



Office: 802.878.9380
Fax: 802.878.9378
Web: www.fifthelementassociates.com
1069 Sunset View Road Colchester, VT 05446

**Consumer Focus Groups
To Assist with
the Successful Implementation of the
VT Aging and Disability Resource Connection
Project**

For



Department of Disabilities, Aging & Independent Living
Agency of Human Services

Merle Edwards-Orr/Heather Johnson

State Unit on Aging
Division of Disability and Aging Services
VT Department of Disabilities, Aging and Independent Living
103 South Main Street
Waterbury, VT 05671-1601

Submitted by:

Claudia Eisinger

claudia@fifthelementassociates.com

802.878.9380

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Executive Summary

Key Insights

March 22, 2011

Background

- The VT ADRC's eight-member partnership, in collaboration with DAIL, commissioned Fifth Element Associates to conduct a series of focus groups and interviews in Burlington and Rutland in January and February 2011. The research was conducted with specific consumer populations (adults 70 plus years, adults with disabilities, caregivers of family members in these groups, including immigrants) who were not currently utilizing long-term, personal care services and support provide by the State.
- The primary research objectives were to 1) determine levels of awareness and knowledge of existing long-term, personal care options, exploring specific barriers to access; 2) identify the ways in which potential consumers seek and access such services and supports 3) explore and give guidance on the most effective and valued communication and marketing approaches.

Key Insights

- Our consumers demonstrate a strong sense of pride in being independent and self-sufficient. As people grow older, live with a disability, or care for someone who is, their attitude and ability to accept the challenges of their circumstances impact their experience and desire to seek out information.
 - Adults who are 70 plus years see their world shrinking but want to continue to live full and vibrant lives. They need help adjusting to the decline of their bodies/minds and are more accepting when the still have some control over their lives and the decisions they make.
 - Adults with disabilities experience their life as limited and constantly face barriers that keep them from fully expressing who they are as they are. They value having a sense of autonomy and are often sensitive to appearing too needy.
 - Caregivers experiencing caring for their family member as an honor, being "the responsible one" in their family. However, it often becomes a burden that is all consuming, leaving them feeling overwhelmed and trapped. They need a break and help with establishing clear boundaries so they can continue to be of help over the long term.
 - Immigrant populations experience the same challenges and emotions as the other consumers groups. However, the root causes of their situations are often extreme and traumatic. Many are refugees who were forced to leave their countries due to unsafe conditions. On top of that, language and cultural differences pose additional barriers, leaving them feeling isolated and helpless.
- It is vital to keep in mind that, whether due to a gradual decline with age, being born with a disability, or having a specific event happen suddenly, such circumstances represent a major disruption to our consumers' world. It tends to rock the very core of who they are, as their expectations about how their life is supposed to play out are shattered. They grapple with adjusting to the sort of change that they certainly aren't prepared for, which leaves them disoriented by the unknowns and feeling as if life is out of their control. For

these individuals and their families, they tend to become inwardly focused as struggle to make sense of what is going on.

- Those who are growing older or have disabilities often feel disconnected from our communities and society at large. Our society places importance on being, young, beautiful, capable, and active. Such people have to confront judgments and stereotypes that make them feel invisible, unworthy, and separate from the rest. Often family caregivers get pulled into their isolated worlds. It becomes hard to ask for help or even see that it is available.
- “Personal care” is the most accurate term to describe the services and supports. “Long term,” as a phrase brings up strongly negative connotations that rub against these consumers’ core values, especially when linked with care: *sitting in a nursing home, where one is no longer in charge of one’s life, waiting to die.*
- As research participants’ circumstances leave them disorientated, they are not sure where to turn and what to ask when it comes to long-term personal care services and supports.
 - They tend to have limited, little, or no awareness of the range of options available to them and have many basic questions unanswered: What help is out there? How do I get it? At what cost? What is supposed to come next?
 - They first turn to a small circle of family and friends, or a close physician, etc. whom they know and trust for help, which often leaves them wanting and still looking to fill major information gaps.
 - The process of gathering information tends to be organic and haphazard. They jump in, not knowing what they are looking for. As a result, they face a number of barriers to accessing the information and actual services and supports, including needing to overcome turbulent mental and emotional states, and being at a loss as to how to navigate the complexities of the system. In addition, seeking, understanding and accessing such information, services, and supports can become very time consuming, which increases stress levels and becomes an added financial burden. Thus, many want to avoid the hassle of dealing with it.
- Ideally, these consumers want to have one, knowledgeable point of contact, a solution-oriented person who takes time to listen and understand them and their situation. They are also seeking a locally-rooted, supportive community network to supplement the role of a central coordinator where information, experiences, and referrals can be shared.
- They want informative messages that convey warmth, hope, and encouragement, and communicate that one is not alone and that help is available. They want to see messages delivered in a variety of formats, especially video, which brings individual and family stories to life, across a broad range of media channels (print, radio, TV, a toll-free phone number, online – YouTube, Facebook, etc.) and outreach to wide variety of community centers, faith communities, doctor offices, pharmacies, schools, etc.

Conclusions and Recommendations

- There is a strong unmet need when it comes to knowing about and utilizing personal care services and supports on an ongoing basis. VT ADRC is clearly on the right track. It is important that they consider the ways they plan to deliver on what they promise as they become a fully functioning ADRC.
- Prior to the delivery of any information or services, a vital first step is to **pause** to really understand each individual and his/her unique situation. VT ADRC can then really be of service by reassuring that help and solutions are available, explain the system and map out key steps to take, and help set expectations about what can be done. It is at this point that consumers will be ready to fully receive such information and services.
- It is important to align with the core values and needs of these consumer populations by focusing on ways to **maximize one's independence** while also helping these people feel a sense of connection and **belonging** to their communities. For communication and service delivery approaches to best serve these consumers, they need to support them living their full potential, empower them to help themselves, and reinforce that they are vital members of our communities.
- Consumers seek a "centralized clearing house" with a primary point of contact, someone they can get to when they have questions, need more information and direction, or get specific resources (ideally supported by phone and web resources perhaps via VT 211).
- The VT ADRC has the potential of becoming a **wise guide** and **personal advocate** for those seeking information and solutions (ideally the same person who oversees their situation). They also can play the role as **a community connector** who links consumers to specific and relevant resources (ideally while remaining in touch with each one's progress and development over time).
- There is clear opportunity to capitalize on the latent community networking potential found in these consumer groups.
 - They demonstrate a deep desire to be connected to others in similar situations. They also want to learn and share their experience and wisdom. Furthermore, it is inherently in their nature to want to give back (especially for the caregivers).
 - There is need for someone to step in and cultivate a forum where people can self organize and communities flourish locally (virtually online, over the phone, and in person in groups or one-on-one meetings).
 - In order to optimize communication and service delivery approaches, we recommend identifying a firm with marketing expertise to develop a marketing plan so the VT ADRC communicates a unified, clear, and compelling value proposition and message:
 - Outline a process where concepts are developed and evaluated in a subsequent stage of research. Campaigns, messages, and communication materials then can be developed, tested and refined via research as well.
 - Help oversee successful implementation of marketing strategies and tactics, such as training staff who serve these populations as "ambassadors." They can model and deliver the clear and compelling message day to day, and help cultivate locally-rooted community networks.