



LONG ISLAND INSTITUTE FOR GROUP WORK WITH CHILDREN & YOUTH

HUH?!?

a newsletter about working with children and youth in groups

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From the Editor

In this issue of *HUH?!?* there are stories and a book review about the plight of brothers and sisters who live with siblings with special needs. The value of forming groups to support siblings is highlighted. I am reminded of a group that I worked with years ago.

The group was composed of middle adolescent boys with extreme learning disabilities who were in alternative classes or schools. A few had physical disabilities as well. They all knew the feeling of being excluded and ridiculed. After the group was underway for several months a colleague asked me if I had room for another boy. The "other boy," Billy, had a thought disorder and experienced auditory hallucinations. Erring on the side of inclusion and against knee-jerk conventional wisdom about group composition, I decided to interview Billy and his parents.

In the interview he stared into space, laughed for no reason, and shared some bizarre thoughts

about alien amusement parks and unusual sexual behaviors. I asked him if he wanted to join a group of boys. He said he did. I asked him if he understood that when he laughs because of what he is thinking or hearing the other kids might not get it. I said he might have to explain to them when it happens in the group. He said he understood, although I wasn't so sure he really did. I said I would help him to explain things to the others if he decided to join the group.

Billy and his parents decided to give it a try. I added him to the group. He found a place. The others thought he was most unusual. Instead of his difference being a reason to exclude him, it piqued their curiosity. They genuinely wanted to understand his "problem" and help him to act "more normal" in the group. They could relate to the trouble he had fitting in.

I met with Billy's parents on occasion and wondered about his younger brother Chet. I asked them to ask Chet if I could meet him. He was a

younger adolescent who really didn't want to come in to see me, but did anyway. Before we met I wondered about what it must feel to have an older brother like Billy.

At first Chet was quiet, cautious. I said that I wanted to meet him to understand Billy a little better and to know what it is like growing up with a special brother. I told Chet that I thought he could help me to understand. We met periodically. I don't think that I learned anything that surprised me. Chet didn't like bringing kids home and didn't know how to answer other kids' questions about Billy. He denied feeling anger at Billy or at his parents for all of the attention Billy required. After all of the group members came to a birthday party for Billy, in Billy's home, he revealed feeling happy for him, "that he has some friends."

I'm glad that I included Chet in the helping equation. However, I know that a siblings' group would have been superior to meeting

with me one-to-one. Would he have joined if such a group was available. Maybe he would have. Or not. What I do know is that a group would have provided validation of his feelings, a level of support that exists nowhere else, and a valuable perspective that might have helped him to better understand his brother and their relationship.

Groups may not be appealing to all siblings of children with special needs. But I think we owe it to them to try. Think about what your agency or school offers siblings. Look into what's possible and try to create a group service for siblings. They deserve it.

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Looking Back ... A Reminiscence

"Why Does She Have to Go to the Hospital (Again)?"

When a Sibling Has Special Needs

This is the
20th
feature in a
continuing
series.

Picture this, it's 10:00 PM and mom and dad exchange distressing glances with one another after speaking to the pediatrician. M. (9 yrs.) asks about her sister, "Is A. (13 yrs.) going to the hospital again? Why does she always have to go to the hospital? It seems that she goes to the hospital every year!" Mom and dad look at each other, realizing the accuracy of M.'s pronouncement. They feel exasperated that despite all efforts to tend to A.'s medical needs in a timely and thorough fashion, the outcome remains the same: rushing to the emergency room in the middle of the night with the possibility of hospitalization looming.

M. insists on joining the family on the trip to the hospital, but dad is not sure that this is a good idea. Mom favors the family going all together because it is, in fact, a family crisis. She argues that M. will be affected wherever she goes. They agree to include her on the trip.

In the emergency room, Mom glances at M. amidst the chaos. She sees her fear, her concern for her sister, beneath a stoic stance. She offers her daughter the chance to express what she is experiencing. "Would you like to write about what it's like to have a sister like A.?", mom asks M.

Without hesitation M. grabs a piece of paper and a green crayon (her favorite color) and writes about how sad it makes her feel that her sister has to go to the hospital so often. She adds how much she loves her and that she's "the best sister."

The next morning M. returns to school. She doesn't mention what happened the night before to her teacher. Nevertheless, she remains worried and preoccupied with the well being of her sister. Will she be able to remember her multiplication table? Will she be able to comprehend the story line of the reading passage in preparation for the fourth-grade reading test? Will she be able to meaningfully connect with her classmates when she is harboring a family crisis about her sister who is "different?" Doubtful.

Later that afternoon, mom asks M. if she would like her to contact her teacher to let her know what happened last night. Her answer was an emphatic, "Yes!" Mom knew that the school class should be an important, stable, safe, group of peers led by a significant adult role model and group leader (teacher.) The purpose of this peer group is to learn academics and appropriate social skills. The longer-term goal is to be prepared to become an independent,

functional, productive adult in society. How could this be realized if the teacher fails to "welcome the whole person" into the classroom group?

