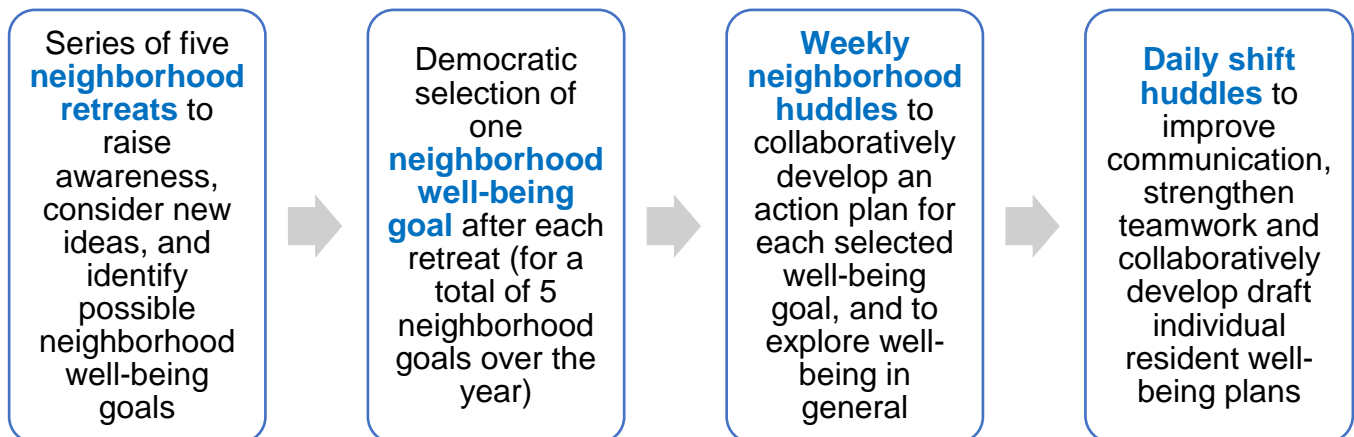


## A Brief Description of *The Quest Upstream*

Carol Woods' Journey to Support the Inclusion of People Living with Dementia and the Well-Being of All Community Members

**Purpose:** Carol Woods Retirement Community has successfully supported people living with dementia in an inclusive setting since opening its doors in 1979. In January 2018, community members reaffirmed their values and deepened their commitment to inclusion by launching a research initiative, *The Quest Upstream*. Working in partnership with Dr. Jennifer Carson (Director, Dementia Engagement, Education and Research Program, University of Nevada, Reno), and guided by participatory action research, *The Quest Upstream* aims to explore, understand and document the organizational requirements of inclusive living for residents living with dementia, while proactively supporting the well-being of all community members. Core to *The Quest Upstream* is the belief that the distress a person living with dementia might express is not an inherent result of dementia (i.e., so-called “behaviors”) but, more often, it is communication of an unmet need. By proactively supporting well-being, so-called “behaviors” are lessened or eliminated altogether.

**Process:** *The Quest Upstream* was developed by a diverse group of 17 community members. This ‘community action team’ guided the higher levels of support (assisted living and skilled nursing ‘neighborhoods’) through an iterative process that included:



The huddles are now part of life at Carol Woods. All neighborhood members are invited to participate in their weekly neighborhood huddle; all team members are required to participate in the daily shift huddle; and each neighborhood is supported by a ‘Guide’ from the Well-Being leadership team.

*The Quest Upstream* is a capacity-building approach to organizational, neighborhood and individual improvements. The primary capacity we are developing is the ability to work together to solve complex issues. This requires communication, partnerships, collaboration and

teamwork! Let's explore why communication, specifically, is vital to our success in supporting resident well-being.

**Group exercise:** Imagine a closed box with two peepholes: A and B. Based on the image below, what would someone see if they only looked into peephole A? What would someone see if they only looked into peephole B? How might this 'Cone-in-a-Box' relate to providing support to a resident living with dementia?

