

“Creating Home: Advocating for Change in How and Where We Age”

PROGRAM EVALUATION EXECUTIVE SUMMARY

“Creating Home: Advocating for Change in How and Where We Age” is a consumer education pilot funded by the Picker Institute. In collaboration with its partners, the Pioneer Network developed this project in response to the growing realization that consumer awareness of and advocacy for culture change are critical to its widespread dissemination. Partners included the American Association of Homes & Services for the Aging, American College of Health Care Administrators, American Health Care Association, American Medical Directors Association, The Coalition of Geriatric Nursing Organizations, and National Consumer Voice for Quality Long-Term Care.

In the spirit of true person-centeredness, the Creating Home project brings to the table those at the center of long-term care — consumers, or potential future residents and family members of residents.

This executive summary will provide an overview of the pilot project, how it was implemented, and results from the program evaluation. This executive summary might also serve to stimulate discussion amongst providers regarding consumer awareness of, and involvement in, person-directed care. Increasingly educated consumers present important implications for providers in terms of their readiness to address questions from consumers about how, or if, they are practicing person-directed care.

Project Overview and Implementation

Three primary goals of the Creating Home project were to: 1) educate consumers about long-term care and culture change; 2) determine if consumers

were interested in the topic and further action; and 3) learn how to best educate consumers about culture change.

The Creating Home curriculum provided an overview of long-term care and culture change. It included the video “Advocating for a New Old Age,” experiential exercises on the personal meaning of home and daily routines, and general information on culture change, contrasting a traditional nursing home with a home that practices person-directed care. Consumer participants were also given a take home document “Creating Home: A Guide to Better Care Options for an Aging America,” which gave additional information on long-term care and culture change. The intention of this document was for it to serve as a guide to consumers when learning about long-term care options. The guide also included a section on key questions for consumers to ask providers to determine if they were practicing person-directed care.

Information was provided to consumers in 2-hour meetings, which were held in small groups

of about 9 people on average. For each group, there was a volunteer facilitator, who had received background information on the meetings and guidance on facilitation. Volunteer hosts organized the location of the meeting, invitations, refreshments, etc.

Creating Home meetings were held in following four pilot states: Florida, Georgia, Massachusetts, and Oregon. A total of 61 meetings occurred, with 502 consumers and 45 hosts and facilitators in attendance. The meetings were held in diverse locations including private homes, long-term care communities, organization offices, and community locations such as libraries or senior centers.

The target audience for the “Creating Home” meetings was baby boomers. This was accomplished, with 68% of participants being in the age range 40-65. Participant experience with long-term care varied, although 97% of participants reported having visited a nursing home or assisted living community at some time. Very few participants had lived in a nursing home or assisted living themselves. Many of the participants were either currently caregivers or had been caregivers. About one-third of participants were currently caring for a family member or friend. Of these, over a third indicated their family members and friends live in a long-term care community. Seventy percent of participants had formerly cared for someone and half of these individuals indicated their care recipients lived in a long-term care community.

Results from Program Evaluation

As mentioned above, a main goal of the Creating Home project was to better understand how to educate consumers about culture change. There were two main types of evaluation of the pilot, one evaluated the meetings themselves and how they operated. The other measured consumer knowledge and interest before and after meetings.

In terms of the meeting process, consumers were generally very satisfied with the way the material was presented and the way the meeting was organized. Meeting hosts and facilitators also reported positive experiences in organizing and facilitating meetings and most expressed interest

in volunteering to do this again.

In order to evaluate whether participants experienced a change in attitudes and knowledge as a result of the “Creating Home” meetings, we asked participants to complete pre test and post test evaluations. On all questions participants demonstrated an increase in knowledge. However, the strongest changes were in two items. The number of respondents who rated the statement “I understand what culture change in long-term care means” as “strongly agree” or “agree” increased 100% after attending the meetings. The number of participants who rated the statement “I understand the difference between traditional nursing homes and those that practice person-directed care,” as “strongly agree” or “agree” increased 89% after attending the meetings.

All in all, feedback from participants regarding the topic was very positive. In fact, 78% of participants indicated they would like to meet again to further discuss the topic and 84% of participants intended to obtain more information about culture change. One of the most frequent comments expressed during the meetings was related to wanting more information about what culture change “looks like” and how it is done. As one facilitator noted, “The listing of changes in long-term care is interesting, but again, folks wanted more info on how these initiatives really worked and how problems implementing culture change are resolved”.

Another measure of participants’ interest was their rating of the importance of culture change. Upon completion of the meeting, nearly all consumers agreed that culture change needs to happen. Ninety-seven percent of consumers strongly agreed or agreed that they would rather live in a culture change community than one that practices a traditional model of nursing care. This is an important message for providers as it suggests consumer preferences for culture change that may lead to consumer expectations.

The most frequent comment from participants questioned the cost feasibility of how culture change could be implemented for people of all economic means. In other words, there was a prevailing thought that culture change is just for those “high

end” homes that could be afforded by wealthy individuals. This speaks to the need to provide more information to consumers about the case for adoption and how communities that have adopted culture change serve various socio-economic groups.

The majority of participants (79%) indicated the desire to become advocates for culture change. Interestingly, only about half of the participants expressed an interest in visiting long-term care communities to see if they were doing culture change. This is likely due to a number of factors, including time, effort, fear, lack of confidence in identifying culture change practices as stated by their interest in knowing more about about what culture change “looks like.”

