Comments given by Mary Hogan at the July 27th NAPA Council Meeting:

**DATE:** July 23, 2015

**SUBJECT:** Monday's presentation

Thank you for the opportunity to address the Council today. Some of you may remember me as a regular attendee during the first two years after the NAPA was implemented. It is a privilege to be back again today.

I am here as a *family advocate* for individuals with intellectual disabilities and their families. I also come as a member of the NTG, a grass roots organization designed to increase the awareness of and services for those with ID who face the challenges of aging and further cognitive decline, including dementia.

My Brother Bill had Down syndrome and died of complications of Alzheimer's disease at age 49. *(Page 1 handout)*. As advocates, our family was dedicated to insuring quality of life and quality of care across his life span, with a focus on physical, mental, emotional and spiritual wellbeing. The diagnosis of Alzheimer's disease required intensified efforts that we could barely muster and was the greatest challenge that we faced as a family in Bill's lifetime. It was a cruel and painful journey, filled with many unanticipated obstacles. After Bill's death I vowed that I would work hard so that other individuals and families would be spared this same experience. Today I am joined in spirit by the NTG and many families as I appeal to you to further include this special population in all aspects of research, care planning and funding.

Over the course of the past five years I have been blessed to meet many families from across the country. Some have been siblings and some aging parents who have continued to care for their loved ones as they all age simultaneously. There are a number of common concerns *(Page 2 handout)* that have been expressed. These include:

- Lack of information, especially at time of diagnosis
- Profound sense of Loss with further diagnosis
- Fear about future-including financial fears
- Difficulty formulating long term plan
- Struggle to access community based coordinated care
- Difficulty partnering with medical community
- Being overwhelmed by demands of caregiving
- Isolation and abandonment
- End of life issues
During my last public statement at a Council meeting a little over two years ago in the spring of 2013, I spoke of the urgent need of aging caregivers. I told of Betty, currently age 86, Frank, currently age 90 and Richard, soon to be 49, a special family who lives in a very small mid-western town (Page 3 handout).

Despite the presence of a small group home for medically fragile in their former community, Richard was not able to access the facility because of his diagnosis of AD. In April 2013, with family care giving resources depleted, Richard made the move to a 60-bed nursing home that was designed to meet the needs of individuals with ID and physical and mental health challenges. Richard was one of very few patients with AD and the staff was not specifically trained in the disease process. He was initially treated with Risperdal, as he was mobile at the time of admission and deemed a "challenging patient". Soon after, he exhibited an adverse drug reaction. His parents alerted the staff to the observable changes and the medication was Dc'ed. However, within 4 months of his admission to the facility, Richard had declined rapidly. By August 2013, Richard became wheel chair bound, had limited oral or physical responses and was totally dependent on others for all care. He experienced more frequent seizures and has been on increased medications.

Because of the distance of the facility from the family home and failing health, Betty, age 86, and Frank, age 90, relocated to the town of 1500 where Richard currently resides. They are a presence in the facility and committed to being there for Richard as he continues his decline. They are grateful for the care that Richard receives but mourn the loss of their socially active, garrulous son who can no longer utter a word. Formerly a man with a robust appetite, he can no longer lift a spoon to feed himself. They are pained by the emptiness in his once sparkling eyes. Richard will mark his 49th birthday in August of this year. (Page 4 handout)

Mr. S., age 87, still works part time including as a statistician for a major league football team, despite Parkinson's disease. His wife, soon to be age 84, has Alzheimer's disease. Their son Georgie, who had Down's syndrome and Alzheimer's disease, died at home, this past March with his parents and sisters at his bedside. He was 51 years old and succumbed to aspiration pneumonia, a common complication of AD. (Page 5 handout)

Georgie's parents paid for 24 hour private care and they honored his wish to stay home for over 3 years, as he declined. The only other option was a nursing home, where he did have a short stay after a broken foot. His sister Mary reported that every day after the nursing home stay, Georgie would wake up and he'd ask his Dad..."I stay home, Daddy?" Three of Georgie's
sisters, Nancy, Pattie and Debbie live nearby and were instrumental in his care and that of their Mother. Georgie also had two special caregivers, Chris and Mark who helped to make home care possible. For all it was a labor of love, performed without question. The high cost was heartbreak. *(Page 6 handout)*

Georgie's family misses his smile and his sense of humor. And when they think of him, they remember his favorite song... *I've got that joy, joy, joy, joy down in my heart...Down in my heart to stay!*

I close with a brief recount of Fran and her family. She notes that 4 generations have been impacted by aging and concomitant decline. Fran's mother had been in a nursing home for a prolonged period of time and diagnosed with Parkinson's diseases and Lewy Body Dementia. The family assumed the cost of her care up until the time of her death. *(Page 7 handout)*

Fran's only sibling is a brother, age 65. He lives 7 hours away from her, has Down syndrome and is in the end stages of AD. Efforts to bring her brother closer to her were complicated by funding restraints from state to state and guardianship challenges. When her brother was no longer able to stay in the group home in which he had lived for 2 decades, a crisis occurred. Where would he live? Who would cover the cost? What happened to his former funding stream? Her brother is now in a nursing home and the family worries from month to month about how the costs will be covered. Hospice came and went when he no longer met their criteria, taking a greatly needed wheel chair with them. The family then funded a $3500 chair so that he would not be bed ridden. Exhausting advocacy issues have intensified as his disease has progressed.

Fran, like many others, is emotionally overwhelmed and plagued by guilt over lost time with and attention to her husband, children and grandchildren as she tends to issues of intergenerational decline. She laments the fact that her brother, with his lifetime of cognitive impairment, was never able to communicate end of life wishes. She is often is faced with guardianship issues that may have best been modified years ago.

Their plight is real...the needs of individuals and families great. Families who have been lifetime caregivers often feel abandoned in the end. They have worked hard to independently provide care in the past. They now need extensive support that they struggle to access. I urge you to leave here today, more than 4 years after NAPA was signed and implemented, with a renewed awareness of the critical needs that remain in existence today for this underserved group of people.
Documents were previously provided for today's presentations. I am hopeful that Director Hoffman of the Dept. of Health, State of NY will review the populations identified as "disproportionately impacted" in the ADCSI initiative and consider including family members with ID. This could serve as a model of what might be done across the USA. Director Hoffman and many other Advisory Council Members have been our great champions in the past and I am hoping to count on all of you in the future. Thanks for this opportunity to be the voice of many who would otherwise not be heard.

Mary Hogan

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