The Forgotten Siblings of Chronically Ill Children

Elizabeth H. Fung, PhD, ACSW, LCSW

Parents of a child with a physical disability or chronic illness may be so consumed by their efforts to meet the needs of that child that the needs of their well children may take a backseat. Although parents are aware of the challenges that exist for their well children, they often have neither the time nor the energy to help them. Well children may need the assistance of social workers to learn to cope with resentment and anger they have toward their ill sibling (Thompson, Curtner, & O’Rear, 1994). Yet they are often left to sort out the situation and cope on their own. The well siblings of chronically ill or disabled children are often overlooked or forgotten. Some well siblings adjust. Others may be at risk for long-term emotional problems.

“I’m living in the shadow of his illness,” says a 15-year-old brother. “I’ve never felt free to talk about the fun I had at a soccer game.” These feelings could come from unwarranted guilt for having a more normal life, or they could reflect a realistic appraisal of an advantage in life over a brother who has a physical disability. Social workers who treat families of chronically ill or disabled children should not forget the psychosocial or emotional needs of well siblings. Many factors can affect the adjustment of well siblings. This article considers the potential effects of gender, developmental stage, race, and birth order.

Gender

When female siblings closely identify with their mothers in the nurturing role, they take on more caretaking responsibilities. Consequently, they are more vulnerable to becoming resentful. According to Eiser (1993), girls may experience more psychosocial problems because of this dynamic. “I resent the fact that I have to pick up homework for my brother and go home right away when other kids can hang around after school.” A child who is given too many responsibilities and who wishes to run away from them may suffer from feelings of guilt.

Developmental Stage and Cognitive Processing

Children learn about the world around them as they observe things, but they need information as they learn. While they receive information from many sources, they most frequently receive it from their parents. Children, especially younger ones, are very responsive and tuned in to their parents’ reactions.
From the **Chair**

Welcome to the first edition of the *Children, Adolescents, and Young Adults (CAYA) SectionConnection* newsletter. We are excited about bringing together current and relevant practice information for social workers whose work is at the forefront in foster care, juvenile justice systems, residential care, schools, community youth programs, hospitals, private practice, early childhood programs, and many other settings where the goal is to improve the lives of children, youths, and young adults. Social workers offer a unique perspective in helping young people. Our ecological and systemic approach brings together the best of psychological, biological, and social practices.

It is within this framework that CAYA’s newsletter will provide helpful practice knowledge. We have made an excellent start with the four diverse articles in this issue.

- **Elizabeth H. Fung, PhD, ACSW, LCSW,** describes the possible impact of a chronically ill child on well siblings.
- **Kimberly Hill,** an MSW student, interviews Pierre Dulaine, co-director of Dancing Classrooms, a program that builds children’s social awareness, confidence, and self-esteem through dance.
- **Lorna Littner, MS, LMSW,** reminds us that an important adolescent developmental task is the understanding of sexuality and offers principles for effective communication about this important topic.
- **Yan Dominic Searcy, PhD, MSSW,** gives us an up-close look at how children in Louisiana fared during the Hurricane Katrina disaster. The state’s child welfare department not only looked after children in foster care but also assumed responsibility for all children in need during the catastrophe.

Gary Plato, a committee member and co-editor of this edition, and I encourage you to log on to the CAYA page through the NASW Web site (www.socialworkers.org) and start a discussion in the online forum. We would like to hear from you regarding the issues and challenges you face working with young people.

It is with great pride that I offer you the first issue of CAYA’s newsletter. Happy reading!

Tonia Caselman, PhD, MSW, LCSW
whether verbal or nonverbal. They may not have the language or know how to talk about it, but they are keenly aware of who receives the parents’ time and attention. Depending on their developmental level, children interpret the behaviors they witness and draw both correct and incorrect conclusions about why one child gets extra attention and the other child does not. Many children are likely to feel angry or jealous of the sibling who gets the extra attention.

Developmentally, two- to four-year-old children are typically egocentric and think in concrete terms. Children in this age group may see toys and treats being given to their ill sibling but do not have the capacity to understand chronic illness or the pain the sibling may be experiencing. Five- to nine-year-old children are developing operational and fantasy thinking and are known to confuse cause and effect. This may result in feelings of guilt as a result of resentment and anger. As children enter adolescence and develop the capacity for formal operational thinking, their capacity for logical thinking and problem solving are increased. In all cases, however, social workers and parents should take care to respond to the questions of well children about a chronically ill sibling in words and concepts appropriate to the developmental level of the children.

