that quality-of-life enhancement is conceptualized as promoting movement along a continuum from survival of essential organs and the achievement of psychophysiologic equilibrium through the development of interpersonal relations and the devotion of personal energy to constructive efforts such as productive work and creative use of discretionary time (3), to the achievement of meaningful social participation and community involvement. This paper presents the initial report of a health-promotion program for youth with disabilities in relation to self-esteem, family dynamics, and locus of control.

Program Development and Content

Adventure, Etc. began in 1979 as a joint effort of the Adolescent Health Program of the University of Minnesota and the Minnesota Outward Bound School.

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Designed as a two-week experience for groups of ten chronically ill, disabled, and able-bodied adolescents, the program consisted of a nine-day wilderness and a five-day urban phase. The focus was on experiential learning by participants as they faced situations requiring active problem solving, peer interdependence, and the exploration of new experiences that tested physical and social capabilities. Table 1 presents the component tasks of the program and the objectives of each task.

The wilderness phase began with safety skills training followed by experiences that directly put this training to use, including rock climbing, white water canoeing, portaging, camping, map and compass orienteering, and an overnight solo experience. Each brigade of 6–10 adolescents was accompanied by a physician and an Outward Bound instructor. Tasks were followed by a “debriefing,” which explored issues of independence, responsibility, leadership, group cohesion, and conflict resolution.

Returning to the city for the urban component of the program, participants learned to apply orienteering skills to the city environment. For many, both able- and non-able-bodied, this was the first time they had explored a city. Throughout the program, both individual goal setting and meeting the collective needs of the entire group were stressed. The final task—a “minimarathon”—was a synthesis of the skills learned over the previous two weeks. Students were dropped off blindfolded in pairs in various parts of the city with a map and bus money. They took a bus to a city lake, canoed a preestablished distance, and completed the third phase of running, walking, or wheeling a distance they set for themselves. The program concluded with a potluck supper with families to give the teens an opportunity to share their new experiences with family and friends.

Research Methods

During 1980 and 1981, four brigades of 8–10 adolescents each participated in Adventure, Etc. Each group was a mixture of disabled/chronically ill and able-bodied youths. The 1980 groups consisted of eight able-bodied and eight disabled/chronically ill youths, with both sexes evenly represented in each group. Conditions of those with disabling and chronic illnesses included lymphoma, cystic fibrosis, chemical dependency, seizures, depression, leukemia, and diabetes mellitus. The 1981 groups had four able-bodied females and 2 able-bodied males ($n = 6$); the nine males and six females with a disability or chronic illness ($n = 15$) had various conditions in-

Table 1. Activities and Objectives of the Adventure, Etc. Program

| Phase/task | Objectives |
|---|---|
| A. Wilderness | |
| 1. Canoeing | 1. Succeed in a new skill, strengthen muscles, work with another person to accomplish a task |
| 2. Portaging | 2. Increase muscle strength, learn to work as part of a group to accomplish a task, learn leadership/followership skills |
| 3. Camping | 3. Increase self-esteem by becoming proficient at survival skills |
| 4. Decreasing contact with staff, final day group is on their own | 4. Learn problem-solving skills, become interdependent with group, independent of adults, manage own medications and treatments with aid from peers, if necessary |
| 5. Solo | 5. Reflect on new relationships, new skills, new sense of self, think about how to transfer this to home setting |
| 6. Rock climbing | 6. Test limitations, experience trust with another person, experience one's body in a new way, improve body image; build a sense of adventure, a willingness to try new experiences |
| B. Urban | |
| 1. Bus Orienteering | 1. Increase mobility in city, decrease dependence upon parent and adults |
| 2. Interviewing | 2. Build a sense of adventure, willingness to take risks; learn interviewing skills, find new role models |
| 3. Service Project | 3. Contribute to others, be on the giving end of caring, work together on a task, improve self image |
| 4. Marathon (bus, canoe, run) | 4. Test limitations, set achievable goal, strengthen muscles, synthesize skills learned on trip |
| 5. Family potluck | 5. Give parents opportunity to see their teens in a new light, allow teens to feel good about accomplishments |

cluding congenital heart disease, polyarteritis with associated cerebral vascular accidents, cerebral palsy, diabetes, Ewing sarcoma, myotonic muscular dystrophy, seizure disorder, juvenile arthritis, myelodysplasia, hearing impairment, cerebral vascular accident, and congenital scoliosis and hearing loss. The mean group age for the 1980 disabled/chronically contingent was 14.6 years; for the able-bodied

component the mean age was 16.1 years. The 1981 brigades had a mean age of 15.2 years for the disabled/chronically ill component and a mean age of 15 years for the able-bodied.

