

## REMEMBERING AND CELEBRATING BELOVED SDMNY DECISION-MAKER ESSIE

From time to time we include here a remembrance of someone from our larger disability rights community who has recently passed. Although their loss is always sad, the “good news” is that we have been blessed with their lives and accomplishments, and the inspiration they have provided.

This week, sadly, we mourn the loss of our own Decision-Maker Essie. At the same time, we recognize and celebrate the life she made, and the activism she embodied, despite her disability and so the many barriers she overcame. Essie has inspired us from the day we met her at a Self-Advocacy Association of NYS (SANYS) regional conference several years ago, and we want to honor her life and what it has meant to those who know and love her.



*Essie in 2021*

Essie Sumpter Walker celebrated her 80th birthday last month. She was born in South Carolina and moved to New York as a little girl. Essie is a Willowbrook survivor; as was common for the time, her mother was pressured to place her at the Willowbrook State School when Essie was still a young child, but visited Essie regularly until her death. When Willowbrook closed, Essie moved into a residence run by what was then United Cerebral Palsy of NYC, now Adapt Community Network, and has been a well-loved member of the Adapt community ever since.

Through Adapt Essie met her dear husband Earnest, himself the survivor of an institution in Maryland, who she married in 1989. Together they successfully advocated for the right to live together, and Adapt supported them in moving into a 2 person residence so that they could share their lives as any other happily married couple. They were widely known as “Mama” and “Papa” to all, and considered mentors to their younger peers and staff alike.



*Essie and Earnest at their wedding*

Karen Liebman, the Coordinator of Programs at Adapt, also served as Essie (and Earnest’s) SDM facilitator, reports how Essie will be remembered in her immediate community. She says that those who knew Essie well “describe her as kind, helpful, gracious, loving, funny, and feisty. She loved wearing dresses, perfume, and looking pretty. She loved life and participated fully in the activities she loved to do such as cooking, art and music. She was a fierce self-advocate who could charm everyone with her smile and laughter but raise hell when she needed to.” Earnest has asked that Essie be remembered for how kind she was to everyone.



*Essie and Earnest, activists*

We were thrilled when, in their late 70’s, Essie and Earnest decided to join our SDMNY project, and to make Supported Decision-Making Agreements. They did so, they said, because they wanted to be role models for others with intellectual disabilities. They generously and enthusiastically agreed to be part of our video *SDM is for Everyone* (click on the link below to view that wonderful cameo appearance). Whenever we need cheering or encouragement for our work, we go back to their emphatic answer to Karen’s question “Is it ever too late to do SDM?”. Their reply, “NEVER!!!”

Essie was not famous, or a household name, but we cannot imagine a more admirable life: a life full of love for her dear husband Earnest; of delight in all she was able to do, but without regret for what she could not; of care for everyone around her; and of her strong advocacy for, and commitment to making the world a better place. We are all better for having known her.

**Our deepest condolences to Earnest, and to all her friends. May she rest in power, and rest in peace.**