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“Keep Me Doing What I Love”: A Photovoice Evaluation of the Missouri AgrAbility Project

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ABSTRACT

The Missouri AgrAbility program links the Cooperative Extension Service at a land-grant university with a nonprofit disability organization to provide practical education and assistance that promotes rural independence. This project utilized Photovoice to describe how Missouri AgrAbility clients perceived how the program impacts their lives. This article relates clients' perceptions of the impact of the AgrAbility program on their lives to the socio-ecologic model framework. Although the primary focus of AgrAbility is to help individuals who have disabilities maintain their independence, all levels of the socio-ecological model are integral in meeting the needs of program participants.

KEYWORDS

AgrAbility; evaluation; Extension; Photovoice; socio-ecological model

Introduction

Learning to live with a disability can be a significant transition, and many individuals struggle with the challenge of examining how the disability will affect who they are and what their role is in the society.^{1,2} Disabilities and health concerns can create unique challenges for farmers and ranchers, who may be unable to separate their personal identity, family life, and agricultural business. For those whose identities are tied with farming and ranching, disabilities, disease, and health challenges threaten not only vocation, but also personal identity and family function. Farmers with disabilities place great value on continued engagement in the farm environment.³

This study describes clients' views of how the Missouri AgrAbility program impacted their lives. Examining the interactions that occur in the individual, social, community, organizational, and public policy layers of the socio-ecological model can help researchers, service providers, and policy-makers understand the complexity that surrounds disability, disease, and chronic health conditions in the context of agriculture. Ultimately, the clients participating in this evaluation will help Missouri AgrAbility staff to understand the program on a

deeper level, consider how all the layers of the socio-ecological model are reflected in the experiences of AgrAbility clients, and ultimately, improve program effectiveness.

Program description

The Missouri AgrAbility program links the Cooperative Extension Service at a land-grant university with a nonprofit disability organization to provide practical education and assistance that promotes rural independence. Congress authorized the AgrAbility Project in the 1990 Farm Bill and the National Institute of Food and Agriculture, an agency of the U.S. Department of Agriculture, administers the AgrAbility Project.⁴

In Missouri, the AgrAbility partnership includes members from the University of Missouri Extension, Lincoln University Cooperative Extension, and the Brain Injury Association of Missouri, Inc. The partnering organizations provide educational workshops, off-site visits, on-site farmstead assessments, technical recommendations, and resource materials to farmers, ranchers, farm workers, and family members who are limited by any type

of physical, cognitive, illness-related disability, or chronic health conditions. Additional partners are contacted to provide services to clients as needs surface during the assessment process.⁵ In 2016, Missouri AgrAbility worked with 30 individual farmers and ranchers who had diseases, disabilities, and/or chronic health conditions. The ultimate goal of the program is to promote the return of these individuals to the farm, their community, and independent living.

Need for evaluation

The Missouri AgrAbility program utilizes the McGill Pre- and Post-Quality of Life surveys to evaluate program outcomes. However, AgrAbility staff desired to add a deeper, richer, qualitative layer to their evaluation process to better understand how the program was impacting the lives of their clients. A natural fit for this project, qualitative research is a situated activity that locates the observer in the world of the participant.⁶ This type of research activity seeks to understand the meaning people have constructed; that is, how people make sense of their world and the experiences they have in the world.⁷

Methods

We used PhotoVoice as a tool for this formative, qualitative evaluation. PhotoVoice is a participatory action research process that allows participants to tell a story through the use of pictures.⁸ This method provided the opportunity to see the Missouri AgrAbility program through the eyes of its clients, read their written words describing their photographs, and listen to how they believed the AgrAbility program impacted their lives. Pictures, combined with written and spoken language, are a powerful communication tool that allows for more richness and depth than traditional survey methods.⁸ The benefit of this type of evaluation is that it allows one to hear the voices of participants, identify program strengths, and even discover unintended program outcomes.⁹ Additionally, the variety of methods included in the PhotoVoice methodology provides triangulated data, which strengthens the ability to analyze and draw conclusions from the data.

Seven clients were recruited for this project upon consultation with the AgrAbility Program Director. Key considerations were engagement with the program, client availability, and including maximum variation in views and perspectives among clients. Ultimately, three AgrAbility clients consented to participate in the evaluation study. We do know that one of the seven clients who were recruited was out of state on a summer job, but it is not clear why the other clients chose not to participate. Informed consent was obtained from all study participants. Research was reviewed by the Institutional Review Board and approval was obtained.

