

# NASW NEWS

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## NASW Teams With Advocacy Group to Boost Services

# Work With Amputees Requires Varied Skills

**An organization works to supply information to health care provider groups.**

By Lyn Stoesen, NEWS Staff

**A**t a meeting last September between NASW and representatives from the Amputee Coalition of America (ACA), the organizations began to forge a collaboration to improve services to amputees.

"One of the difficulties we have is getting people the information they need when they need it," said Paddy Rossbach, ACA president. The organization has been working to establish relationships with a number of health care provider groups, including physical therapists, nurses and social workers.

Rossbach said ACA has developed an initiative to provide a package of information for everyone going into the hospital facing amputation, and making contact with these health care provider groups is an important part of ACA's strategy to implement the program.

**Varied practice.** Social work with amputees is much like social work with any other group of people — there are many factors that make each client's situation unique, and it is a practice with a broad range of responsibilities.

Social workers should be aware that "much of the time a person is working with this population isn't necessarily working intensely in the therapy piece," said Omal Bani Saberi, a social worker who works with amputees.

While social workers do provide psychotherapy to some amputee clients, "most of the time what one is trying to deal with is finding the right prosthetist,

how to talk to the doctor, [and helping provide] advocacy skills," Saberi said.

Some of the help people need when coping with an amputation includes how to find a prosthetist, dealing with insurance and finding support groups, Rossbach said.

Finding the right prosthetist is an important step for an amputee, Rossbach explained. "A problem that occurs so frequently is that when people are in the hospital, they're really not told they have a choice of prosthetists," Rossbach said. "They are treated by who happens to be in the hospital that week, who may not necessarily be the best person for them. . . . Making the right choice from the beginning can make the difference to someone successfully going back to being ambulatory." Social workers working with amputee clients can help them navigate this territory.

**Providing the best outcome.** "We recognize that for most health care providers, caring for an amputee is a small part of their practice," Rossbach said. "Because of that, a majority of people don't get any continuing education into [amputation issues] and continue to do what they've done for a long time, which may not be the best thing."

Rossbach said ACA has developed a one-day seminar for health care providers that addresses many aspects of amputation, including surgical techniques, rehabilitation, prosthetics and emotional reactions. Rossbach said the seminar "really concentrates on trying to show how everybody communicating with everybody else [can result in] the best outcome for the amputee."

"NASW has many points of intersec-

tion" with ACA, said NASW Executive Director Elizabeth J. Clark. "Working with ACA is a natural fit for social workers." Clark noted that social workers are skilled in a wide range of issues affecting amputees, including a strong knowledge of available resources, experience dealing with insurance companies and addressing pain control, as well as working on a macro scale with legislative issues that affect amputees.

During the September meeting between ACA and NASW, representatives from the organizations discussed strategies for bringing information about amputees to social workers. Clark offered ACA suggestions on social work sources to contact, and the groups conferred on ways to educate NASW members about limb loss.

**A unified voice.** The Amputee Coalition of America (ACA) was founded in 1986 to provide information and resources for amputees and was incorporated as a nonprofit organization in 1989, when it expanded its goals to educate the public and health care professionals on amputee concerns and provide a unified voice for amputee consumers.

In 1997, ACA was awarded a \$2.4 million, three-year Centers for Disease Control and Prevention grant to establish the National Limb Loss Information Center. The center was established to develop a comprehensive library of resources and materials on limb loss and an amputee resource database. The center also expanded ACA's bimonthly publication, *In-Motion* magazine, and ACA's peer visitation training program. In 1999, the center published its first edition of "First Step

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— A Guide for Adapting to Limb Loss,” which is revised and re-published biennially. The center also maintains a toll-free hotline staffed by people trained to answer questions for consumers, families and health care providers.

ACA hosts annual conferences, including an expanding youth-activities program. “One of the most important things is an opportunity for people to get together and spend time with other people with similar problems,” Rossbach said.

The peer visitation program, Rossbach said, is an important component of ACA’s work. “One of the most significant interventions is a visit from another amputee in similar circumstances,” she said. “They’re not there to give advice, they’re not a counselor, they are there to listen, give information on what [resources are] available and listen to them and show that it is possible to get back into an enjoyable lifestyle after this devastating thing.”

