The need for observable and measurable outcomes in dementia care, especially in the areas of competency, sensitivity, empathy, dignity and respect, is imperative. The healthcare system is mainly comprised of a medical model which is driven by concrete data to ensure treatment pathways and provide benchmarks to care. While critical to care provision, the medical field is recognizing the need for the addition of social models of care. Social models of health recognize that our health is influenced by a wide range of individual, interpersonal, organization, social, environmental, political and economic factors. They encourage us to have a deeper understanding of health than a focus on biology, physiology and anatomy. The advent of social models of care provide a more wholistic approach which has led to the development of person-centered care. This model of care is about considering people’s desires, values, family situations, social circumstances and lifestyles; seeing the person as an individual and working together to develop appropriate solutions. Being compassionate, thinking about things from the person’s point of view and being respectful are all important. A weakness in person-centered care is while greatly needed and necessary, it doesn’t have observable and measurable benchmarks to determine when person-centered care is happening. Placing a value on human behavior is subjective and hard to assess.

In the area of dementia, the person-centered care approach brings a new form of relationship building with the person at the center. This approach has brought to the forefront the importance of developing relationships with those with dementia that tailors an environment of support and to treat them as individuals with individual needs. Person- and relational-centered care practices are accepted as the gold standard globally. In the middle and later stages of the disease, the person with dementia is unable to communicate accurately their wants and needs and in many cases the ability to communicate is relegated to passivity or acting out. Most conflicts in dementia care happen when care providers are unfamiliar with behaviors that are normal hallmarks of dementia. For example, a person with dementia who is unable to modulate his or her voice may sound brash and threatening which then causes untrained caregivers to get louder and more impatient. This simple misunderstanding can result in increased agitation, possible

1 https://sustainingcommunity.wordpress.com/2015/06/02/social-model-of-health/
2 http://healthinnovationnetwork.com/system/file/assets/attachments/41/what_is_person-centred_care_and_why_is_it_important.pdf
3 Institute on Medicine, 2001; World Health Organization, 2007
unnecessary medications and ultimately in hospitalizations, costing Medicare and Medicaid billions of dollars each year not to mention the emotional toll on all involved.

Many times, the care provider, whether family or healthcare professional, is left with trying to interpret needs. Sadly, many care providers have given up trying to communicate with the person and simply provide care as though the person isn’t there. In some cases, giving psychoactive medication to mitigate behavior challenges are used and in others, caregivers do not provide necessary care for fear of outbursts.

Inherent in person-centered care of dementia are two issues. 1. Inability to accurately communicate with the caregiver. 2. The need to assist caregivers in the development of person-centered care. 3. The need to turn the abstract concept of person-centered care into practical benchmarks that caregivers can meet to move closer to relationship building and comfort for both the caregiver and the person with dementia.

Second Wind Dreams®, a nonprofit with international reach and home of the Virtual Dementia Tour® (VDT®), is addressing the three issues above. The DACE (Dementia Aware Competency Evaluation) methodology, created by PK Beville, author of the VDT, helps caregivers learn how their behavior in the caregiving role are perceived by the person with dementia which directly impacts both the relationship and the quality of care provided. It allows for real-world feedback and training based on the caregiver’s specific situation. DACE competencies have been developed according to best practices associated with positive outcomes of care. This approach follows the principles of person-centered care by offering a humanistic and holistic approach to care.

In order to provide competent care to people with dementia, the provider has to be aware of what dementia is and have the ability to perceive, feel, or to be conscious of events, thoughts, emotions, or sensory patterns. It means there is a basic understanding of the nuances of dementia and how it impacts the way the person with dementia behaves. Simply being aware of dementia in no way suggests that there is an understanding of HOW to provide care and support for the person with dementia. To be competent, a person would need to be able to interpret a situation in the context of dementia and to have a repertoire of possible actions to take and have been trained in the possible actions. Regardless of training, competency grows through experience and the extent of an individual to learn and adapt. Competencies provide organizations with a way to define in behavioral terms what it is that people need to do to produce the results that the organization desires. In this case, person-centered dementia care. It provides an observable and measurable method of quantifying sensitivity toward the person with dementia by defining competencies that result in person-centered care. Properly defined, competencies allow organizations to evaluate the extent to which behaviors employees are demonstrating and where they may be lacking. Hallmarks of good care of those with dementia are seen when there is empathy with their plight while ensuring dignity is preserved and care is provided in a respectful manner.