Race
Most children from ages three to 17 years who need a mental health evaluation do not receive services, according to a report by the Institute of Medicine (2002) and a study by Kataoka, Zhang, and Wells (2002). Both found that Latino and uninsured children have especially high rates of unmet mental health care needs compared with other children. Additionally, black and Asian males are more reluctant to ask for help compared with other minority groups. For siblings of chronically ill or disabled children, this can mean that the mental health services are even less frequently accessed on behalf of siblings from minority populations.

Birth Order
Studies show that firstborn children tend to be more aggressive and to strive for achievement. Firstborn girls often are involved in advising younger siblings, and in many cases the youngest child receives favored treatment. Additionally, with younger children, parents have acquired more parenting skills through raising the older children, and may have become more relaxed and lenient. Many middle children often have adjustment issues in the family, behaviors that have been referred to as the middle child syndrome. Pilkington, White, and Matheny (1997) found that oldest children tend to have the most environmental and emotional resources, and middle children tend to have the fewest. Middle children, girls in particular, may experience feelings of isolation. Fung (2005) found that among siblings of children with a bleeding disorder, the middle child of both genders seemed to experience more depression, anxiety, and stress.

Gallo and others (1992) have found that younger well siblings are more at risk for problems because illness may create role confusion when the ill child becomes the dependent child, displacing a younger child. These studies, however, generally focus on devastating, progressively deteriorating conditions such as cystic fibrosis.
Practice Implications

What practice implications can we draw regarding the well sibling? While it is crucial that social workers explore the parents’ grief and sorrow over the loss of a “perfect” child, it is also wise to educate parents to be sensitive to the effects of the child’s chronic illness on well siblings. Donald Meyer, director of the Sibling Support Project in Seattle, says, “Brothers and sisters of children with special needs experience all the feelings that their parents do, plus some that are exclusive to them.”

In summary, social workers should advise parents to do the following:

• Approach children at their level of development and comprehension. Respond to questions in a simple and sensitive way. Most children benefit from being able to talk about concerns with their parents.

• Discuss in an open, honest way what the parents feel, experience, and expect of all their children. Avoid sending shame or guilt messages.

• Let well siblings know that unpleasant feelings are normal. Help them eliminate feelings of shame and guilt.

• Provide a safe atmosphere for honest feedback from children. Especially, support the middle child’s efforts to be more assertive.

• If a well sibling is acting out, it is not always an unhealthy expression, because the child is not turning inward. Such behavior can be dealt with together.

• Acknowledge and praise any behavior that you want to see. Let well siblings know exactly what it is that you like: “I really liked the way you played with Jenny just now, when I was talking on the phone with Aunt Suzy.”

• Be clear in communicating that well siblings are not expected to compensate for what may be perceived as lacking in the ill child. The well sibling is not the automatic torch bearer, playmate, or babysitter. Be especially careful with older sisters, who may feel that they should always be available to babysit.

Social workers can help families with chronically ill or disabled children build resilience. An important part of accomplishing this is building cohesion between the sick child and well siblings. This may include helping the parents and the children develop age-appropriate coping strategies, tolerance, and communication skills.

Elizabeth H. Fung, PhD, ACSW, LCSW, is a senior social worker at Children’s Memorial Hospital in Chicago, and she is also in private practice. She can be reached at elfung@childrensmemorial.org

References


AN INTERVIEW WITH PIERRE DULAIANE
CO-DIRECTOR OF DANCING CLASSROOMS TALKS ABOUT HIS INSPIRATION

Kimberly Hill, BA, MSW student

Pierre Dulaine is the co-artistic director and founder of the American Ballroom Theater Company. Among other awards, Mr. Dulaine is the four-time winner of the World Exhibition Championship and an Astaire Award winner for Best Dancing on Broadway. He is director of the American Ballroom Theater Company’s outreach program, Dancing Classrooms.