**Different experiences.** Limb loss can be congenital or can result from traumatic injury or disease. More than 60 percent of nontraumatic lower-limb amputations in the U.S. occur among people with diabetes.

Saberi is currently in private practice in California and has contributed articles to the National Limb Loss Information Center’s “First Step” publication. She is an above-knee bilateral amputee, resulting from an accident that occurred when she was a child growing up in Iran.

Saberi earned her MSW from San Francisco State University, is also trained in art therapy and hypnotherapy and has a degree in counseling psychology. She said the social work model “best fit my world view and values.” She said she found other approaches can be “so limited and do not consider the person in their whole context, their whole life. . . . I found social work because that fit with [my view of approaching] physical, mental, emotional and spiritual realms, rather than just psychological ones.”

Social work with an amputee, Saberi said, should be practiced with attention to the variables of the client’s circumstances. Social workers must consider

“how they were disabled, how the amputation occurred, whether it was accident or disease, the age of the person, the type of amputation.”

“If it was an accident, there is more of a sense of, ‘I could have avoided it,’ there is a lot of guilt involved,” Saberi said. “With disease, there is more understanding and compassion from others as well as the person who is an amputee.”

Age can also be a factor in how the amputee deals with his or her situation, she said. “In my case, due to a fire accident as a young child, I fantasize about what would it be like. Someone later on in life [losing a limb due to] diabetes may have less fantasy and more reality.”

Another aspect to consider, Saberi said, “is who is supportive of [the amputee]. Family dynamics — are they supportive and encouraging, or uncomfortable and hiding? Do they push on, ‘let’s go get a prosthesis, we can do it, I’m here,’ versus fear or shame from family and friends. That will help an amputee develop more self-confidence or not.”

“Gender also plays a part,” Saberi said. For men, she said, losing a limb can be “a matter of virility [or wondering] what kind of job they can get.” Women, she said, sometimes have responses related to “body image, which can be a big deal, especially in this society.” She said that someone missing a leg, for example, must grapple with his or her sense of sexuality and sensuality. “We have to think of other ways of feeling and looking sensual and sexual.”

**Being prepared.** Saberi said she would ask any social worker considering working with amputees what motivates them to enter the field. She would also ask, “Do they have enough support systems themselves? Because there are going to be issues that will bring up major losses in their [own] lives.”

In one of Saberi’s articles in ACA’s “First Step” publication, “Dealing with Grief and Depression,” she writes that “when a part of our body is lost, we experience a grieving process much like a death.” Social workers need to be aware of this, she said. “They need to not be afraid of loss issues, because a person with an amputation is constantly looking

at loss every day. Hopefully, as they progress in life it will be less intense, but it will always be a loss.”

“This [also] applies to [those in a client’s] support system — they need support too. A social worker needs to be aware of how to help families adjust,” she said.

“The social worker has to be okay with feelings of anger, frustration, depression,” Saberi said. She also noted that “pain is a constant [for many people with amputations, and [social workers need to know] how to deal with pain and pain management.”

Saberi said that financial and employment issues are also major concerns for amputees. Grappling with “daily survival is what many people who are amputees have to live with on a regular basis.”

When dealing with a prosthetist, Saberi said, clients want someone who is “understanding, patient and willing to discuss personal issues. . . . For me, with legs missing, it’s really uncomfortable if it’s a male prosthetist. Not only do I have to feel comfortable, but safe enough [with someone] who can make me feel at ease.”

Saberi has presented several workshops through the NASW California Chapter addressing social work practice with people with disabilities. One of the major points she stresses in the workshops is cultural competency. “If a person has come from a different country, how you work with them through different stages is largely based on language and family or religion. . . . It is helpful to have the amputee as well as their family share about their belief systems, have them be the teacher: ‘This is what I do with my family, this is how we deal with things.’”

Saberi said that despite the challenges of working with amputees, “I find it extremely rewarding. It’s wonderful to be able to share with people how they can get their needs met. We are teaching advocacy skills, ingraining what we already know, [and seeing how] it can work in our own lives. That’s very satisfying.”

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*Amputee Coalition of America:*  
www.amputee-coalition.org