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--TESTIMONY—
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Good Morning Mr. Chairman, Ranking Member and Members of the Subcommittee, thank you for convening this hearing on the important topic of long-term care, community services, and supports for individuals with disabilities. My name is Monica Herring and I am honored to speak to you as the parent and caregiver of a young man who was born with significant physical and mental disabilities.

As I speak to you, my son Ellington is now aged 14. He and I are embarking on a significant and difficult phase of our life journey together. In fact, we are beginning to plan for his transition to adulthood. As a maturing young man, he -- and I too -- are facing an environment that is as yet unknown to us. Although, I am certain to find a new and very complex set of access and eligibility issues, questions about service delivery, and a whole new way to navigate systems and locate essential services concerns me most.

My intent today is to share with you my vision for my son's future driven by what I believe are his likes, wants, and needs. I also want to share with you my fears as I face this inevitable part of our journey. My primary fear is that the vision I have for him, the goals I have strived to achieve with him, may not happen as I had hoped.

From very early on in his life, Ellington participated in the Maryland Model Waver program. Through this program he has received all of the essential medical, health, therapeutic, nutritional and rehabilitation services he needs to be fully a part of our family and our community. The Model Waiver is a home and community based waiver. In Maryland, we are fortunate to have through this program care coordination through The Coordinating Center to

help us with eligibility not only for the waiver program, but also for access to a variety of community supports that have meant so much to me in my efforts to provide him with a good quality of life. Currently, Ellington attends Longview School in Germantown, Maryland where we live. His school program, like his health plan, is individualized to his needs – which are considerable. As his mother, I have significant input into the planning and implementation of his program. The services that he receives include care and service coordination, private duty nursing, respite services, and school-based occupational, speech and language, physical therapy, and vocational services.

In plotting the course for what I hope to be a seamless transition, I am striving to address not only his immediate needs, but also to lay the foundation for the support of long-term life goals. It is my dream, hope, and expectation that Ellington will have the opportunity to do the following:

(1) Participate fully in community life. Community life is independent living in the community of his choice with a roommate of his choice, access to community resources that are available to all individuals, participation in community activities that allow for social interactions and can foster the development of new relationships, and securing supportive employment that would allow him to give back to the community. Today Ellington enjoys times out in the community whether it's shopping at the local grocery, trips to the shopping mall, strolls in the community, attending family and friend gatherings, his regular appointments to the barber, going to the movies or attending church worship service. He thrives from the experience and exposure. I can not contemplate the idea that my son would not have this option, that he would be considered for a facility or institution, or would not have the freedom to make his own choices in life. Next is

(2) To receive funded quality support services backed by service providers that are adequately compensated; certified; educated enough about across-public agency funding and private funding resources that will maximize use of all available resources without jeopardizing his needed benefits; that are well trained in quality assurance and compliance monitoring federal and state regulation and guidelines; and operate with the understanding that all people are

valued – those needing the supports and those helping to provide it. Ellington at birth was given up to five years to survive with no assurance of what his progress or accomplishments would be. I think his appearance here today is testament to the value of quality support services.

One of the major issues that concern me – especially since Ellington has come so far -- is the fact that there is a dearth of expert attendant care providers who have little or no training in the diverse needs of the consumers they serve, and poor compensation for people who provide such a necessary service to the most vulnerable among us. With this being said, I ask myself are my goals reasonable and obtainable, taking into consideration Ellington's, multiple disabilities and daily support needs? And the answer is yes, yes. However, listening to the buzz around current state and federal disability issues and the voices of family members and service providers, I have developed real fears about whether the innovative support systems put in place over the last decade or so will accommodate him.

- Will there be the necessary changes in response to increased enrollment due to families' willingness to offer independence to their children?
- Will there be a track record of program successes and failures leading to new best practices designed for young people like my son?
- Will housing, accessible and affordable, be available for him?
- Will the changing perspective of the major players in long term care financing (federal and state government) give up on the notions of choice, inclusion, and independence? Will they find these ideas too challenging to put in place, despite the fact that maintaining this philosophical approach can truly save cost while doing the right thing for people with complex needs and disability?
- And what about the families, the self advocates and the advocacy organizations --- will they be able to stand firm for the fundamental rights of all people with disabilities?

The concerns that I bring to this committee today are:

(1) Inadequate compensation and training for direct care staff resulting in an increased chance of hiring unqualified staff and incidences negatively affecting the health and safety of the individual in their care;
(2) On-going struggles to build capacity for inclusion of individuals with disabilities in the community resulting in families making undesirable placement decisions, such as in nursing homes or assisted living facilities;
(3) The tremendous tasks of navigating a system that is highly complex, confusing, and often intimidating;
(4) Some programs income and asset restrictions that can prevent an individual's access to appropriate services.
(5) Supportive Employment and other community support services that must be expanded and adequately funded so that the individual – with the right supports – will be ultimately successful and achieve as best as he/she can.
(6) Day Programs that are essentially day care for adults that offer little besides supervision, when people attending the program need to get meaningful services to build on the skills that they have and provide them with community experiences to enhance there lives.

In closing, I urge you to examine the long term care system as it currently exists carefully. Like so many aspects of health care in the United States, it is fragmented and often managed by people who are not committed to the principles that people with disabilities have fought for long and hard. These principles include the ideas

- That home is better than a nursing home
- That people with disabilities are best able to articulate their needs, their desires, their aspirations
- That even those individuals most affected by chronic illnesses and disabilities have skills and gifts that are theirs alone to give
- That there is no disability that is too severe to keep people away from their homes, community, and families when the appropriate supports are provided

- That there is no one who can't benefit from being respected, from being included, from being valued, from being loved.

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