Of the three consenting clients, two fully participated by sending pictures with captions and participating in a phone interview. The third, who was the newest to the AgrAbility program, requested to participate in the phone interview portion of the evaluation only. Although it is not known why the third client did not participate in the photography component of the project, we do know that this client was the most recently disabled and was currently undergoing treatment for cancer.

Although three clients is a small number, the aim of qualitative studies is not to be representative of the population. Rather, insight and meaning shared by each of these unique AgrAbility clients provides the program with information that can help provide insight to inform program improvement.

To begin the project, the three consenting AgrAbility clients were invited to use their own device to take pictures that show how the Missouri AgrAbility program impacted their lives. They were then invited to choose one to three of their favorite photos and write captions of 50 words or less that described the picture. Clients emailed the pictures and captions to the researcher, who then contacted the client via email to set up a time for a phone interview.

Semi-structured phone interviews with each participant lasted from 15 to 30 minutes, and the evaluator took notes during this process. Phone interviews were not recorded in hopes of helping participants feel more comfortable during the interview process. An adapted SHOWeD model of questioning was used to serve as a structural guide for the interview process.^{10,11}

Questions included:

- (1) *What do we see in this picture?*
- (2) *What is really happening?*
- (3) *How can this information be used to help others?*
- (4) *Why does this problem or strength exist?*
- (5) *What can be done about this situation?*

The interviewer also probed deeper on statements that had significant meaning as they emerged, and the interview format remained flexible and responsive to facilitate deeper understanding. As an agricultural producer herself, the evaluator was able to relate to AgrAbility clients' farm experiences and ask for clarification on tasks such as cattle handling and pasture rotation. This knowledge allowed for a more thorough understanding of the clients' lived experiences.

Following the phone interviews, the research team examined pictures, interview notes, and the captions that clients developed to explain their photos. These items were hand coded using an inductive process to allow the voices of the AgrAbility clients guide the project. Next, statements that added significant meaning to the evaluation and helped tell the story of the participants' perception of the AgrAbility program were highlighted, and these meaningful statements were transformed into themes. The research team then looked for connections in and among the themes and adapted them throughout the project as appropriate. The final themes identified in this process included independence, adaptation, accomplishment/satisfaction, social support, sharing your story, practical assistance, and jumping through hoops. Lastly, these themes were inserted into the appropriate levels of the socio-ecological model framework, where there is complex interaction between the individual and environment.

Findings

To protect the identities of AgrAbility clients, each client was assigned a pseudonym. Mary was a young woman in her late 30s who was hit by a drunk driver several years ago and left with severe injuries and limited mobility. Mary explained that her "condition will continue to deteriorate." John,

who was in his 60s and the most recently enrolled AgrAbility client in this sample, was paralyzed after surgery to remove a cancerous tumor. He was undergoing radiation treatments at the time of the interview. Sam, a middle-aged male with severely limited vision, has been involved with AgrAbility since 1987. The results obtained from this evaluation should not be generalized to other programs and settings, but describe perspectives of the individual clients who participated in the Missouri AgrAbility PhotoVoice project.

Themes related to the individual

Independence

An important role of the Missouri AgrAbility program is to work with individuals with disabilities to help them maintain their independence on their farm or ranch. AgrAbility clients who participated in this evaluation had the desire to maintain as much of their lifestyle as they could, and were fearful about losing the rural way of life that they knew. Mary, who was eager to share once she learned the evaluator was also a cattle producer, explained, "Raising cattle is just in me...you know? I thought to myself [after the accident], What if I can't do this anymore?"

Adaptation

Through the help of the AgrAbility program, Mary was able to adapt her daily chore routine by using a Polaris Ranger with a gravity flow grain feeder attached to drive down to the troughs and feed calves. The Polaris allowed her to feed without the risk of being knocked over or stepped on. She submitted a picture of herself using the Ranger to feed cattle and explained, "The Polaris keeps me out of harms' way at all times and saves the amount of steps I need to take each day because I only have so many I can take." As part of the program, staff members conduct on-farm assessments to identify such adaptations that can make farming easier and safer for AgrAbility clients like Mary.

All of the clients involved in this project needed to modify their farming operations to some extent to adapt to their new realities. For example, Sam sent a picture of himself preparing to open a gap to turn cows onto fresh pasture and explained,

Since 2008 I have been converting my livestock operation to a managed grazing system with the goal of putting myself out of the hay baling business. AgrAbility helped me map out water crossings so that I could access all parts of my acreage without driving on the highway.

Sam, who had originally farmed with his dad, had impaired vision. When Sam's father passed away, he adapted by raising more sheep and cattle on his farm in place of row crops and hay (which had required extensive tractor work and thus, better vision).