Dancing Classrooms was launched in 1994 with the mission of developing children’s social awareness, confidence, and self-esteem. The program includes a 10-week series of 50-minute classes twice a week. Dancing Classrooms reaches nearly 12,000 students in 150 New York City schools.

Kimberly Hill: How did you become interested in helping and inspiring public school children?

Pierre Dulaine: People come to a certain age in their lives where they feel they want to give something back to society. I had free time during the day when I was working on a show on Broadway, so I volunteered at one of the schools in Manhattan where I knew a principal.

KH: How has the program grown over the years?

PD: The program went from one school to six to 12 to 14, and so on. Two years ago, when the movie Mad Hot Ballroom was made, we were already in 60 schools. This year, we are in 150 schools, working with almost 12,000 children. We are having to put people on a waiting list.

KH: What age groups do you target, and why?

PD: We target fourth and fifth graders, ages 9 to 11. Younger children are not coordinated enough to work with a partner. This is the best age, because they are still malleable and part of an elementary school culture. They are still at an impressionable age, so they can accept the movement. Sixth and seventh graders are difficult because bodies are changing and hormones are raging. We are currently working with eighth graders in five or six schools. This is also a very good age, because their bodies have grown out of the awkward stage, and they don’t mind touching each other.

KH: Do you offer the program only through schools, or have you done it through other community programs dedicated to youth?

PD: We are a curriculum-based, arts-in-education program. We are guests in the schools. We are not licensed schoolteachers, so the classroom teacher must be present with our teaching artists. Then the classroom teachers can take it and make it part of their social studies lessons—the history of the dance, the geography of the dance—and the children can really learn about the country they visit in dancing classes.

KH: Do your dance instructors have any other special training, such as handling angry youth?

See Dulaine, Page 6
**PD:** They have 60 hours of training before they are enlisted to work with our organization. We have a syllabus and a curriculum. We teach them how to teach each step and what we call “classroom management skills.” We teach them how to capture the students’ attention and keep them having fun.

**KH:** Do you have any interaction with the families of the students?

**PD:** Not as a rule, but we have worked with some schools where we have parents as partners. This is an evening course. In the regular curriculum, Lesson 20 is a culminating event where the parents are invited to watch the children perform. At these events, we get the parents to dance with the children so they are able to learn the steps.

**KH:** How is the program funded?

**PD:** We are a nonprofit organization. We have fundraising events, such as our dinner dance. Our schools pay us 40 to 50 percent of what it costs us; we have to subsidize the rest. We are funded by private foundations, family foundations, friends and neighbors—anyone who can give us money.

**KH:** The movie shows a wonderful transformation in the lives of several students. Do you experience this phenomenon on a regular basis?

**PD:** Yes! Of course! There is unbelievable transformation in every child.

**KH:** How do you explain this transformation?

**PD:** Dance is simply the vehicle. The real engine, the real thing that students learn, is civility: to be polite to each other, to be respectful to each other, to know how to escort a lady, to know how to talk to somebody, to know how to walk straight, to enter a room, to shake hands. All these things are what they take with them; these are the transferable skills for life.

**KH:** Any stories?

**PD:** It is just repeated many, many times. The little boy, Wilson, who did not speak English: This was the perfect opportunity for him, because learning to dance is visual. And when he heard the same words over and over, it helped him learn English. He learned how to dance and learned English at the same time.

**KH:** Some children cannot participate for religious reasons. Do you think this has a negative impact on any of these children?

**PD:** We have to respect that. What happened with the two boys in the documentary happens all the time. It is good for them to participate in the class mentally, however, even if they cannot participate physically. They can write about the cultures that produce dances like the waltz, the fox-trot, the tango. Just because you may not dance with a partner doesn’t mean that you should not learn about dance.

**KH:** Has the program fulfilled your expectations?

**PD:** And beyond.

**KH:** Has anyone done any formal research or program evaluation on your program?

**PD:** There will be one this year to be used for funding.

**KH:** What are some important steps to keeping it going?

**PD:** Quality control. This isn’t just teaching dance steps. There are many things happening all at once. It’s important to have a great
personality as you get down and have fun with the children. To make it successful, you have to have fun with it.

**KH:** Where do you see this program in the future?

**PD:** The program is being replicated in Chicago; Omaha; Lexington, Kentucky; Phoenix; Newark; and other places. The program is much bigger than I am, bigger than any one person. I’m going out to do the training in different cities, and we are licensing our work out to these cities. It can grow as much as people want it to.