Cone-in-a-Box (Brown, 2008)

	<p style="text-align: center;">Key Points</p> <ul style="list-style-type: none"><li>• When we are trying to figure out an important [or complex] situation, especially when it involves people, we have to hear everyone's perspective in order to understand what is really going on.</li><li>• When you keep your perspective to yourself, staying silent out of shyness, fear or the desire not to rock the boat, you put lives at risk.</li><li>• When you, out of rank, brilliance, expertise or power, inadvertently silence others, you put lives at risk.</li></ul>
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Dementia support is complex. There is no one-size-fits-all solution, and while expertise is helpful, rigid protocols, even when they are evidence-based, have limited application and can even be damaging when mechanically applied without regard for each individual's uniqueness. The best solutions, while ever-changing, will come when we ask the right questions, share our perspectives and work together to identify solutions. This is how you develop a responsive organization capable of making the most effective and sustainable improvements in dementia support. One vehicle that can assist organizations in developing this capacity is the huddle, which can be thought of as Having Useful Dialogue Daily Linking Everyone (H.U.D.D.L.E.). Through our weekly neighborhood huddles and daily shift huddles, neighborhood teams are working together to better support the inclusion of residents living with dementia and the well-being of all community members.

If this process sounds kind of messy and uncertain, that's because it is. Dementia support cannot afford rigidity, and it is not a place for control freaks. Uncertainty is just another word for openness – openness to another person's inner experience, openness to possibilities. We must

embrace complexity, and relationships are the key. Everyone's participation must be valued and incorporated as we seek to create a better tomorrow, because that is very dream we seek – inclusion, relationships, role, purpose, meaning and well-being.

**Reflection:** Each neighborhood completed a series of five 3-hour neighborhood retreats over 13 months. Currently, in addition to working toward 20 well-being goals planned through weekly neighborhood huddles, each neighborhood team is using daily shift huddles to explore better ways to proactively support the well-being of individual residents and/or respond to episodes of distress (e.g., resident well-being plans). According to neighborhood members during a reflection exercise at the third retreat, our capacity-building approach was gaining momentum and strength. Specifically, neighborhood members were asked to “reflect on *The Quest Upstream* by drawing a river map that shows your neighborhood's progress and achievements, as well as your neighborhood's obstacles, challenges and new learnings.” By the third retreat, every neighborhood reported significant progress, but not without having to overcome some difficult challenges, as the quotes below describe:

Neighborhood 'River Map' Reflections (January 2019; paraphrased):

Selected Quotes about **Challenges:**

- Prior to *The Quest*, you felt alone in your cluster. Choppy water to start. It was messy in the beginning. Limited voices were at the table, limited engagement, got shift report usually from one person and then went your separate way. At first, *The Quest* made little sense and so much confusion of what is this all about.
- In the beginning, we wondered, “What is my role in all of this? How do I fit into this bigger picture?” There was reluctance to have an idea that would give another person more work (a gap between having an idea and the practicality of making it happen). Getting all disciplines involved and helping them see their instrumental part in life on the neighborhood was a challenge. We hit confusion along the way. People were reluctant to admit challenges; “I can figure this out myself - don't want to bother the group and don't want to be judged.”
- We lost momentum when folks did not speak up - people were afraid their perspective would be dismissed, and having your ideas judged is not a risk some wanted to take. Other challenges: getting indirect staff involved; getting residents and families involved; reluctance to admit challenges (e.g., it's silly, it's my own weakness, it's too big, it's too small). We can get set in our ways and sometimes it feels easier to keep your head down and not to rock the boat.