Another interesting result was consumers response to the statement “As consumers, we have the power to transform nursing homes and assisted living communities.” Prior to the meetings, about 76% of consumers agreed or strongly agreed with this statement. After the meetings, almost 90% of consumers agreed or strongly agreed that they had the power to transform nursing homes or assisted living. Consumers also identified the power they held in becoming advocates in their own personal situations. This speaks to the point that consumers may not have been aware of the lack of choice provided in long-term care, and that they can promote choice by advocating on behalf of family members in long-term care. For example, a daughter whose father lives in a nursing home decided that she would talk to the nursing home administrator about giving her father more choices in his daily life.

The role of state culture change coalitions in consumer advocacy will continue to grow as well over a half of participants expressed interest in being a part of a coalition. This finding will certainly challenge state coalitions to find ways to involve consumers, and will challenge providers to prepare for an organized group of increasingly educated consumers.

Considerations and What We Learned

While most consumers in this pilot were appreciative of the information about culture change and generally saw its importance, it was clear that this was not on their radar screen prior to the meetings. This further validates the need for our efforts. It is important to recognize that there may still be a sizeable lack of attention to long-term care amongst consumers. Clearly, people who attended these meetings had some level of interest in the topic. However, some participants commented that they did not see the personal relevance of this topic, either because they do not see themselves ever being in a situation in which they would need long-term care, or they prefer to wait until that situation occurs.

The Creating Home program evaluation validated that consumer experiences with long-term care, or lack thereof, is an important consideration in consumer education about long-term care and culture change. On one hand, for those with limited long-term care experience prior to this program, there was a lack of awareness about institutional routines. On the other hand, for those with long-term care experience, there was also a lack of awareness about a possible alternative to the traditional model because their only experience had been with the traditional nursing home model. Consumers “only know what they know” and may be entirely unaware of opportunities for change. Alternatively, consumers may experience an “institutional nihilism” in which they accept the routines and limitations of a traditional nursing home environment as “the way it is.” This was confirmed by the state project leaders. Alissa Weintraub of Massachusetts stated: “The meetings seemed to vary as far as the consumer’s experiences go. But I found that over all, people knew very little of the culture change movement. Their opinions of long-term care were greatly based on personal experiences, so some consumers found it difficult to fully embrace the idea of culture change, since they have never seen it played out.” Kim McRae of Georgia echoed these sentiments: “As we are doing our analysis of

the survey results and figuring out ‘what’s next’ we have to remember this — these consumers only know what they know. Until someone is ‘in one’ they don’t realize or have not thought about the fact that people can’t get up/eat/bathe when they want. ‘Virgin consumers’ don’t know that’s the way it is because who could even imagine that...you mean people CAN’T do these things?”

These thoughts will need further consideration as we prepare to educate more consumers about culture change. The Creating Home pilot was successful in helping consumers gain perspective through experiential exercises that provided a personal connection and a taste of the experience of a traditional nursing home routine. Additional efforts to involve consumers, particularly those outside these meetings, may also need to include helping consumers see the personal relevance of culture change.

Consumers’ lack of knowledge of culture change and the need for change presents a big challenge. Simply stated, we need to reach more people. From this pilot, we know that when we do, there is interest in getting involved. Continuing to build consumer education partnerships with state coalitions, the long-term care community, citizen advocacy groups, and community organizations not traditionally involved in long-term care will be key to increased outreach. It will also be important to identify ways to continue to support consumers as culture change advocates. During the meetings, we encouraged consumers to visit long-term care communities and ask them “key questions” to determine whether they are offering person-directed care. One of the challenges inherent in this is that, for many consumers, most of the communities they visit will not be involved in culture change. While we hope that this consumer advocacy will encourage these homes to engage in culture change, consumers may find themselves frustrated and disappointed that person-directed options do not always exist. They may also be unsure how to encourage long-term care communities to adopt and how to direct their advocacy. It will be very important for the Pioneer Network, state culture change coalitions, and long-

term care partners to support consumers in providing information to long-term care communities about culture change and to be available to consumers as a resource.

The fact that consumers are being educated about culture change and long-term care has important implications for providers in terms of their readiness to address questions about how, or if, they are practicing person-directed care. It also provides a great opportunity to join consumers in advocating for person-directed care. Educated consumers who become residents and family members in long-term care communities are likely to champion culture change in those communities. Increased understanding and involvement of consumers in culture change produces partners who can support providers in advocating for change. Informed consumers can advocate for regulatory and financial incentives that support culture change. When consumers articulate the message that culture change is what they want and that they will not accept traditional models of care, widespread adoption will occur.

Next Steps

The Pioneer Network has received funding from the Picker Institute to expand efforts to further engage consumers in culture change. “Phase Two” activities include revising the Creating Home consumer education materials based on feedback we received through the evaluation; expanding consumer education to additional states; developing a “train-the-trainer” model to prepare consumers and advocates as facilitators for Creating Home sessions; creating webinars and online “virtual experiences” for consumers regarding culture change topics; and developing a pilot consumer outreach program with financial planners and elder law attorneys. The success of these projects will be dependent on our continued collaboration with national, state, and local partners. We look forward to working together in creating knowledgeable consumers and advocates for culture change.