I went to England last fall, where my nephew is a schoolteacher. He teaches fifth graders, and I wanted to experiment with English children. It was wonderful—kids are kids all over the world. This program can go anywhere, if you know how to teach them, if you know how to reach them.

**KH:** Do you have anything to add?

**PD:** There’s a new movie out called *Take the Lead*, starring Antonio Banderas. It’s the story of my first efforts at a school and the challenges I had to overcome.

**KH:** Thank you, Mr. Dulaine, for taking time to tell us about your inspirational and dynamic program with social workers across the country.

Visit www.americanballroomtheater.com/dancingclassrooms.htm for more information on Pierre Dulaine and Dancing Classrooms.

**Kimberly K. Hill, BA,** is a behavioral health rehabilitation specialist at Grand Lake Mental Health Center in Bartlesville, Oklahoma. She earned her BA in psychology at the University of Tulsa and is currently an MSW student at the University of Oklahoma–Tulsa, where she is a graduate research assistant. She can be reached at kimberly.k.hill-1@ou.edu

---

**COMMUNICATING WITH ADOLESCENTS ABOUT SEXUALITY**

**Lorna Littner, MS, LMSW**

Sexuality is a core aspect of our being. It reflects our biology, psychology, cultural and social context, and religious and spiritual roots. Understanding the holistic nature of sexuality is important for social workers who treat or provide services for adolescents in various practice settings.

Sexuality can be expressed in many ways, not just through genital behavior. For example, we express sexuality through body image, gender presentation, and social roles, and through the nongenital expression of affection, love, and intimacy. Learning about intimacy and relationships and understanding their sexuality are important developmental tasks for adolescents.

**Sexuality and Communication**

Many contradictory attitudes and mixed messages about sexuality leave unanswered questions for adolescents who are developing sexually and want to understand sexuality and intimacy. Even though sexual images and messages are commonplace, many social workers are not sure how to address sexuality with adolescents and how open and forthright they should be.

*See Communicating, Page 8*
Common barriers to open communication about sexuality are embarrassment, lack of information, concern about language and how much should be said, cultural beliefs, religious beliefs, lack of skills and experience, and the social taboo against talking openly about sexuality.

**Impact of Developmental Stage**
As practitioners, we should consider fundamental aspects of adolescent development that affect communication about sexuality with adolescent clients.

- **Peer influence**: As a teen’s involvement and identification with the peer group becomes increasingly important, he or she tends to minimize or reject adult messages about sexuality.

- **Conflicting needs for autonomy and dependence**: At the same time that adolescents are asserting their independence and assuming adult roles and behavior, they still want to be cared for and remain dependent in many ways. Significant adults in their lives may push them to be more responsible and mature while continuing to hold on to them, providing a degree of protection and guidance. Teens often express the conflict inherent in this transitional phase through sexuality and sexual behavior; adults express it by preaching and becoming hypervigilant.

- **Processing information**: A mature and responsible approach to sexuality requires the ability to think abstractly. Most teens think concretely and have a difficult time projecting beyond their immediate reality. As adults, we try to get them to think about and prepare for a future they often cannot fathom.

**Principles for Effective Communication about Sexuality**
The following approaches are important in addressing sexuality with clients:

- **Be informed**: Keep current on sexuality-related information, especially issues that are significant for adolescents, such as relationships, sexual orientation, contraceptive technology, safer sex, and the range of sexual behaviors.

- **Be realistic**: Set reasonable goals and expectations for your interactions with clients. Remember, they bring years of learning and experience to the transaction that can take a long-term commitment to redirect.

- **Check all assumptions**: Do not assume that clients who engage in a particular behavior, especially genital behavior, understand all the implications of that behavior. Many young people engage in behaviors they don’t fully understand. Learn as much as you can about each person, and tailor your communication to his or her specific needs.

- **Be nonjudgmental**: Know yourself—your strengths and weaknesses—and be aware of your values and attitudes that relate to sexuality. Try not to let your personal values and attitudes affect or define your discussion with clients. Be receptive to what clients say or do, particularly when it differs from your own point of view.