DACE tracks behavior dynamics of caregivers that promote strong outcomes of care as evidenced by fewer behavior challenges, compliance with care, and as much involvement in care as is cognitively possible. The determination of these core behaviors and philosophy are derived from staff observations conducted at two healthcare facilities and one home health location. The
Dementia Action Alliance work in person-centered care has also been a force in the creation of DACE.\(^4\)

The DACE methodology is easy to administer by a person trained in dementia care and used to assess a caregiver’s ability to engage positively with those living with cognitive impairments. Further education about DACE is provided in a webinar with accompanying assessment and provides CEUs to nurses. DACE includes an online database application for creating records and running automated reports that provide comparative analysis between care providers, departments, shifts and, most importantly, each of the person-centered competencies. This data analysis quickly provides targets for training and improvement in care and gives insight into the most competent staff for the provision of person-centered care for those with dementia. This tool places a value on how the caregivers respond to those with dementia in the real-world setting.

It is recommended that a DACE assessment is completed for all those involved in the caregiving setting (home care, day program, long term care, family caregivers, hospitals, etc.). Caregiver behavior is tabulated on a five-point Likert scale. The caregiver is observed during at least two domains of ADL (Activities of Daily Living) care on the DACE form. The DACE form produces a total score for each caregiver in addition to a score for each ADL activity. Scoring provides information about areas of improvement, baseline scores for caregivers and a mechanism for tracking progress.

The DACE assessment can be conducted before and after dementia training, which may include the Virtual Dementia Tour program, to determine the success of the training program. However, it can be used on an ongoing basis to determine level of competency of anyone providing care for a person with dementia. DACE is also used as a part of performance reviews for caregiving staff. Over time, results from DACE assessments will provide invaluable insight to supervisory personnel by showing clearly which caregivers need specific areas of training to enhance quality performance. For example, if a caregiver consistently continues to speak to those with dementia briskly and without verbal and visual cues, this information will be indicated during DACE and provide concrete steps for training.

On DACE, the competencies of caregivers providing person-centered care for people with dementia are Tone of Voice, Body Language, Touch, Greeting, Giving Choices, Making Eye Contact, Talking during caregiving tasks, Break Down task/cue/model. In addition, Behavior Challenges are recorded for further training.

More than two-thirds of communication is understood through nonverbal methods. This is the last thing that a person with dementia will be able to decipher in the environment. Consequently, it is the most important part of ensuring strong person-centered dementia care. Behavior challenges can occur simply as a result of negative nonverbal expressions on the part of the caregiver. Negative facial expressions, hurried touch, clipped language and no eye contact can all contribute to negative behavior on the part of the person with dementia. Even though they may not be able to understand what is said to them, they can almost always pick up on negative care approaches. Studies show that even people in the middle to late stages of dementia can pick up on negativity and tone of voice. In addition, once a behavior challenge occurs, the caregiver can further escalate the challenge simply by responding negatively. A great deal of negative

behavior occurs due to the way the caregiver interacts with the person while providing care. Studies show that even those in the middle to late stages of dementia can pick up on negativity and brisk tone of voice. By including people with dementia in their care by giving choices, talking with them, maintaining eye contact, just to name a few, results in people becoming more involved in their care and slows cognitive decline.

Staff turnover in long term care is high, which makes new staff orientation a priority to ensure continuity of care. DACE is helpful to determine the best new staff to work with people with dementia and can provide supervisory personnel the information they need additional coaching and encouragement. Families, too, experience burnout and frustration with the many demands inherent in caregiving. DACE can help shed light into how best to provide care in light of dementia by allowing them to be coached through their own experience.

In 2017 and 2018 DACE was conducted in 169 nursing homes in Georgia to determine the staff’s level of understanding and implementation of the tenets of person-centered care. DACE forms have been submitted to the University of Georgia school of epidemiology for tabulation. The chart below shows the results. The data accounts for differences in the variation in the means of the two groups. The t-test is testing the hypothesis of zero difference between the mean. The p-values for each comparison is below the 0.05 cutoff which indicates there is a significant difference between the two mean scores. Each DACE observation in each domain has a maximum of 40 possible points. The closer the mean score gets to that number, the more likely the staff is providing person-centered care.

