

6-1-2005

## Caregiving in the Heartland: Outreach Through Adaptation and Collaboration

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### Recommended Citation

Jones, P., & Field, W. (2005). Caregiving in the Heartland: Outreach Through Adaptation and Collaboration. *The Journal of Extension*, 43(3), Article 22. <https://tigerprints.clemson.edu/joe/vol43/iss3/22>

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June 2005 // Volume 43 // Number 3 // Ideas at Work // 3IAW4



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## Caregiving in the Heartland: Outreach Through Adaptation and Collaboration

### Abstract

Extension programs must often adapt to meet the needs of those they serve. Purdue University's Breaking New Ground (BNG) Resource Center, while focused mainly on the assistive technology needs of agricultural workers with disabilities, realized that the caregivers of these individuals could also benefit from instruction and educational resources. This article describes the development of BNG's caregiver initiative and shares lessons learned from several years of workshop coordination.

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## Introduction

Since 1979, the mission of Purdue University's Breaking New Ground (BNG) Resource Center has been to assist farmers and ranchers with physical disabilities. The program's services often take the form of technical information on such topics as equipment modification and farmstead accessibility. Additionally, since 1998, BNG has provided leadership for the planning and conducting of a series of workshops for caregivers of people with disabilities. The 14 sessions have drawn nearly 900 attendees, many from rural communities.

At first glance, it may seem incongruous for a program located in an agricultural engineering department to address caregiving issues, because these matters are normally the domain of those involved in social work, family life education, or nursing. However, BNG's outreach to caregivers has been a logical expansion of its core services to agricultural workers with disabilities.

## Adapting to Meet Needs

Though focused primarily on assistive technology issues during the early years of the program, the BNG staff realized that it is not only the person with the disability who struggles to adjust to lifestyle changes--there is usually a caregiver, frequently a family member, who also needs assistance. For example, following a disabling injury or illness, spouses are key players in the rehabilitation process, but are often thrust into caregiving responsibilities with no forewarning or training.

Therefore, to assist caregivers in transitioning to their new roles, BNG in 1997 developed *To Everything There is a Season*, a resource kit for rural caregivers consisting of a video and workbook for caregivers, plus a leader's guide for professionals interested in conducting workshops for caregivers. In developing the resources, BNG staff members referred to existing caregiving materials and consulted directly with caregivers and experts in Purdue's Department of Child Development and Family Studies. The materials focused on such topics as the impact of disability, caring for caregiver, commitment to marriage, and healthy communication. This effort was

targeted toward farm and ranch women because severe farm-related injuries predominantly affect male workers.

## Workshop Development

In addition to distributing the *To Everything There Is a Season* materials to professionals in more than 18 states through the USDA/CSREES AgrAbility Program, BNG secured funding from the Indiana State Department of Health (ISDH) in 1998 to conduct a workshop for caregivers based on the resource kit. In 1999, funding was again acquired from ISDH to plan a series of caregiver workshops to be held at various sites around Indiana. These Caregiving in the Heartland workshops grew from two in 2000, to three in 2001, to four each in 2002 and 2003.

Each workshop lasted for approximately 6 hours and was comprised of plenary and concurrent sessions. Some of the topics commonly addressed included financial planning, stress management, navigating the social service system, transportation issues, and caregiving for special populations, such as those with Alzheimer's disease and arthritis. Humor was also an essential component of the sessions, because planners recognized the importance of making the workshops a day of respite for the attendees.

The thrust of Caregiving in the Heartland shifted somewhat in 2004. Instead of multiple regional workshops, a single train-the-trainer workshop was conducted for professionals and volunteers working with caregivers. Sessions focused on equipping professionals to serve as resource specialists for caregivers and conduct caregiver workshops in their own communities.

As part of the 2004 caregiving outreach effort, BNG also developed <http://www.ruralcare.info>, a Web site for rural caregivers. The site includes a variety of resources, including electronic versions of BNG's *To Everything There is a Season* materials for caregivers, and numerous links to other organizations that can benefit caregivers.

## The Importance of Collaboration

In facilitating the planning process, BNG staff members strived to partner with as many interested organizations as possible. Some of the main players over the years have included the state's centers for independent living, the Arthritis Foundation, Attain (the state's assistive technology project), and regional Area Agencies on Aging. In addition, representatives from 10 of the state's county Extension offices participated in the planning process through the years.

While BNG staff members led the overall organizational effort, each workshop also had a local planning committee responsible for tasks such as making on-site arrangements and securing local speakers. The BNG staff recognized the need to allow freedom to local planners, thereby enabling them to feel that they were essential stakeholders in the effort.

More than 50 organizations have participated in planning or sponsoring the workshops. The networking and collaborative relationships developed through the workshop planning process have been some of the most positive outcomes of the effort. These relationships have also led to increased collaboration on other projects not directly related to caregiving and significant opportunities for the exchange of resources and information.

## Lessons Learned

Certain patterns emerged during the years of workshop coordination.

1. The most important task, and most difficult, was effectively promoting the workshops and getting participants to actually show up. Success in this area usually involved local committee members making personal contacts with individuals, organizations, and the news media in their communities.
2. While it is important to give the local committee autonomy, this must be balanced with direction from and communication with the workshop series facilitators (i.e., BNG). Local planning organizations may choose session topics or speakers that fit with their missions but do not dovetail well with the overall theme of the workshops, and periodic follow-up communication helps ensure that essential planning tasks are completed appropriately.
3. It is important that local committees understand that a significant amount of work on their part is required to make the workshops successful. Three workshops had to be cancelled, often related to a lack of investment on the part of local committees.
4. Some organizations, such as churches, are willing to provide meeting space free of charge, thereby keeping overhead costs low and enabling funds to be channeled to resource materials or other expenses, such as speakers' fees and scholarships.
5. Part of the workshops' success was due to the humor, relaxed atmosphere, and other factors that contributed to a sense of respite. Some caregivers may also need standard respite care in order to even attend the workshops, and local organizations, such as Area Agencies on

Aging, may be able to assist with this.

6. While BNG's focus is primarily rural audiences, it was important to address issues relevant to both rural and urban caregivers, thereby increasing the number of people who could benefit from the workshops.
7. Because the workshops are held in rural communities, rural caregivers are given greater access to information and resources often restricted to urban areas.

## Evaluation

The original purpose of BNG's caregiver initiative was to encourage and equip caregivers, especially those in rural areas. While it is difficult to measure impact for such a broad objective, several positive outcomes can be reported. Participants at the workshops have consistently rated the sessions at 8.5 or higher on a scale of 1-10 in regard to overall effectiveness. Hundreds of caregivers and professionals have received direct training, and thousands of print and audiovisual resources have been distributed. In addition, BNG's caregiving efforts received the 2000 State-Level Distinguished Community Service Rural Health Award from the Indiana Rural Health Association, the 2004 Purdue Cooperative Extension Specialists Association Team Award, and were part of a successful application for the 2001 National Safety Council Award for the Improvement of the Quality of Life for People with Disabilities.

## Conclusion

Extension programs must be open to adapting to meet client needs while maintaining their core mission. BNG recognized the needs of rural caregivers and expanded its services to assist them. In doing so, the program found it essential to collaborate with programs that were already working in the field. This allowed for the leveraging of intellectual and financial resources that has resulted in significant information gains for Extension consumers.

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