Able-bodied youths joined the brigades for a variety of reasons including the opportunity to experience an Outward Bound program, an interest in the program participants, and the experience of meeting youth with disabilities. In addition, several had good friends or siblings with a disability or chronic illness and they wanted to gain a better understanding of the condition and their reaction(s) to it. For youths with disability, the motivations for participation were as varied as for their able-bodied peers and included a desire to experience the wilderness, a "vacation" from home, coercion from significant others who believed it to be "a good experience," and the recommendation of a physician or therapist.

Psychometric instruments were selected based on documented age-appropriate norms and their measurement of those elements of adolescent development and adjustment central to the program's objectives. The instruments used were the Offer Self-Image Questionnaire for Adolescents (5), the Nowicki-Strickland Personal Reaction Survey (locus of control) (6), and the Moos Family Environment Scale (7). In addition, a semistructured interview was used. There were two testing times; the first was immediately prior to the program and the second was within two weeks after completion of the program. In addition, a six-month postprogram interview with participants and their parents was completed by phone. Each pre- to postmean comparison was made using the nonparametric Walsh Test to rule out distortion due to small sample size (8). Separate analyses were conducted for each group by year and condition, resulting in four comparison groups. Completed pre- and postprogram data plus interviews were obtained from 14 of the 16 1980 participants. One able-bodied adolescent left for college after the course, while another with lymphoma died shortly afterwards. Complete data were obtained from 17 of the 21 1981 participants. Participants with incomplete data included four disabled adolescents: two females and two males. For one of these teens, no pretest data were collected. A second of these disabled teens moved shortly after returning from the program; the other two did not respond to follow-up data collection efforts. An analysis of pretest scores for these three teens revealed no significant mean differences on any scale or subscales when compared with the rest of the disabled cohort and it was therefore concluded that the omission of these

teen's scores did not distort the overall findings for study participants.

Results

Locus of Control

It was anticipated that participants would show a significant shift toward increased personal efficacy (internal locus of control). Chronically ill/disabled participants showed a significant increase in personal efficacy in the posttest (Table 2). This was evident for both 1980 ($p < 0.055$) and 1981 ($p < 0.048$) participants. No change was seen among the able-bodied adolescents.

Parental observations reinforced the quantitative data of an increased movement toward an internal locus of control. In postprogram and follow-up interviews, parents described their children in terms of increased independence including greater responsibility for self-care and illness management as well as more social involvement outside the family.

Parents who said that their chronically ill children were assuming greater responsibility for their own care noted that this was partially due to the child

Table 2. Pre- to Posttest Scores for Nowicki-Strickland Locus of Control Test (Personal Reaction Survey)

| Pre | Post | Differ- ence | Ranked differ- ences | Pre | Post | Differ- ence | Ranked differ- ences |
|---|------|-----------------|----------------------------|-----------------------------|------|-----------------|----------------------------|
| 1980 CHRONICALLY ILL/DISABLED ($n = 7$) | | | | | | | |
| 15 | 10 | 5 | -2 | 15 | 9 | 6 | -3 |
| 11 | 7 | 4 | -1 | 10 | 8 | 2 | -2 |
| 13 | 10 | 3 | 1 | 6 | 6 | 0 | -2 |
| 10 | 9 | 1 | 2 | 6 | 4 | 2 | 0 |
| 7 | 9 | -2 | 3 | 4 | 6 | -2 | 2 |
| 10 | 8 | 2 | 4 | 4 | 7 | -3 | 2 |
| 4 | 5 | -1 | 5 | 1 | 3 | -2 | 6 |
| Walsh test: $p < 0.055$ | | | | Walsh test: Not significant | | | |
| 1981 CHRONICALLY ILL/DISABLED ($n = 11$) | | | | | | | |
| 16 | 12 | 4 | -2 | 11 | 10 | 1 | -3 |
| 14 | 10 | 4 | -1 | 10 | 10 | 0 | -2 |
| 15 | 12 | 3 | 0 | 11 | 13 | -2 | 0 |
| 10 | 10 | 0 | 0 | 8 | 11 | -3 | 1 |
| 8 | 9 | -1 | 2 | 5 | 3 | 2 | 1 |
| 8 | 8 | 0 | 2 | 4 | 3 | 1 | 2 |
| 9 | 11 | -2 | 2 | Walsh test: Not significant | | | |
| 7 | 4 | 3 | 3 | | | | |
| 5 | 3 | 2 | 3 | | | | |
| 5 | 3 | 2 | 4 | | | | |
| 6 | 4 | 2 | 4 | | | | |
| Walsh test: $p < 0.048$ | | | | | | | |

