



NY Connects Council Members Share Personal Experience



Most of the people contacting NY Connects Niagara County are caregivers and family members that are looking to help their loved ones live at home and remain independent for as long as possible. Knowing this, our Long Term Care Advisory Council (LTCAC) has four very important members: Robert Bohall, Delphine Bohall, Janet Slack and Laura Slack, our community representatives. I asked our community representatives to talk a little about their experiences and why they joined our council. Here are their stories.

Laura Slack was born with Spina Bifida and has been paraplegic for her whole life. Spina Bifida is a birth defect that happens in the 3rd week of pregnancy when the baby's spinal column fails to close properly, causing the spinal cord and nerves to protrude outside the bony structure that normally protects them. Any nerves outside it are usually irreparably damaged. There are many different severities to Spina Bifida depending on how high or low the opening is on the spine. Laura's is a fairly high lesion and as a result, she is paraplegic and uses a wheelchair for all mobility. Spina Bifida is often accompanied by hydrocephalus and some associated learning disabilities.

Laura was asked to join the LTCAC as a community representative after her involvement with the Dale Association as a volunteer front desk receptionist. She is always looking to meet new people and thought the council might be fun and interesting as well as helpful to her in finding services such as independent housing, transportation, and home health care. The council does a great job of putting together lists of what services are available in the area. Laura hopes that her involvement helps the group in some way – maybe by helping the members to see what it's like to be living with a disability.

Janet Slack is Laura's mother. Laura had done some volunteer and paid work for the Dale Association and Linda Roberts, their volunteer coordinator, had called and asked if they'd be interested in serving on the council. Janet decided to do it because she felt it was a way for her to give back to the community and because she thought the networking, connections, and knowledge she'd gain would be helpful in advocating and obtaining services for Laura. She was also impressed that a group like this was including and asking for input from the folks who actually use the services that NY Connects provides information about.

Because she's the parent of a disabled young adult, Janet's focus is more on the needs of the younger disabled population as opposed to those of the elderly. Janet is happy to see the LTCAC is concerned about some of these issues such as appropriate housing, home health care options, transportation, employment (with supports), social activities, etc. The needs of the two groups (elderly and young disabled) often overlap as well, and as she's getting older, she is also using what she learns to help older family members like grandparents, parents, etc. Janet thinks the LTCAC and NY Connects serve a very important purpose in bringing together what services are available to the elderly and disabled community.

Robert Bohall is the caregiver for his wife Delphine and together they are the caregiver for their daughter Leslie. Delphine had polio 56 years ago and since then, has needed assistance with walking. She mainly uses a cane and walker. Their daughter Leslie was born with Down's syndrome. Thankfully, the Bohall's were connected to services through Women & Children's Hospital when Leslie was 3 months old. Dr. Robert Warner, a Down's syndrome specialist, spent a lot of time with them explaining everything and answering all their questions.

Leslie lived at home with Robert and Delphine until she was 30 years old. Mr. & Mrs. Bohall wanted to make sure there was a plan in place for Leslie's future instead of shifting the responsibility to one of their other children so they worked toward moving her into a residential home. Although Leslie's siblings are very involved in her life, they live farther away and day-to-day care would have been hard. It was very important to them that they find a faith based organization and decided on Heritage Christian Services. Robert and Delphine did not face a lot of issues while making this transition and found people to be very cooperative. It took Leslie about one year to adapt to the change but now Leslie loves her home and the friends she has made. She spends each weekend in her parents' home.

Mr. & Mrs. Bohall joined the council because another member, Glenda Reardon, asked them if they were interested. Their experiences with the long term care system have been mostly positive and they feel NY Connects is very important for those who are seeking information and assistance about long term care. Robert and Delphine feel that the system was very prosperous when they were looking at options for Leslie, but now it has gotten harder for parents. Many agencies are facing obstacles when trying to build new residential homes and this a direct effect on the number of available beds. They are hoping the LTCAC can advocate for changes to help with these types of issues.

Although some calls to NY Connects are to help people through a difficult situation or experience, just as many calls are from people that simply need referral and linkage to available services in our community. Individuals in need of information regarding NY Connects Niagara County or long term care services that are available in our community are encouraged to call (716) 438-3030 for assistance.

The NY Connects column appears in the Union-Sun & Journal the last Saturday of each month. Submissions for topics or agency spotlights for future articles are welcome. To recommend a topic or make a suggestion, call 438-3030 or email nyconnects@niagaracounty.com.