- **Keep communication in context**: Match your expectations, communication, and content with your client’s developmental stage and cognitive ability. For example, be as concrete as possible with younger clients, whose thought processes are very literal.

- **Be mindful of the religious and cultural context**: The more you know about your clients’ backgrounds, the more likely your communication will be sensitive to their upbringing, values, and beliefs.
• **Reward young people for asking:** When a client asks a question or makes a personal comment about sexuality or sexual behavior, acknowledge it by saying, for example, “That's a really good question—I'm glad you asked” or “I realize how difficult that must have been for you to say.”

• **Start where the adolescent is:** Communicate at your client's level. You may have a clear idea of where you would like your clients to be, but to help them get there you have to start where they are.

• **Make the communication transactional:** Young people expect adults to preach, particularly about sexuality. Try to talk with them, not at them. If you find yourself doing all the talking, stop and ask them for feedback. If you want them to listen to you, invite their participation and then listen.

Finally, social workers should seek out training in human sexuality, a core practice-related topic that is rarely required in the social work curriculum. The more knowledgeable, comfortable, and skilled social workers are, the better they will be at setting a tone that puts adolescent clients at ease. Training and experience are integral parts of developing the skills necessary to meaningfully engage with teens on this difficult and complex topic.

**Lorna Littner, MS, LMSW,** is a certified sexuality educator who has worked for the Children's Aid Society in New York City since 1979, providing training in adolescent sexuality and pregnancy prevention to medical and social work professionals. She can be reached at llittner@verizon.net

---

**IDENTIFYING QUALITY TRAINING FOR SOCIAL WORKERS**

There are continuing education programs and staff development trainings that can guide social workers with additional information on addressing the issue of sexuality with adolescents. Quality training programs will include the three following elements:

- Facts and information on adolescent sexuality;
- The exploration of attitudes, feelings, cultural and religious tenets that affect beliefs about sexuality; and
- Practical strategies for facilitating communication on sexuality with adolescents.

---

**PROTECTING CHILDREN IN THE MIDST OF THE STORM LOUISIANA’S DSS ASSUMES RESPONSIBILITY FOR ALL CHILDREN IN NEED**

**Yan Dominic Searcy, PhD, MSSW**

The stories of children often do not get told, in order to protect their confidentiality. This practice frequently results in the needs of children being overshadowed by more highly publicized needs. In the Gulf Coast catastrophe, however, the needs of children traumatized by Hurricanes Katrina and Rita were not overlooked—thanks to Louisiana’s Department of Social Services (DSS) child welfare agency, the Office of Community Services (OCS).

When Hurricane Katrina hit the central Gulf Coast on August 29, 2005, there were 4,241 children in Louisiana’s child welfare system, including children living with relatives, in foster care homes, in group homes, and in other care facilities. More
than 1,700 of these children were displaced by the catastrophic flooding and devastation caused by Hurricane Katrina and compounded by Hurricane Rita on September 24.

Countless more children who were not in the custody of the state were also displaced and required help finding their families. The OCS traditionally covers only children in the state’s care. During the hurricanes, however, the office assumed responsibility for all children in need. In a recent interview with this author, Louisiana child welfare section administrator Joel McLain recalled the long hours, hard work, and endless devotion of staff that cared for and found homes for these children.

**Rush to Action**

While the Federal Emergency Management Agency (FEMA) rushed to provide assistance after Hurricane Katrina, many of the 1,900 OCS employees were already taking telephone calls and staffing shelters throughout the state. OCS workers staffed children’s shelters for several weeks, even though nearly 25 OCS staff members had themselves been displaced by the hurricanes. “Many left with just the clothes on their backs,” said McLain, “yet they appeared for work the next day.”

Special needs shelters were established statewide; initially, the New Orleans Superdome was designated as one of these shelters. “The staff at the Superdome worked very hard,” he said. “There was no electricity and no way to communicate.” Baton Rouge, where OCS is based, was the first major evacuation site and became a conduit to other evacuation shelters throughout Louisiana.

As the Superdome and other shelters began to fill to capacity, the OCS set up a toll-free telephone number to help get information out. Parents and others could call to get information ranging from shelter locations to board payment and reimbursement information.

