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May 2014

Research Report

Self-Advocacy for Rural American Health (SARAH) Program Overview and Implementation

Brief Summary

Self-Advocacy for Rural American Health was a program developed for a research project that helped consumers locate community resources to support their health. Those who used community resources to manage health and pursue goals experienced long term positive outcomes.

Self-Advocacy for Rural American Health (SARAH) was designed to help people self-manage and improve their health status by eliciting the support of available community resources. The program was specifically directed toward staff members of centers for independent living (CILs) to work one-on-one with program participants and thereby increase capacity to reach rural consumers who were not able to participate in a group-based program due to scheduling or other difficulties.

SARAH was a four-session program that CIL staff used with consumers once independent living (IL) goals were established, such as budget, housing and transportation. If a consumer had health issues that challenged personal IL goals, he or she could potentially benefit from the SARAH program.

Program participants were able to connect their health management needs with community resources using personalized community resource mapping (PCRM); in doing so, they were better equipped to advocate for their own healthcare needs. This report provides a description of the SARAH program, with program outcomes and considerations. (For more information on mapping see our [Rural Practice Guidelines PCRM](#) and [A Guide for Creating a Community Resource Map](#).)

Program Overview

SARAH participants began the program by completing a brief self-assessment on health maintenance and independent living. The assessment helped the individuals to prioritize their needs. For example, an individual who identified nutrition as a relative weakness in the self-management plan would search for resources to improve his/her diet.

Once a priority was identified, a SARAH participant set a goal and created a personal resource map with the help of the IL specialist. These maps aided individuals in identifying potential services and supports in the community. For example, someone with nutrition as a priority looked to a nutritionist or nurse in a local public health office to help him/her get started. People who lived in a large town were able to locate resources nearby; however, those who lived in small towns or in open country located resources regionally. Participants used Google maps to determine resources and the distance to these resources from their homes. Next, they practiced self-advocacy techniques to obtain assistance from the community to meet their needs.

Participants completed the program using a workbook that included program slides and notes about the program content, or by using a computer to go

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through the slides. The IL specialist and consumer met face-to-face at the CIL office or other location (e.g., the participant's home, public library, community center, etc.). They could also meet by phone, or online using screen share. Although the program did have a great deal of flexibility in presentation, the IL specialist had to be familiar with computers to use the Google products. Prior to initiating the program, facilitators attended tele-training and completed the program on their own to experience it firsthand.

Content Overview

Session 1 – On Your Mark

The purpose of the first session was to help participants develop a positive and healthy outlook and to identify their IL and self-management needs. This session introduced the importance of balance and goals for health maintenance. Participants considered their past in order to set goals for the future. Maps were used to help them think about where they were living when they were their happiest. They remembered their physical and social environment as well as their life activities at that time and then used this information to consider their needs for the future. Finally, participants created a visual representation of their future goals using vision boards (i.e., an electronic or paper collage) as a tangible reminder. At the end of the first session, participants completed the Get Ready Survey, a health self-assessment of IL needs and personal health behavior.

Session 2 – Get Ready

Session two focused on developing a plan for reaching goals. Participants used their vision board from session one to set realistic goals; they were encouraged to set SMART goals – specific, measurable, attainable, realistic, and timely. Having written down their goals, individuals reviewed the results of their self-assessment to determine which IL and self-management areas they needed to address. Participants then recorded their goals and began mapping out the steps toward reaching them using the Go Planner, a tailored day planner used to “chart the course” for working toward goals.

Session 3 – Get Set

Session three focused on personalized community resource mapping (PCRM). PCRM has helped people use their strengths to identify potential resources for overcoming challenges. Through guided steps, participants created a map of resources unique to

their community by identifying known resources and searching for new ones using Google products. The maps were printed for the participant and included in the Go Planner, or they were emailed to the participant. More information could be added to the map at any time. IL specialists ended session three by encouraging participants to obtain help through their mapped resources. For example, participants were encouraged to introduce themselves to an identified resource provider, explain their reasons for pursuing the goal, and then ask for advice. This provided a brief introduction to individual health advocacy and connected it directly to resources available to the participant.

Session 4 – Go

Session four focused on self-advocacy to assist participants in attaining better health and achieving their goals. Facilitators shared advocacy techniques and options, and they presented the risks and personal costs that could be associated with advocacy efforts. Assessing the costs and benefits to advocacy was particularly important in a rural setting as the risks could have presented themselves as barriers to taking action. Participants explored advocacy in terms of educating one's community. They also learned to distinguish between desires, needs, and rights in order to evaluate different advocacy methods (e.g., writing a letter versus hiring a lawyer). This session concluded by helping participants put the new skills they learned into action. Participants were encouraged to continue using their personal resource map and their advocacy skills to take charge of their health.