For M., the sister of a child with special needs, the "whole person" includes her sister A. The classroom should be a safe haven, a protective environment in every sense. Children should be given support when in crisis, so that the trauma doesn't interfere with the learning process.

What better place is there for a child to learn how to appropriately handle a crisis? They can learn how to ask for help and how to offer help. They can also learn appropriate and effective coping strategies to deal with the emotions associated with having a sibling with special needs. It is through this connection with their school, their teacher(s), and their peers that these siblings can create meaning out of what all too often may seem like unfair life circumstances.

The next day M. goes to school a bit tired and anxious, but comfortable knowing that her teacher "knows" and that she has someone to turn to who "understands". The day passes

uneventfully until dismissal when M. realizes that she has an after-school activity that she did not discuss with her parents. She urgently tells her teacher that she's worried that her parents may have forgotten about the after-school arrangements because "you know what happened last night with my sister." M.'s teacher caringly offers to call mom and check things out. M. is reassured and relieved to learn that she was not forgotten and could go on to enjoy her activities.

Later that night M. says to mom, "You know I was worried about A. all day." Mom replies, "I know," and gives her a hug. Mom felt reassured in knowing that this "sibling" has a safe, secure group to turn to each and every day: her class.

Michelle Laser, ASCW is Director of School/Community Collaboratives for North Shore Child and Family Guidance Center. She is also the mother of two daughters, the eldest of whom has special needs, both developmentally and medically. The youngest daughter is the "sibling".

My Sister A.
My sister A. is Autistic and diabetic. Lots of times she has to go to the hospital. a couple of days ago she had to go to the emergency room. I got really sad her toe was infected. It was not fun. But otherwise she is the best sister. I love her. by M. L.

Groups for Siblings ... *programs that go far beyond fad or passing fancy*

Professional interest in the familial consequences of a child with a handicapping condition - such as mental retardation - is relatively recent. The professional literature says that the child who is different might constitute a threat to the family unit. The care and management required is reported to disrupt family routines, restrict extra-familial contacts, create strains in family relationships, and impact negatively on family morale. Nevertheless, a significant amount of writing by parents and siblings, as well as some professionals, argue that these professional views do not match with their own experiences and research.

A great deal of research and practice experience has focused on the needs and concerns of the parent of a child with a handicapping condition. But too little attention has been paid to significant

others in the family, particularly brothers and sisters. What are the effects on a sibling who has a brother or sister labeled mentally retarded or mentally ill?

Social group workers employed by parent support groups were quick to grasp the need for reaching out to these siblings. In 1962 I developed the first sibling group for adolescent brothers and sisters at the New York City Association for the Help of Retarded Children. I aimed to learn from siblings through group activity, and help them to tell what their worlds were like and to deal more effectively with their own concerns.

This group of ten brothers and sisters met every week from October through May. Several themes emerged in the meetings. They include, how to tell our friends about our retarded sibling, and especially friends of

the opposite sex; how to deal with our parents when they have not discussed mental retardation in the family and its implications for us; how group meetings are helpful when it sometimes feels like a betrayal of the family to discuss private matters in a public; expectations and fairness concerning our role, and our parents' role, in the ongoing care of our siblings; our responsibility toward our brother or sister in the event of our parents' deaths; and coping with our feelings when our friends show off their brothers and sisters and talk about their accomplishments.

Social group workers who wish to provide a group service for siblings need to build their knowledge base to include the meaning of disability in our culture. Agencies interested in providing such services need to make a commitment to stay with such a program at least

three years in order to understand the nature of this new client group. Families with children with developmental disabilities need to be assured that a new sibling program is not a fad or passing fancy.

The challenge that siblings of brothers and sisters with handicapping conditions offer to the group worker is profound. Offering a group services to individuals previously factored out of the helping equation is an important avenue for group workers to explore.

Meyer S. Schreiber, DSW. A long time pioneer in sibling activity of persons with disabilities.

☞ For resources about Siblings contact the New York City Association for the Help of Retarded Children, 200 Park Ave. So., New York, NY 10003 where Dr. Schreiber's accumulated materials are housed in a collection entitled the Meyer Schreiber Sibling Archive. Call the Association at 212-7800-2500 for information about how to utilize these resources.



Book Briefs



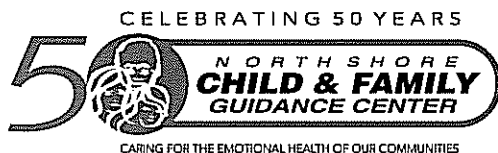
SIBSHOPS-WORKSHOPS FOR CHILDREN WITH SPECIAL NEEDS; Donald J. Meyer and Patricia F. Vadasy. Baltimore: Paul H. Brookes Publishing Company, 1994, 256 pages with illustrations, \$32.00 paper.