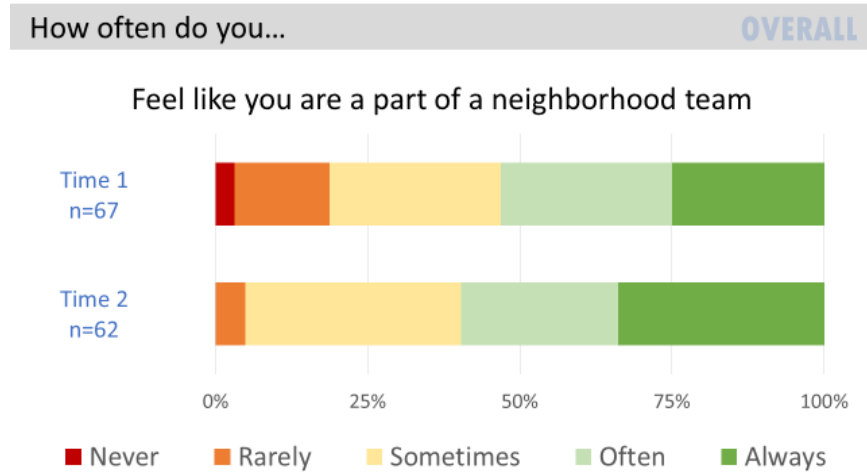
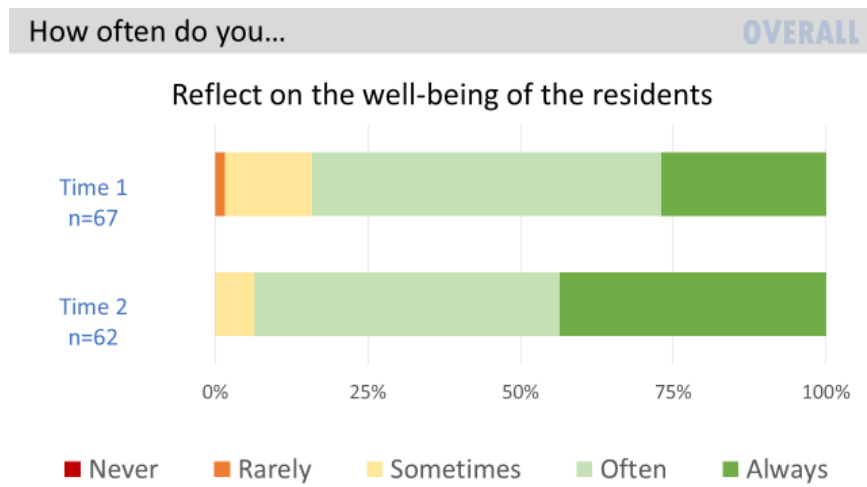
- Our journey started narrow because that is where we were in our thinking and rocky due to lack of understanding of what we were doing. The biggest obstacle was understanding what *The Quest* was. The concept was abstract; more about shaping practice and thoughts.

#### Selected Quotes about *Successes*:

- Now we are learning how to communicate better. Huddles are key. This is not in addition to our work; this is our work.
- We starting asking why distress was happening. There was a sense we were starting to gain momentum. Instead of reporting 'what is going on', we switched to 'why is this happening?' The third retreat led to a faster current and better attendance, improved interventions, better communication and better follow-up. Now we have about a dozen at our huddles. Real interventions are discussed and we follow-up. More disciplines started coming and sharing different perspective on dining, residents, OT, etc. We are getting creative with our approaches and have better teamwork. We started asking, "How can we help each other". We started to take more initiative. We are so much further along than when we started.
- We are a better team because we got all voices at the table. Shift report was very clinical and opening it up meant we could talk about the other things that are important in residents' lives. This change to be open, to hear other perspectives, and being curious created buy-in among those who brought the non-clinical ideas.
- The room went from one or two people coming to the huddle to standing room only. Staff began to see possibilities in suggesting improvements and trying out new ideas. Then the real change came when we focused on one resident – one person at a time – and the coordination was better and folks realized how to come together to rally around one specific person. Now there is a true focus on the team coming together. Staff feel like they have something important to offer, are heard and changes are implemented.
- We use cone-in-the-box to identify what our needs really are. Most important part of shift huddle is that everyone participates. What seems like a big problem can become so much smaller because we can find a great solution in just 5 minutes with all the right perspectives at the table. It actually makes our job easier.
- Successes are that it started good conversations between residents and staff and got us thinking more proactively. We don't have a specific destination but do have a direction.

The community action team observed several other ‘milestones along the stream’: 1) success in achieving neighborhood and resident well-being goals, and less distress; 2) improved communication and teamwork; 3) greater initiative among community members to engage with residents living with dementia; 4) increased enthusiasm and engagement among direct support team members; 5) increased energy and discussion during neighborhood retreats; 6) more team members volunteering for leadership roles during huddles; 7) rising voices from community members who were previously quiet; and 8) less reliance on 1:1 companionship to ease distress.

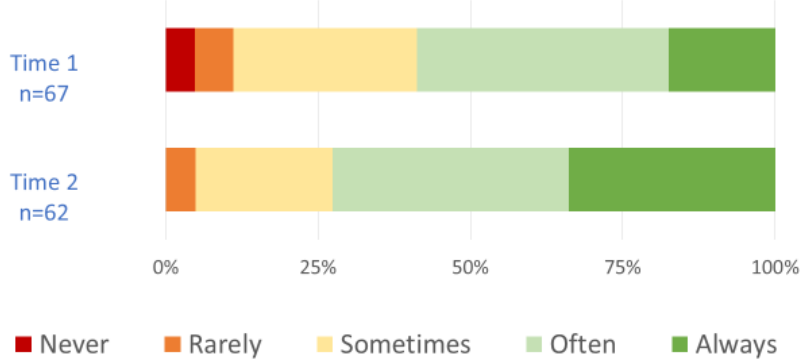
At Retreats #1 (March 2018) and #5 (April 2019), team members were asked to complete a 14-item Neighborhood Team Assessment as part of our evaluation on *The Quest Upstream*. The graphs below represent 10 of the most significant shifts.