Accomplishment and satisfaction

The ability to perform activities that many take for granted, even in a modified form, was a positive impact of AgrAbility. John, who recently became a wheelchair user, explained that it felt good to get out of the house and to the barn lot, adding, "I really can't do much chores, but you feel like you're doing something that way." Mary also explained, "My pride hurts sometimes; it is a slow process to figure out how to do things". Farming is an important part of AgrAbility clients' identities, and contributing to life and work on the farm provides them with a sense of accomplishment and satisfaction.

Themes related to social support

Farm and ranch families are unique, because daily farm work is embedded in the family, or family is embedded in daily work on the farm; it is hard to distinguish which is which. When an individual becomes disabled, farm life and family life, which are intertwined in a complicated web, are greatly impacted. Even when a farmer is unable to work, livestock still must be fed and crops must be harvested. Management of the farm operation can be a particular challenge when a farmer faces chronic health concerns or a disability. An individual who has made his or her living as a farmer may suddenly have to depend on a multitude of immediate and extended family members, friends, and neighbors who alter their lives to help with his operation. For example, one AgrAbility client explained that his wife had to quit her job in town so she could help take care of the farm and care for him.

Clients involved in this project received social support, not only from family members, but also friends and neighbors. John told about friends from his church constructing a "makeshift shower" in his basement because he was unable to access the main floor in the wheelchair. The wheelchair he used was borrowed from a cousin of an extended family member. This support from friends and neighbors was critical for John during this early stage while he worked through the necessary steps to receive support from organizations and agencies.

One of the photographs submitted by Sam demonstrated the importance of social support from a unique angle; whereas other participants discussed social support provided to them by others, Sam supplied evidence that he is providing social support himself by including a picture of himself and his son checking the electric fence together. He wrote,

My son Chris is 9 years old. He has autism. Chris often goes with me when we check cattle. In this photo I am showing Chris how to check the fence with a voltage tester. My son has unique challenges. AgrAbility has helped me pursue a vocational lifestyle that is supportive to Chris' need for open spaces.

Sam perceived the AgrAbility program as making it possible for him to provide social support to his son.

Themes related to community

Sharing your story

While the Missouri AgrAbility program's intended audience is the individual and their families, this project suggests the program also affects the manner in which participants contribute to their communities, which is the third layer of the socio-ecological model. Some AgrAbility clients feel that the program has opened doors for them to be able to tell their stories and share what they have learned with others.

Sam shared,

I really enjoy participating in ag functions and farmer panels that I found out about through AgrAbility. I've even gone to international workshops and talked to people. Being involved in panels gives you an

opportunity to give back. And it helps you not feel so bad about your own situation when you see someone farming without the use of their legs.

Sam added that he had received a phone call after the workshop from a young farmer in another state who was also struggling with vision loss. Sam reported that he enjoyed talking to the young man on the phone and encouraged him to keep farming.

The youngest of the three participants, Mary created a blog where she shares about adaptations she made to basic farm tasks in order to perform them successfully and safely. She reported developing this blog after spending a great deal of time looking for this type of information after her accident. She explained that she quickly realized there was not much information out there to help farmers with disabilities learn how to adapt their chores. Mary is now a regular speaker at agriculture workshops and seminars around the state. She believes that AgrAbility gave her the confidence to move forward and connect with others in the agriculture industry.

Themes related to the institution/organization

Practical assistance

The Missouri AgrAbility program comes under the institutional/organizational layer of the socio-ecological model. Interviews with AgrAbility clients indicated that this program, and the services provided by it, was critical to them. Mary commented, “The AgrAbility staff just want to help me, and I could totally feel that. They just want to keep me doing what I love”.

Clients mentioned that in addition to helping them access resources, the AgrAbility program provided them with practical assistance to do their work in a safer way. Mary continued, “Even without equipment, AgrAbility is helpful. The tips, and helping me think more creatively about how to do things...and more safely.” Clients saw the problem solving assistance from experts in the areas of agriculture, health, and safety to be very beneficial.

However, each of the three AgrAbility clients voiced concerns that there were people in their community who need help who were unaware of the AgrAbility program. They felt others could

benefit from the support the program has to offer. Mary explained that she originally learned about the program at an Extension event. Participants suggested making sure there are marketing materials in various county and state agriculture-related offices, but agree that word of mouth is the most powerful marketing strategy.

