I imagine you are 55 years old and moving to a different city and a new “home.” The only time you’ve lived anywhere but your lifelong family home was when you went to college; even then, your older brother was your roommate, and all your courses were together! You notice there is a lot of hustle and bustle going on in your family’s home. People you don’t know are moving furniture out to trucks, packing away books in boxes, touching your most cherished personal possessions, even going into your room without asking permission. You start pacing back and forth in the long living room, from wall to wall; you start pulling on your hair. Suddenly you hear a loud roar — once, twice, three times — each time getting louder. Where is that sound coming from? You realize it is coming from you. Everyone in the room has stopped their work and is looking at you.

You hate to be stared at, and you start to bang your head forcefully into the plaster wall. Bang! Bang! Bang! One of the movers rushes over to stop you from hurting yourself; he grabs one of your arms and tries to pull you toward the center of the room, away from the wall. You start screaming, flailing your arms and fists, knocking the mover to the wooden floor where he hits his head. You hate being touched! You don’t understand why all these strangers are in your home.

Can you envision this scenario? What if you had more information? Would you know what to do? Would you understand why all these strangers are in your house! The only time you’ve lived anywhere but your lifelong family home was when you went to college; even then, your older brother was your roommate, and all your courses were together! You notice there is a lot of hustle and bustle going on in your family’s home. People you don’t know are moving furniture out to trucks, packing away books in boxes, touching your most cherished personal possessions, even going into your room without asking permission. You start pacing back and forth in the long living room, from wall to wall; you start pulling on your hair. Suddenly you hear a loud roar — once, twice, three times — each time getting louder. Where is that sound coming from? You realize it is coming from you. Everyone in the room has stopped their work and is looking at you.

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Can you envision this scenario? What if you had more information? Would that help you understand your situation and the situation of others?

Meet Peter

Peter is a single white male who has lived with an intellectual and developmental disability (IDD) since birth, although his condition was not accurately diagnosed for decades. He was raised by his parents in the family home along with his four older siblings. Peter was sheltered from the curiosity of their community, and he never met others like himself. He was home-schooled and had a gift for music. His college experience was to strengthen that gift: he played seven instruments (which he had taught himself), and he wrote music, mainly marches. Songs by John Philip Sousa were his favorites. He loved entertaining people — but only in his own way and in his own time. He was particular about whom he honored with his gift.

Individuals with intellectual disability generally have below average cognitive abilities, and their ability to independently perform activities of daily living may also be compromised. Their adaptive behaviors such as speaking, communicating, and socializing are often limited. With support and encouragement from his family, Peter was able to perform his activities of daily living with some assistance. However, he had his own way of putting on clothes, which included donning two pairs of underwear and two pairs of socks every morning. That is a whole other part of Peter’s story!

When Peter was born in 1955, little was known about autism or developmental disabilities. Peter’s incredible musical skills were labeled as savant; in fact, 17% of individuals with autism have extraordinary musical skills (World Psychiatry 2018; 17:280–281). Peter’s siblings were out of the home by the time he graduated college. The patriarch of the family died of a myocardial infarction at age 50. Over the years, Peter’s mother began to have a variety of health issues including chronic comorbid conditions. When Peter was 50 years old, his mother, age 90, had her first stroke of many. During his mother’s first stroke, Peter became so distraught that he had a severe myocardial infarction with vascular changes, eventually leading to a diagnosis of vascular dementia. With paid caregiver help, she and Peter were able to continue living in their home.

With his cardiac disease and after two more myocardial infarctions, Peter was becoming more dependent. Also, his brain had changed due to the dementia. He had violent mood swings and had lost interest in his music and instruments: when he was offered one of his instruments, he would look at it and not know what to do with it. His caregivers had a difficult time handling his impatience and unpredictability.

During this time, Peter’s mother had several more strokes and developed pressure ulcers after being confined to bed. The family decided that after Peter and his mother were both hospitalized, they would need to go into long-term care.

Peter’s Move to LTC

After Peter was discharged to home and before his move to LTC, and some of his nephews stayed with him. Although he was happy to be in an environment he recognized, Peter missed his mother and was acting out. When Peter’s mother was transferred to LTC from the hospital, Peter was admitted to the same facility in a different unit. Because the staff had not been provided with any personal information about Peter, a long list of mishaps ensued. These difficulties could have been avoided had they known his story and had they been trained in how to approach and communicate with a younger adult with IDD.

Peter’s first day was a disaster for him. It started when one of the nursing assistants tried to help him get dressed by laying out his clothes. Of course, she only provided a single pair of underwear and socks. Then, to help him dress, she tried to touch him without telling him first or asking permission. The resulting ruckus brought the unit nurse, who decided to listen to his apical rate because he was on digoxin and it was med pas time — more touching sent Peter into a verbal and physical tirade.

The staff had an idea that he loved music, so they brought some drums from the activity room for him. This wasn’t a good idea: the drums ended up thrown on the roommate’s bed — while his roommate was in it! As one mistake led to another, the staff became frustrated and were truly at their wits’ end. Peter himself was fearful, confused, and extremely upset, and he ended up locking himself in the bathroom.

Welcoming IDD Adults

IDD is a universal component of many individuals’ lived experience. In the past, these individuals did not have an extended life expectancy, and most died well before reaching their 50th year. The reality now is that individuals with IDD are outliving their caregivers and entering their older years. As of 2019, the average life expectancy of an individual with IDD was in the high 50s to low 70s (Scaife et al., 2019; https://bit.ly/2Q0KYSI).

What is also true is that aging individuals with IDD are entering LTC as younger adults. They are living longer and have their own unique needs and life goals. These younger adults are living with significant limitations in reasoning, learning, problem solving, and adaptive behavior related to everyday social and practical skills. Staff need to learn how to engage in a therapeutic manner with this new LTC population.

What is truly lacking in most health care curricula is significant education about younger — and becoming older — adults with IDD. Many health care providers report a lack of knowledge and confidence in managing the complex needs of this population. This situation must change because LTC is accepting more and more long-term admissions for younger adults with IDD. We need to engage in culture change related to welcoming younger adults into our facilities and ensuring their lives are as enjoyable and as high quality as possible.

That is what we tried to do with Peter, who has now outlived his mother and two of his siblings. He recently developed a new behavior: singing! That this behavior makes him, other residents, staff, and visitors happy is just plain wonderful!

A Man Named Peter: Living in Long-Term Care as a Younger Adult

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RESOURCES