How often do you...

OVERALL

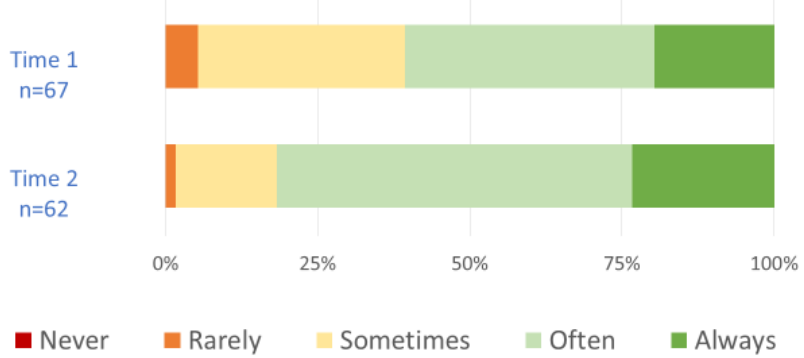
Work collaboratively on your neighborhood (i.e., teamwork)



How often do you...

OVERALL

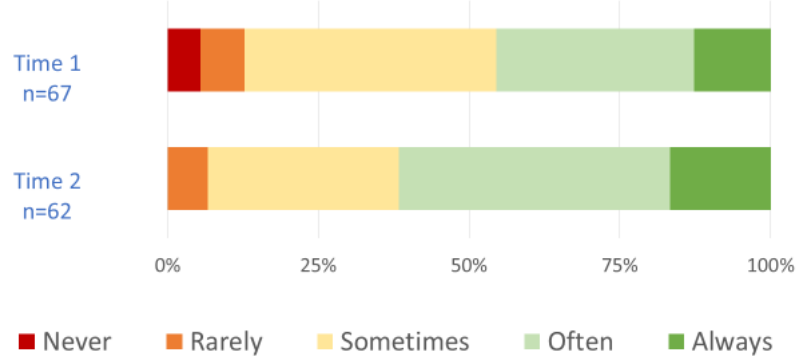
Feel a sense of trust on your neighborhood



How often do you...

OVERALL

Express your views and opinions on your neighborhood



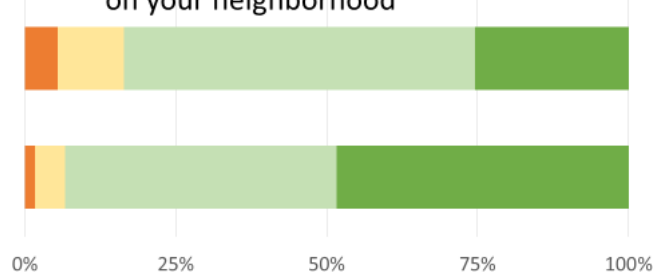
How often do you...

OVERALL

Demonstrate respect for the views and opinions of others on your neighborhood

Time 1  
n=67

Time 2  
n=62



■ Never ■ Rarely ■ Sometimes ■ Often ■ Always

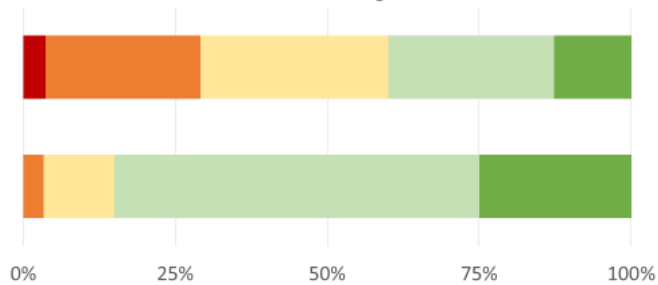
How often do you...