learning new skills and attitudes, as well as the parents being more willing to relinquish control to their children. As one parent noted:

She learned to manage her own shots and take responsibility for her diet and herself. *Not all*, not everything, but much more than before. It was a relief. Because the counselors made her do it on the trail, I saw she could do it and saw she was capable of it. You know, before, I just couldn't let go—and then I saw it could be done.

In terms of daily interaction, other parents also described the reciprocal impact of greater independence on *both* parents and children:

She has become more verbal and demanding—more assertive. I think the program gave her the push to bring us [her parents] to a new level of treating her as an adult, as an independent person. You know that parents usually need a good push from their kids to do this.

Body Image and Social Competence

The hypothesized improvements in body image did occur in both years for able-bodied and disabled participants (Table 3). Within each year, this change,

Table 3. Pre- to Posttest Scores for the Body Image Scale of the Offer Self-Image Questionnaire

| Pre | | Post | | Differ- ence | Ranked differ- ences | Pre | | Post | | Differ- ences | Ranked differ- ences |
|---|----|------|----|-----------------|----------------------------|-------------------------|----|------|----|------------------|----------------------------|
| 1980 CHRONICALLY ILL/DISABLED (n = 7) | | | | | | | | | | | |
| 35 | 29 | 6 | -1 | | | 32 | 30 | 2 | -3 | | |
| 25 | 22 | 3 | 1 | | | 27 | 22 | 5 | -2 | | |
| 27 | 22 | 5 | 3 | | | 20 | 22 | -2 | 2 | | |
| 28 | 27 | 1 | 3 | | | 35 | 30 | 5 | 4 | | |
| 32 | 26 | 6 | 5 | | | 23 | 26 | -3 | 5 | | |
| 20 | 17 | 3 | 6 | | | 19 | 15 | 4 | 5 | | |
| 23 | 24 | -1 | 6 | | | 26 | 19 | 7 | 7 | | |
| Walsh test: $p < 0.023$ | | | | | | Walsh test: $p < 0.055$ | | | | | |
| 1981 CHRONICALLY ILL/DISABLED (n = 11) | | | | | | | | | | | |
| 35 | 52 | 10 | -2 | | | 33 | 32 | 1 | -2 | | |
| 20 | 19 | 1 | 1 | | | 28 | 21 | 7 | 1 | | |
| 18 | 10 | 8 | 1 | | | 35 | 32 | 3 | 3 | | |
| 20 | 15 | 5 | 2 | | | 20 | 22 | -2 | 7 | | |
| 28 | 22 | 6 | 3 | | | 18 | 11 | 7 | 7 | | |
| 34 | 30 | 4 | 4 | | | 26 | 17 | 9 | 9 | | |
| 32 | 31 | 1 | 5 | | | Walsh test: $p < 0.047$ | | | | | |
| 27 | 29 | -2 | 6 | | | | | | | | |
| 22 | 20 | 2 | 8 | | | | | | | | |
| 32 | 21 | 11 | 10 | | | | | | | | |
| 33 | 30 | 3 | 11 | | | | | | | | |
| Walsh test: $p < 0.055$ | | | | | | | | | | | |

while statistically significant for both groups, was more significant among those with disabilities (1980 $p < 0.023$; 1981 $p < 0.055$).

