

Testimony Provided by Nancy Murray for the Pennsylvania House of
Representative's Human Services Committee's Hearing on the Waiting Lists for
People with Intellectual Disabilities and Autism and the Impact on Families

March 21, 2016

"Let me live just one day longer than my child."

Among families of people with disabilities, that is a familiar thought and prayer.

Good Morning. My name is Nancy Murray. I am the President of the Arc of Greater Pittsburgh at ACHIEVA, and my husband and I have two adult children with intellectual disabilities. ACHIEVA supports more than 12,800 children and adults with disabilities and their families throughout western Pennsylvania by providing early intervention, advocacy, family support, inclusive community activities, employment and residential supports, in-home care, and special needs trusts and long term planning for families.

Waiting for supports and services has an impact not only on the person who is waiting, but also the family. While waiting, individuals tend to lose educational and employment skills and families have to ensure that a caregiver is always available. In two wage earner families, one person often has to give up a job to stay at home to provide care and supervision. In a family, in which there is a single caregiver, that person will desperately have to juggle care giving demands with trying to work. Many families are forced into near poverty, relying on SNAP and other government benefits, they lose health care coverage and they lose their retirement benefits.

And, then there are the families in which there is an elderly caregiver, in their 60s, 70s or 80s, who is still caring for an adult child, who is 40, 50 or 60. These mothers and fathers are just not caring day in and day out for their adult child with a disability, they may be doing this alone as their spouse may have died or is not physically able to help any longer. These mothers and fathers are also living with the issues that accompany aging that all of us face, including serious or chronic health issues, loss of stamina and energy and the daily worry and fear of who will care for their adult child when they are no longer able to do so.

I want to tell you about Cathy, a mother I met almost 40 years ago who is now in her late 70s and is a cancer survivor. Cathy had 6 children when her husband was sent to prison. When he was released years later, he moved to Florida, he never really supported his family yet came home at the end of his life when he was dying and needed someone to care for him. Cathy worked and supported her family. One of Cathy's 6 children is now in her 50s. Amy has Down syndrome and when she was younger, Amy attended high school alongside students who did not have

disabilities and was extremely social. Amy had a promising future and was looking forward to having a job and maybe living independently. Gradually, that dream evaporated. Amy has since experienced a multitude of physical and emotional issues. She lost her ability to speak, eat and walk. She endured countless surgeries and medication regimens. She requires someone to be with her 24/7 and she lives with her mother who thank goodness has other people to help her care for Amy.

Amy's mother just prays that she will outlive Amy by one day.

Then, there is Daniel who is in his 50s and whose mother recently died, leaving Daniel in the family home. Daniel has some family members but none of them are stepping up to assist. In fact, I got the call about Daniel from a friend and her husband who had agreed to be his power of attorney when his mother was dying. When his mother died, Daniel was unknown to the system. Since then, this couple has completed eligibility paperwork for government benefits and a special needs trust, has gotten him much needed medical attention, and has organized a group of people to check in on him multiple times each day. However, at some point, Daniel will be moved into a group home with people he does not know and he is still wondering what happened to his mother.

Daniel's mother did not outlive him by one day.

Then, there is Nan, who is in her 70s and her son, Drayton, who is in his 50s. Nan's husband died a few years ago. Drayton was a successful businessman until one day, 7 years ago, while on a fishing trip; he had a heart arrhythmia, lost consciousness, thus cutting off his air supply. When he awoke from a coma 5 days later, he had no memory of the event. Today, he is unable to work and cannot retain his short term memory. He has now moved back home with his mother as he needs daily supervision.

Nan hopes and prays that she will outlive Drayton.

There are thousands of elderly caregivers across Pennsylvania who are facing the need to be a caregiver at the same time that they are dealing with the death of a spouse, their own failing health and the end of their own lives. Maybe you know one of these families. If not, just try to imagine what it must be like to be in your 70s, to be someone's sole caregiver, to be exhausted at the end of every day, to be dealing with your own medical issues, and to wake up every day worrying about who will take care of your adult child when you become too sick or die.

*Nancy Murray, President, Arc of Greater Pittsburgh at ACHIEVA
711 Bingham Street, Pittsburgh, PA 15203, 412-995-5000 x 424
nmurray@achieva.info*