OCS employees manually set aside payment checks for foster parents until their locations were determined. There was no mail service in many areas affected by the hurricanes. When foster parents were located, payments were mailed or, in some instances, hand-delivered by staff.

**The Public’s Response**

The national media captured compelling images of stranded families being airlifted out one member at a time. Because of the lack of coordination and the sheer volume of people who had to be evacuated, some children were separated from their parents. As the media continued to air stories on the devastation in the area, the reports of children in need sparked a national response.

OCS staff answered calls from people around the country who wanted to help care for children. Callers volunteered to become foster parents, to pick up foster children, and to share their homes. Children under the care of the state typically cannot be placed in homes that have not been licensed, so callers were encouraged to work with their respective states to become licensed foster parents. OCS recorded caller information and made referrals as necessary.

During the days and weeks following Hurricanes Katrina and Rita, some news stories reported inaccurate information. For example, television footage showed children roaming the streets unaccompanied. According to McLain, reports of roaming children...
were not substantiated. The national media did, however, accurately report on the dire needs of displaced children. As a result of the actions of OCS and its partners, any children who were separated from their families during the early days after the hurricanes have been reunited with them.

**Partners**
The Louisiana DSS and OCS partnered with, and continue to work very closely with, officials in Texas, which provided temporary housing for many evacuees. One-fourth of Louisiana’s displaced children in care relocated outside of Louisiana. The DSS Medicaid division worked with Texas and with many other states to honor the medical insurance cards of displaced families who sought medical care.

OCS worked closely with the National Center for Missing and Exploited Children (NCMEC) to reunite children with their families. NCMEC and OCS received help from Angel Flight, a nonprofit organization that provides free air transportation to those in need. NCMEC coordinated nearly all the trips and was able to fly a number of children to rejoin their families.

**Lessons Learned**
In the aftermath of the hurricanes, many lessons have been learned. Although OCS was prepared, the vast devastation caused by Hurricanes Katrina and Rita and the limited initial response of FEMA showed the need for a more comprehensive emergency response plan. McLain said that OCS learned a number of lessons, including these:

- Emergency evacuation plans should be established and updated annually for foster parents, contracted agencies, contractual staff, and child welfare staff.
- Emergency telephone numbers should be established to provide information and referrals.
- A communication network with federal emergency response officials should be established.
- Staff training should be enhanced to address a variety of emergency situations.
- Vital records—such as birth certificates, case files, and court documents—should be maintained in areas that are secure from natural disasters.
- Administration should be flexible to respond to emergency situations that may require mailings to be stopped or rerouted.
- All financial payments to foster parents should be made by direct deposit, so that payments do not depend on the family’s physical location.

**Where to Now?**
New Orleans, along with other cities in Louisiana, Alabama, and Mississippi, is on the long road to recovery. Recognizing that the damage was not only physical but also emotional, NASW and Louisiana State University partnered with the U.S. Department of Veterans Affairs’ National Center on Post-Traumatic Stress Disorder to sponsor a Day of Understanding and Healing for Mental Health Professionals on December 2, 2005. Numerous OCS staff attended. The most important lesson to be learned is that when states like Louisiana make children’s needs a priority, there can be positive stories even in times of a disaster.

**Yan Dominic Searcy, PhD, MSSW**, is an associate professor with the Department of Social Work at Chicago State University. He is also a member of NASW’s Child Welfare Section Committee. He can be reached at ysearcy@csu.edu
SPECIAL OFFER
FIRST-TIME APPLICANTS ONLY
Expires July 31, 2006

50% OFF the ACSW Credential and NASW Specialty Certifications for Specialty Practice Section Members

Now through July 31, you will receive a 50% discount on the application fee for the Academy of Certified Social Workers (ACSW) credential and on the application fee for an NASW specialty certification of your choice if you are applying for the ACSW and certification for the first time.*

This is the perfect opportunity to become a member of the prestigious Academy of Certified Social Workers and to receive a certification in your practice area.

Take the discount on the ACSW. Take the discount on a specialty certification. Take the discount on both.

Visit www.socialworkers.org/credentials for more information.

*You must be a current member of an NASW Specialty Practice Section and be applying for the ACSW or specialty certification for the first time to be eligible for the 50% discount. Discount does not apply to Section members who are renewing or reinstating their ACSW or specialty certification.