Program Materials

The SARAH program used electronic materials, but hard copy versions were available when electronic access was limited. These materials included slides with facilitator notes, the Get Ready Survey, the Go Planner, and search procedures for creating a personal community resource map.

The Get Ready Survey tool had 89 questions that measured eight common secondary conditions (pain, fatigue, depression, diabetes, sleep problems, weight problems, bladder/bowel problems, and heart problems), six health behavior areas (health responsibility, physical activity, nutrition, personal growth, social support, and stress management), and six IL areas (transportation, accessibility, IL skills, choice/control, personal assistance, and finances). A participant's results were immediately graphed as bar charts that showed relative strengths and

weaknesses in each area. See Figure 1 for an example bar chart on the health behavior areas.

Participants recorded results from the Get Ready Survey in the Go Planner and used them as a reference to work toward their goals. The planner served as a guide and provided a space for participants to document health status, health behaviors, IL resources, goals, accomplishments, challenges, and community resources.

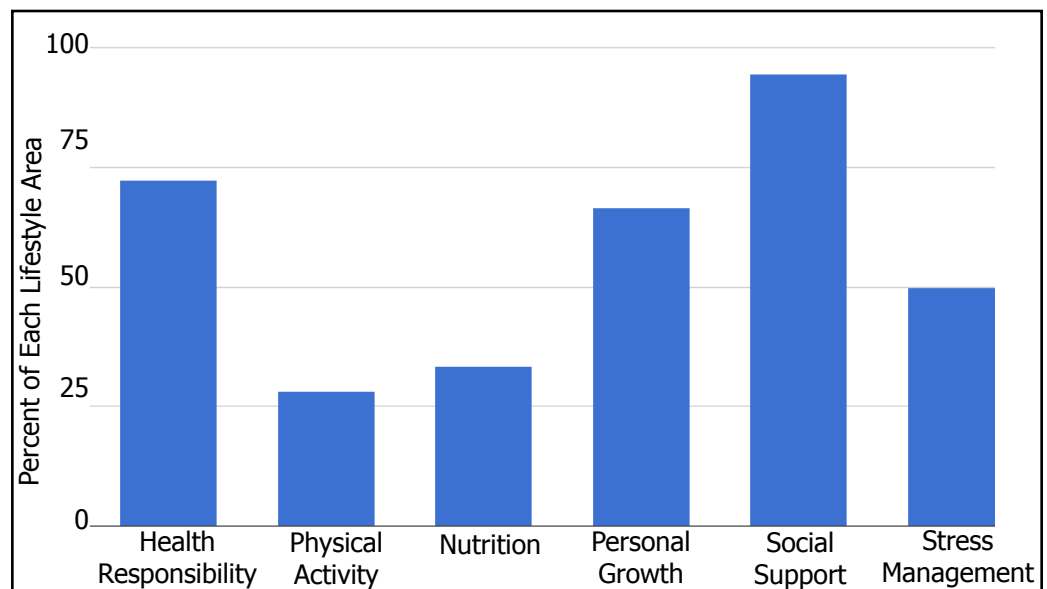
The personal resource map showed the locations of community resources that had potential to meet the participant's needs that were identified in the Get Ready Survey. Additional resources were included as well. Figure 2 shows a map for an individual who identified a variety of resources to improve health status and reach a recorded goal.

SARAH Program Outcomes

The combination of personal values, health goals, community resources, and advocacy led to long term maintenance of health behavior change for SARAH participants. The program presented health promotion information in a context that was linked to the individual's community environment, setting SARAH apart from other health promotion programs. Participants reported healthier lifestyles, less limitation from secondary health conditions, and more trips into their community following their participation in the program. (For additional research outcomes see our Research Report on [Rural Self-Management Support](#).)

Some evidence has indicated that directing consumers toward resources in the community and helping them make use of those resources has supported health behavior better than only providing information about a healthy lifestyle. PCRM provided SARAH participants resources and tools for making use of the surrounding environment to benefit their health. Lastly, both participants and facilitators commented on the usefulness of the Go Planner. They found weekly tracking important for staying focused, especially when plans to reach a goal were altered.