This wonderful book takes the reader, step by step, through the process of planning for and actually running groups for siblings of children with special needs. The "special needs" may include a wide variety of chronic illnesses and all types of disabilities. The *Sibshop* model is meant to be an educational and recreational program for school-age (8-13 years) brothers and sisters who can provide each other with peer support...(the authors) set forth five goals...and then use the book to explain how to meet those goals. These include helping children to: (1) Meet other siblings in a recreational setting; (2) Talk and share concerns and joys; (3) Learn how to handle situations which arise as a result of a sibling with a disability; (4) Learn more about the implications of their siblings' needs; and (5) Provide parents and professionals with opportunities to become more aware of sibling issues. In general, *Sibshops* is clear, detailed, and enjoyable. It provides the reader with background on a previously ignored topic and everything one would need to get started doing these types of groups for children. As the parent of a child who is "typical" and one who is autistic, this book was a wonderful reminder of the many issues my "typical" child faces in life. I know how useful these groups can be because my son has participated in sibling workshops... and prefers going to them over anything else he might do on a Saturday! As a professional, having read this book makes me want to run out and start Sibshops myself!

• By Ronda Fein, Ph.D. (excerpted from Dr. Fein's review originally appearing in the journal *Social Work with Groups*, 19:1)

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❖ EVENTS & RESOURCES ❖

◆ **2003 GROUP WORK TRAINING:** This workshop series features professional group work training appropriate for professionals and lay persons working with children and youth in groups. The entire series will be held at the Roslyn Heights Office of North shore Child & Family Guidance Center. **The fee is \$35 per workshop.** A "Group" rate of \$30 per workshop is offered for groups of six or more who register together. A special "Series" rate of \$100 is available for any individual registering for the entire series. To register send your check payable to Long Island Institute for Group Work/NSC&FGC; 480 Old Westbury Rd.; Roslyn Hgts., NY 11577-2215; Attn: Barney Navas. For questions call Mr. Navas at (516) 626-1971 Ext. 337.

- ◆ **February 24, 2003 @ 6:30 PM: *Sports Teams as a Vehicle for Youth Development***
- ◆ **March 14, 2003 @ 9:30 AM: *Using Activities to Promote Youth Development***
- ◆ **April 11, 2003 @ 9:30 AM: *Helping Youth to Become Culturally Competent through Ethnic Sharing***
- ◆ **May 16, 2003 @ 9:30 AM: *Group Work at Warp Speed (or when a bus ride is more than a bus ride)***

HUH?! is the quarterly newsletter of the Long Island Institute for Group Work With Children and Youth, a program of North Shore Child & Family Guidance Center; 480 Old Westbury Road; Roslyn Hgts., NY 11577-2215; Phone: (516) 626-1971 ** Fax: 626-8043. **Executive Director/CEO:** Marion S. Lavine, ACSW; **Associate Director/NSC&FGC** and **Newsletter Editor:** Andrew Malekoff, ACSW, CASAC. **Newsletter Design and Layout:** Jane E. Meckwood-Yazdpoor, BS. **Participating Agencies:** Coalition on Child Abuse & Neglect, Garden City; Youth Directions and Alternatives, E.Northport; Herricks School District, Albertson; Sanctuary Project, Huntington; Plainedge School District; L.I. Chapter/Assoc. for Advancement of Social Work With Groups; L.I.Crisis Center, Bellmore; Temple Sinai of Roslyn; Huntington Youth Bureau, Huntington; South Huntington School District, South Huntington, NY. © Copyright January 1, 2003/USA.

TIPS for ... Getting Sibling Groups Started

Siblings of children with special needs deserve good group experiences with other siblings. Siblings groups can validate their feelings, teach them about their siblings' unique needs, provide them valuable perspectives to aid them in coping, and enable them to express concerns and joys. The first step, if you work in an agency or school, is to do an informal poll to see what your colleagues think. This is a way of teasing out the needs that forming a sibling group might address. If you find one or more like minded colleagues ask them to join you in doing a more formal needs assessment, maybe in the form of simple survey. When the results are in ask to make a presentation of "findings" at a staff meeting. If interest is generated then you can begin the process of developing a recruitment strategy which will be a big step towards the formation of a group. Make sure to tune in to how siblings might feel about being approached to be part of such a group And, don't forget to include parents in the process. If you successfully get a group off the ground, evaluate its progress and report back to the gatekeepers to ensure continued support.

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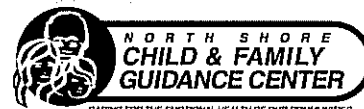
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Mission Statement: Long Island Institute for Group Work with Children & Youth

The Mission of the Long Island Institute for Group Work With Children and Youth is: To promote and enhance effective group work practice with children and youth through advocacy, education, and collegial support. **HUH???** is the Institute's quarterly newsletter dedicated to providing information, inspiration and support for anyone working with young people in group settings.

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