Themes related to policy

Jumping through hoops

Missouri AgrAbility clients shared policy-related concerns about their experiences with the AgrAbility program and other partner non-profit organizations including time and money. Clients felt that receiving financial support involved “jumping through hoops” and a great deal of waiting. They did, however, comment that Missouri AgrAbility staff helped them figure out what they needed to do to navigate these “hoops”, which included paperwork, emails, and phone calls to provide information to health care providers and support agencies. Clients reported being frustrated and feeling helpless to do anything to speed up processes. However, Mary and Sam both mentioned that the help they received from support agencies was “worth the wait.”

One client expressed reluctance to depend on what he referred to as “government programs” for support. John, the most recently disabled AgrAbility client stated, “I know it’s government, but it sounds like it’s really going to help”. Accepting help can be a challenge for farmers and ranchers, who tend to consider themselves to be independent and self-reliant. John explained, “I know I need help. But I don’t want AgrAbility to do more than I need. I want to do as much as I can.” Although John had the desire to be as independent as possible, it seemed he was willing to accept help from AgrAbility and other supporting agencies, because he was in a position where he perceived it as really necessary.

Conclusion, implications, and recommendations

This study contributes to a body of literature that emphasizes the importance for individuals with disabilities to maintain their farm and ranch

lifestyle. Clients talk about how living and contributing to work on their farms and ranches helps them feel more like themselves. These comments parallel Reed's 2004 study with farmers with upper-extremity amputations, where study participants stated that "real recovery" happened for them when they were back working on the farm again.¹²

This PhotoVoice evaluation allows us to understand that AgrAbility clients were fiercely committed to staying as independent as possible while adapting the way they operate their farms and ranches to maintain their rural lifestyles. Clients placed great value on the adaptive tools and technology the AgrAbility program helped them obtain.

One sign of the importance of this adaptive technology to the AgrAbility clients was found in their photographs. While they were asked to *take photos*, both of the clients who participated *asked someone else to photograph them doing a job on the farm*. Both Mary and Sam submitted photographs showing themselves continuing work in their farming operating by using an adaptive or assistive device. This choice may suggest that AgrAbility clients saw the identification and procurement of technology and devices that allowed them to continue to farm as one of the key functions of the AgrAbility program. Other researchers have also confirmed that technology helps to equalize opportunities that allow farmers to continue to be involved in the farming operation in prior studies.^{13,14}

Comments from AgrAbility clients indicated that social support from spouses and immediate family members, friends, and neighbors was essential, particularly in accomplishing the jobs on the farm that have to be done in order for the business to survive. These perspectives align with previous studies that indicated farmers' injuries affect the entire family, particularly spouses who often take over more farm responsibilities¹³ and that help from community members is critical if the farming operation is going to survive.¹⁵

AgrAbility clients said that the practical, on-farm assistance they received from the AgrAbility program helped keep them working, and they understood getting the help they need takes time. Although they reported that waiting for resources can be frustrating, they said getting the assistance they needed was worth the wait, and they knew

AgrAbility staff were doing everything they could to help them continue farming and ranching in ways that are safe. This is in great contrast to perceptions of other farmers and ranchers have regarding health care professionals. According to previous studies that involved farmers with amputations, these farmers sometimes perceived that health care professionals created barriers to stop them from returning to farm work, because those in health care settings may believe farm labor is too physically taxing.^{12,13} It seems that AgrAbility staff see the return to the farm and ranch vocation as an important part of clients' well-being.

Viewing results of the PhotoVoice evaluation using a socio-ecological model illustrates the ways the individual, social, community, organizational, and policy levels of the model interact with and depend on one another. AgrAbility clients do not live their lives in an isolated fashion. Rather, they interact across multiple levels of the socio-ecological model. The results of this small study indicate that the AgrAbility program helps to create positive environmental conditions in all layers of the socio-ecological model that support and promote effective change for farmer and rancher clients.

AgrAbility clients' photographs, captions, and interviews suggest that the Missouri AgrAbility program is fulfilling its purpose and contributing to client resiliency by addressing the individual, social, community, organizational, and policy levels of the socio-ecological model. When the results of this PhotoVoice evaluation are viewed alongside the McGill Pre- and Post-Quality of Life surveys, AgrAbility staff can see a clearer picture of how AgrAbility clients perceive and make meaning of their world.

Recommendations for program improvement include identifying ways to market the AgrAbility program in places where farm families go to do business, such as feed stores, grain elevators, banks, or crop insurance offices. Clients believed there are many individuals in the state who are unaware of the services AgrAbility offers. Suggesting other organizations and programs that can help build social support systems to current AgrAbility clients may also be valuable in helping farmers, ranchers, and their families address complex issues surrounding disability and

agriculture. In the future, the AgrAbility program may benefit from longitudinal evaluation work with a larger sample size, tracking clients for a number of years to determine long-term impact of AgrAbility on their lives.

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