Figure 1. Get Ready Health Behavior Results



SARAH Success Stories

SARAH facilitators collected participant experiences through surveys and interviews. Overall, participants rated the SARAH program as worthwhile, interesting, and easy to use. As reported, participants found the sessions to be engaging. Most learned something new and were able to set an obtainable goal. Participants said they would both recommend the program to a friend and participate in a similar course in the future.

Two participants with weight loss goals lost weight over the course of four weeks. Facilitators were optimistic and believed that program participants would continue to work toward their goals and make use of the resources in their communities.

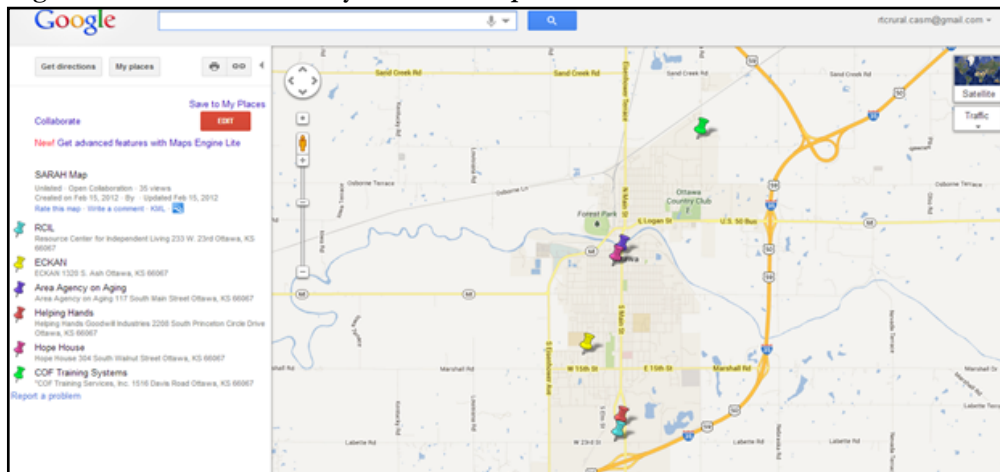
One facilitator chose the shift in a participant's attitude as a highlight of the program. The participant began the program very down and lacked confidence in her ability to make changes, but by the end of the SARAH program she had worked through small steps to reach a goal.

Several participants made small changes with larger impacts on their overall health, such as changing their daily trips for snacks to a location with healthier choices, or making use of resources to support their goal to quit smoking. One participant identified walking trails on her personal resource map and used the map to support her physical activity goal of walking more each week.

The SARAH program led several participants to learn more about technology and computer use. Although not necessarily an intended purpose of the program, it provided a comfortable, one-on-one environment

for program participants to work with a computer. One participant planned to purchase a computer after completing the SARAH program. Others gained more computer exposure and felt more comfortable with technology in general by the end of the fourth session.

Figure 2. Personal Community Resource Map



Program Considerations

The SARAH program helped participants identify and use community resources to make health behavior changes using products like Google Drive, Google Maps and Google Search. The use of this technology, however, raised a few considerations for implementing the SARAH program.

The SARAH program required that facilitators had the requisite computer skills to learn the Google products. The procedures for using these products were included in the facilitator training, but staff new to internet based applications had to spend extra time getting familiar with these products.

Program implementation required an internet connection. IL specialists with meeting places outside the CIL had to travel with a laptop or other mobile device and needed access to the internet. When using an individual's home computer, facilitators had to assess the computer for internet access, internet speed, and available programs. In rural communities, locating wireless internet access could be challenging; facilitators had to locate an internet broadband connection in advance. When scheduling a program session in a public location, IL specialists needed to be aware of privacy regulations and of the participant's comfort level with sharing personal health information in public.

In addition, the CIL needed staff resources and time to devote to the SARAH program. This included reviewing and learning the materials; participating in tele-training activities; recruiting participants; and, most importantly, having time in 90 minute blocks to go through the program with participants. Beyond program implementation, facilitators needed time to follow up with participants between meetings and after completion of the program.

Summary

Our evaluation of the SARAH program demonstrated that one-on-one programs could be beneficial. The SARAH program offered more flexibility than group programs, and it was able to reach individuals who were not likely to participate in a group program. IL specialists were able to visit the homes of participants, meeting them where they were most comfortable until they were ready to engage in their community more regularly.

The program worked to overcome the challenges that tended to be more specific to rural individuals. Scheduling was flexible, making transportation less of a barrier for participants. Further, SARAH was a program tailored to a participant's vision for the future. It provided a new framework for examining health promotion programming, and specifically, suggested that teaching individuals how to identify and make use of resources in their community supported sustained changes in health behavior.

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