In the area of enhanced social competence, parents described greater self-confidence and assertiveness as well as improvement in attitudes towards peers, both able-bodied and disabled:

It was good for her to see other kids with problems because it helped her understand her own situation in perspective. It helps kids to be less critical of individuals and to take longer before they are judgemental—they reach out and help others more readily and get outside of preoccupation with themselves. They are reinforced for coping, and it broadens their outlook on other individuals, while it breaks down myths about others—especially kids that aren't "cool."

Family Environment (Activities and Conflict)

While anticipating that the program would result in an increase in family recreational activity, the Moos Family Environment Subscale used to assess this dimension showed a highly significant decline in active recreational orientation for both the able-bodied and disabled 1980 participants. No 1980 participants showed an increased score (i.e., greater orientation toward recreation) in the posttest; most showed a substantial decline. No consistent pattern was evident among either of the 1981 groups.

An item-by-item analysis of the questions revealed that the measure is one of mutual family participation in recreational activities. The 1980 interview data from both parents and adolescents suggest a rise in the individual adolescent's recreational pursuits following the Adventure, Etc. program. Subsequently, a drop in such family activity is evident. It is not clear why this was not also the case for 1981 participants. Finally, all but the 1981 able-bodied participants showed a significant decline in family conflict (Table 4). It should be noted that only the parent(s) of each participant completed the Moos Test, therefore the data is derived from their perspective. (In subsequent years (1983–84), adolescents as well as parents were asked to complete an assessment at three time intervals: preprogram, two weeks, and six months after completion of the experience.) No changes in the remaining Moos subscales were present.

Discussion

In normal adolescence, the issues of separation and control are frequently causes of family discord.

Table 4. Pre- to Posttest Scores for the Conflict Subscale of the Moos Family Environment Test

| Pre | Post | Differ- ence | Ranked differ- ences | Pre | Post | Differ- ences | Ranked differ- ences |
|---|------|-----------------|----------------------------|----------------------------------|------|------------------|----------------------------|
| 1980 CHRONICALLY ILL/DISABLED (<i>n</i> = 7) | | | | 1980 ABLE BODIED (<i>n</i> = 7) | | | |
| 42 | 36 | 6 | -5 | 57 | 32 | 25 | -5 |
| 37 | 27 | 10 | -5 | 52 | 37 | 15 | -5 |
| 52 | 42 | 10 | 1 | 47 | 52 | -5 | 1 |
| 42 | 47 | -5 | 6 | 61 | 42 | 19 | 6 |
| 47 | 52 | -5 | 6 | 42 | 41 | 1 | 15 |
| 66 | 65 | 1 | 10 | 42 | 47 | -5 | 19 |
| 32 | 26 | 6 | 10 | 47 | 41 | 6 | 25 |
| Walsh test: <i>p</i> < 0.055 | | | | Walsh test: <i>p</i> < 0.055 | | | |
| 1981 CHRONICALLY ILL/DISABLED (<i>n</i> = 11) | | | | 1981 ABLE BODIED (<i>n</i> = 6) | | | |
| 50 | 52 | -2 | -4 | 55 | 59 | -4 | -7 |
| 43 | 47 | -4 | -2 | 42 | 39 | 3 | -4 |
| 53 | 40 | 13 | -2 | 48 | 40 | 8 | 0 |
| 62 | 61 | 1 | -1 | 39 | 46 | -7 | 3 |
| 55 | 49 | 6 | 1 | 52 | 52 | 0 | 8 |
| 38 | 31 | 7 | 1 | 49 | 41 | 8 | 8 |
| 42 | 35 | 7 | 4 | Walsh test: Not significant | | | |
| 47 | 43 | 4 | 6 | | | | |
| 44 | 46 | -2 | 7 | | | | |
| 51 | 50 | 1 | 7 | | | | |
| 54 | 55 | -1 | 13 | | | | |
| Walsh test: <i>p</i> < 0.048 | | | | | | | |

