

Introduction

Welcome to our first installment of articles focusing mainly on staff. Over the past few years we have highlighted a number of very successful faculty conducting their research through the Aging Center. However, we also know that successful programs require dedicated, competent staff. While usually working quietly in the background, they nonetheless are a major building block for thriving programs and research activities. We are proud to highlight our staff in this and future articles.

The Duke Family Support Program (DFSP) was started in 1980 by Lisa Gwyther, a social worker and an Associate Professor in the Department of Psychiatry and Behavioral Sciences. Lisa recognized the gaps in services for those struggling with memory disorders due to neurocognitive disorders like Alzheimer's disease and other dementias. Since then, the DFSP has steadily expanded from two to four compassionate staff members and a wider range of programs.

The DFSP is an integral part of Project CARE, a state-level program, which provides in-home consulting education, support, and respite options for those caring for adults with dementia in North Carolina. The Program also offers an 8-week early stage program called Memory Makers for those who have recently been diagnosed and their care partners, a Look, Listen and Lunches Reflections program at the Nasher Art Museum, and a What's Next program for families whose disease has progressed to moderate or severe stages. Through a contract with Duke Human Resources, the staff members also provide free confidential consultation services to Duke employees to talk confidentially about concerns they have about aging relatives.



| Bobbi Matchar

Because the work they do is so extensive, the team members have seamless communication and are always aware of each other's work. Bobbi Matchar, who recently became the Director of the DFSP says each of the members on staff wear many hats in terms of the work they do.

“We are a staff of four social workers and there isn't a task any of us won't do. It is important to me that there's nothing that only one person knows, because if that one person is sick or goes on vacation, at least two of us know how to do everything. That is something I've worked hard to encourage in the past few years.”

Bobbi believes that the team's constant communication is fundamental to their success and enjoys going to work every day because of how well the team works together.

Natalie



| Natalie Leary

Natalie Leary is a social worker on staff at the DFSP who spends the most time with Project CARE. Project CARE is a state-funded program specific for family caregivers caring at home for someone with dementia. It provides some modified care management and funds to award respite vouchers. On the DFSP staff, Natalie is the first point of contact for Project CARE and triages the calls. She does an initial telephone assessment of the situation and determines how to move forward from there, often doing home visits to get a better understanding of the situation.

Natalie also supports the other programs that the DFSP runs, specifically the Early Stage and Beyond community program, which includes Memory Makers, the 8-week educational support group for early stage memory loss. She provides help for three additional support groups: the Daughters' Group, the Evening Family Caregiver Group, and the Greystone Group, a group for individuals living with memory change and their care partners. In addition to her work with the support groups. Natalie coordinates the Nasher Art Museum Look, Listen and Lunch program, a program for people involved in the DFSP community to meet once a month for a free guided tour of the Nasher Art Museum including live music in the gallery or hands-on art projects related to each tour's theme. Natalie also writes the DFSP e-news, a newsletter that highlights new ideas, tips, research opportunities, and updates about neurocognitive diseases emailed monthly to families on the DFSP mailing list.

Janeli



| Janeli McNeal

Janeli McNeal is also a social worker on the team who primarily helps with outreach, answering the phone from family or professional caregivers calling about support services, adult day programs, or looking for general education about diagnosis. She also works with many of the aforementioned programs in one way or another. She co-facilitates the Memory Makers group and works with Project Care families.

Over time Janeli has taken on a clinical role as well, collaborating with doctors and physicians assistants at Duke Neurology, seeing patients and their families in a clinical setting. At the clinic, she helps with family education and bridges families to resources, offering help with adaptation to and understanding of a new diagnosis. She helps families manage symptoms and reduce their negative

effects when they do occur. Janeli also assists patients with disability applications, helping with Family Medical Leave Act forms and legal matters.

Recently, she has been able to perform cognitive assessments with patients. Her work ranges from direct practice with patients at the clinic to more macro work with legislation and programs that help meet the needs of those in the community. Both Janeli and Natalie speak Spanish and are able to assist our Spanish-speaking population.

Their Journey to the DFSP

Each team member had a different journey to their roles at the Duke Family Support Program, but their passion for serving the older population remains consistent. Natalie was inspired by her parents' care for her grandparents. Her experience with her family members and seeing the value of caregiving first-hand sparked her interest in issues around aging and end of life. Thus, she decided to pursue a Masters in Social Work and worked as an intern at the DFSP during her last year of graduate school before joining the team full time.

Janeli's decision to work in geriatrics followed a mission trip to India during her undergraduate career. She embarked on this trip with about ten women who were able to experience the broken healthcare system of Chennai and Mumbai, the cities they visited. She vividly remembers the slum-like healthcare facilities and the shortage of something as basic as adequate clothing to cover the patients' bodies. She realized then that while most people take interest in serving young populations, she would find her niche in serving older adults.

Challenges

The work that the staff in the DFSP do is undoubtedly difficult. The broad scope of services provided by the Program cannot be sustained without funding. Much of the funding comes from the North Carolina Department of Health and Human Services through the Division of Aging and Adult Services. However, Bobbi says that they look primarily to grants and the generosity of donors in order to sustain the growth of local programs and services specific to the DFSP. Another challenge staff may face is broadening their reach of to ensure that as many people are educated about memory disorders and service options available from the Program.

Staff also work hard not to be disheartened by the limitations of preventive care for neurological disorders and the fact that many of the medications are

only for symptom management. However, according to Janeli, they are often encouraged by the relief that the people they serve may feel after their diagnosis. They are finally able to cope with and process the disease after months of frustration memory and other symptoms they may have been facing. Being able to put a label on the issues and knowing that it is something affecting a larger community encourages people living with memory disorders and their caregivers to move forward through the journey with the support they need.

Impact

The work that the staff at the Duke Family Support Program does has great impact in the community of individuals dealing with memory disorders and their friends, family, and caregivers. Through the services the Program offers, individuals are able to meet others and become part of a community through which they can share their experiences and acknowledge the hardships that come with the diagnoses. Natalie points out that she witnessed numerous new friendships blossom into supporting relationships where individuals help each other through the “ups and downs and the unknowns that come with memory loss and memory change.” Lasting communities are made through the program and the relationships that emerge have been immensely helpful for those who may not know of others struggling with memory disorders. This impact on community-building has been Natalie’s favorite part of her job.

Having impact on this community has allowed the staff to engage with all of the participants. In doing so, Janeli emphasizes it is important to staff that they are able to strike a balance between being part of the community to provide support, yet educating and leading the community in larger discussions about memory disorders. Through the program, the public becomes more educated about memory disorders, such as the differences between cognitive aging, Alzheimer’s, and dementia, and more aware of the resources available for them through the DFSP. Furthermore, providing these services and receiving feedback increases the awareness of the team as they strive to meet the changing needs and preferences of participants in ways that are lasting and most valuable.

Future

Bobbi hopes that the Program continues to grow steadily as it has throughout the years. Since she started the early-stage program, she has seen tremendous impact on the lives of participants. She has truly enjoyed growing this program

for the past six years and aims for more growth in other services. Another possible area of growth for the DFSP is in outreach. Many people do not know about the DFSP and therefore cannot benefit in a timely manner from the remarkable services offered by the Program.

The staff members hope that whenever people in the community believe that there is memory loss or changes in thinking, they will turn to the staff for guidance. Families, long distance caregivers, grandchildren, spouses, friends, aides—everyone involved in this situation, whether directly or indirectly—would find it invaluable to have the Duke Family Support Program as a resource.