OVERALL

Meet and communicate as a neighborhood

Time 1  
n=67

Time 2  
n=62



■ Never ■ Rarely ■ Sometimes ■ Often ■ Always

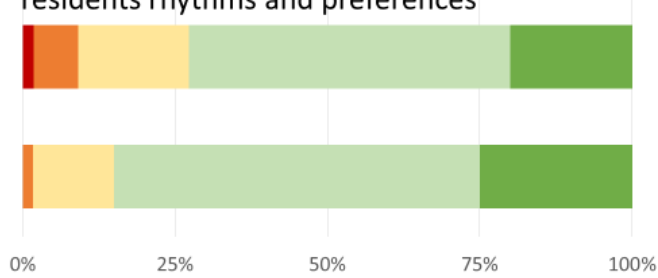
How often do you...

OVERALL

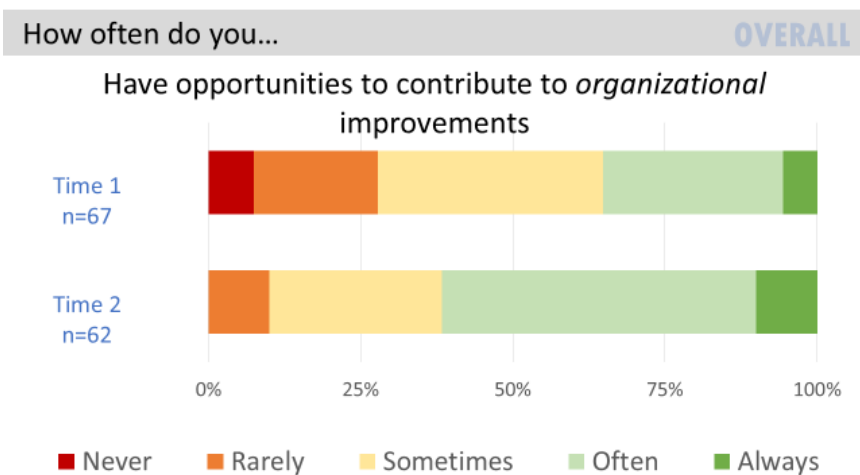
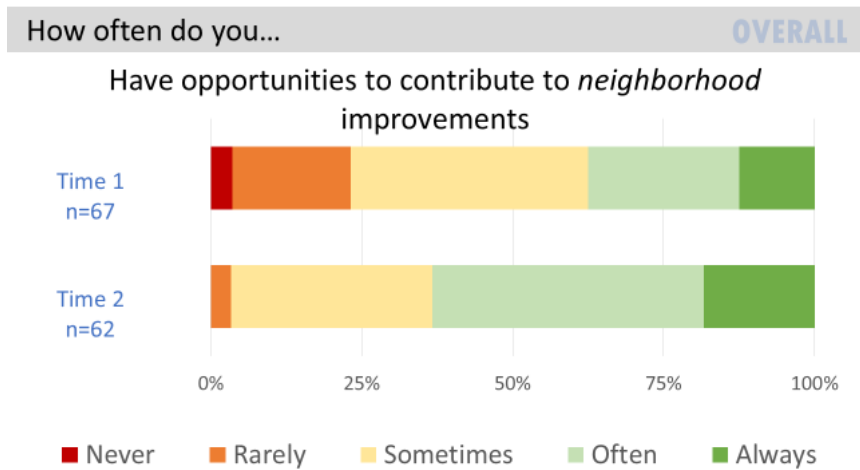
Make changes within your routine to flexibly support each residents rhythms and preferences

Time 1  
n=67

Time 2  
n=62



■ Never ■ Rarely ■ Sometimes ■ Often ■ Always



And *The Quest Upstream* continues!

**Sharing Our Story:** Participatory action research calls for local movements, such as *The Quest Upstream*, to build connections and alliances with broader social movements as a way of enhancing the understanding and political efficacy of those involved and contribute to social and cultural transformation. We are sharing our story of *The Quest Upstream* with the broader field of senior living through a series of online blogs ([www.changingaging.org](http://www.changingaging.org)) and presentations at professional and research conferences. *The Quest Upstream* will also be featured in a new book co-authored by Dr. Jennifer Carson and Dr. Al Power about dementia inclusion. A peer-reviewed journal article will also be prepared and submitted.

Finally, Carol Woods received a 2018 Facility Best Practice Award from Friends of Residents in Long-Term Care for our work on *The Quest Upstream*. The award honors Carol Woods “for providing exemplary programming which reflects person-centered values, supports the rights of residents and improves quality of care.” For more information about *The Quest Upstream*, please email: Dr. Jennifer Carson at: [jennifercarson@unr.edu](mailto:jennifercarson@unr.edu)