These are also pivotal issues around which normal changes in family role relations occur during the course of adolescent development and maturation. When chronic illness or disability is involved, these issues are frequently accentuated as areas of conflict manifested in problems with compliance behavior, self-care, individuation, peer relations, and the preparation of the adolescent for life outside the immediate family setting. The control and management of the condition are often assumed by a parent and/or health care provider who is reluctant to see the adolescent take "unnecessary" risks and thus face further harm. While well intended, this attitude frequently results in overprotectiveness, which does not allow the adolescent to ultimately take responsibility for self-management and the realization of his or her physical and psychological potential. Parental overprotectiveness may manifest itself in minimal opportunities for the adolescent to make routine decisions about everyday events, excessive caution regarding social activities and peer involvements, and covert or overt communication to the adolescent that his or her parents do not perceive the adolescent to

be capable of making such decisions themselves. The consequences for the adolescent have been described as increasing passivity and immaturity (9), greater self-consciousness and anxiety, and diminished levels of self-esteem, happiness, and self-perceived popularity (3).

Normal teen separation from parents is made more difficult by dependency on the family and difficulty with peer relationships. Teens with disabilities and chronic illnesses are frequently cut off from activities with able-bodied peers because of frequent hospitalization, delayed physical development, and real or imagined limitations stemming from their physical condition and social ostracism (10). Body image is often distorted (11). In this way, excessive self-consciousness, which frequently characterizes the adolescent undergoing normal changes in physical and cognitive development, may not be offset by accurate feedback and "reality testing" provided by peers. Separation and even isolation from peers, coupled with strained interactions when they do interact, may accentuate the chronically ill or disabled adolescent's sense of difference from peers and a concept of self as deviant.

Issues of locus of control (12) and body image are central issues for all youth. The acquisition of an internalized control locus allows a person to view him or herself as personally powerful and able to influence his or her future direction(s). It is in the development of an affirmative body image that one is able to acknowledge physical limitations and then proceed to maximize potential. Adolescents tend to be concrete learners; while there is a central role for individual and family therapies in dealing with these central issues, so too is there a role for less verbal, more experiential modalities.

With greater capacity for successful medical intervention in chronic illness and physical disability, the need to focus on quality-of-life issues becomes paramount. In childhood and adolescence, this attention must be devoted to the attainment of optimal psychological and social development. For adolescents, the enhancement of normal development rests in meaningful social participation and decision making, learning new skills, and the opportunity to grow beyond entrenched patterns of interaction that may promote passivity both within and outside the family. Our preliminary evaluation suggests that the involvement of able-bodied and disabled adolescents, along with their parents, in an experiential health-promotion program, may help move disabled teens toward achieving the developmental tasks of adolescence.

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References

1. Blum RW. The adolescent with spina bifida. *Clin Pediatr* 1983;22:331-5.
2. Resnick M. The social construction of disability and handicap in America. In: Blum RW, ed. *Chronic illness and disabilities in childhood and adolescence*. New York, Grune and Stratton, 1984.
3. Resnick M. Cerebral palsy in adolescence. In: Blum RW, ed. *Chronic illness and disabilities in childhood and adolescence*. New York, Grune and Stratton, 1984.
4. Kottke F. Philosophic considerations of quality of life for the disabled. *Arch Phys Med Rehabil* 1982;63:60-3.
5. Offer D, Howard K. The offer self-image questionnaire for adolescents. *Arch Gen Psychiatry* 1972;27:529-37.
6. Nowicki S, Strickland B. A locus of control scale for children. *J Consult Clini Psychol* 1973;40:148-54.
7. Moos R, Moos B. *Family environment scale*. Palo Alto, CA, Consulting Psychologists Press, Inc., 1981.
8. Siegel S. The Walsh test. In: *Nonparametric statistics for the behavioral sciences*. New York, McGraw-Hill, Inc., 1956, pp. 83-7.
9. Poznanski E. Emotional issues in raising handicapped children. *Rehabil Lit* 1973;34:322-6.
10. Seidl A, Altshuler A. Interventions for adolescents who are chronically ill. *Child Today* 1979;16-19.
11. Skellern J. The self-concept of children and adolescents and the effects of physical disability. *Australian Nurses' Journal* 1979;8:36-8.
12. Korsch B. Locus of control in juvenile diabetic campers. *J Pediatr* 1983;103:73-4.