<table>
<thead>
<tr>
<th></th>
<th>BATHING SCORE t-test p-value = &lt;0.0001</th>
<th>MEALTIME SCORE t-test p-value = &lt;0.0001</th>
<th>TOILET/CHANGING SCORE t-test p-value = &lt;0.0001</th>
<th>DRESSING/GROOMING SCORE t-test p-value = &lt;0.0001</th>
</tr>
</thead>
<tbody>
<tr>
<td>N Mean</td>
<td>N Mean</td>
<td>N Mean</td>
<td>N Mean</td>
<td>N Mean</td>
</tr>
<tr>
<td>Pre VDT</td>
<td>208 30.26</td>
<td>265 29.13</td>
<td>235 29.18</td>
<td>224 29.66</td>
</tr>
<tr>
<td>Post VDT</td>
<td>286 34.62</td>
<td>344 34.72</td>
<td>320 34.46</td>
<td>313 34.76</td>
</tr>
</tbody>
</table>

These scores show the mean score difference between pre and post is significant suggesting that in this case, the VDT helped provide staff with a simulation of dementia and debrief that opened the door for an improvement in person-centered care in every domain.

In addition to UGA’s findings above, SWD also conducted a DACE analysis on 36 nursing homes and 142 staff before and after the first VDT visit. For this study we isolated several variables to control as many variables as possible. We only tabulated DACE when the same
staff were observed before and after the VDT. We also controlled the observer variable so that the same observer was conducting DACE. Finally, we only tabulated scores when the same domains were observed pre and post the VDT.

In the chart above there was an 18% increase in person-centered care attributes during meals. This is compelling information that could impact resident caloric intake. Further study would need to be conducted to show a statistically significant change in weight.

Bathing can be such a traumatic time for everyone but in the above study, we saw a significant increase in all aspects of staff behavior as it relates to person-centered care. As data about behavior incidents, psychoactive medication and abuse incidents are compared we will have a good picture of the depth of these statistics over time.
The chart above shows that there was a 19% increase in breaking down tasks for residents and giving choices during care. Caregivers who include people with dementia in activities of daily living tasks begin to see more engagement which in turn has been shown to lessen cognitive decline. Feelings of incompetence, along with misconceptions about abilities, may accelerate the progression of dementia. Caregivers who experience the VDT and are a part of DACE learn that it is important to include the person with dementia in all aspects of care regardless of the caregiver’s perception of level of cognition.

Benefits to people with dementia

Studies indicate that the only cure for abuse and neglect is education. This project sheds light on education from the experiential perspective which has been shown to be most effective for changing staff behavior over time. We are unable to change the course of dementia but we can change the course of how they are cared for. Once they have walked in the shoes of a person with cognitive decline, staff state that they will be more patient, understanding, less hurried, more sensitive to what is going on around the resident, among other things. Even simply turning on more lights, turning off the TV, turning on music and cutting down on loud abrupt noise makes all the difference to a person with dementia. Staff becomes more aware of these easy strategies after the experience.

DACE will provide concrete feedback about how to provide person-centered care. The residents deserve to be cared for by staff who maintain eye contact, talk with them during care, provide a caring touch not just a clinical touch. For example, if staff consistently continues to speak to

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those with dementia briskly and without verbal and visual cues, this information will be indicated during DACE and provides us with concrete steps for training. DACE will be the springboard to ensure the residents are treated with dignity and respect as individuals and not as a disease. The benefit to residents lies in empathetic, sensitive treatment by staff members.

The lack of consistent, direct observation of care has led to negative outcomes regarding increased medications, increased short term hospitalizations, abuse, and in some cases horrible neglect. It is time for those of us in dementia care to start insisting that the person-centered care model is followed. A pragmatic approach like DACE will provide caregivers a benchmark to follow that will show progress and encourage additional training where needed. Most importantly, we can be assured that people with dementia are being treated in caring environments where the person with dementia is honored and respected no matter the level of function.