



AACPD

2016 Annual Meeting
General Session Lay Summary
Thursday, September 22, 2016 - Afternoon General Session

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Richard Ellenson, CEO of the Cerebral Palsy Foundation, gave update of the Foundation's work including the success of the "Just Say Hi" campaign, its partnerships other organizations, and the expansion of their scientific advisory council.

Donna Thomson, an author and consultant on issues of family caregiving, gave the Chambers Family Lifespan Lectureship entitled *After 27 Years of Treatment: A Report Card on Developmental Medicine From a Consumer*, which detailed her journey in caregiving for her son with cerebral palsy. Her story began from the diagnosis of her son's cerebral palsy and then flowed to her experience working with different care teams over the years. Their family's journey crossed periods of hope and help, as well as despair and dependency. Ms. Thomson highlighted that a family narrative evolves from acceptance of the diagnosis in the earliest years to then focusing on the child's health, function, and ability to be part of society. Finally, she concluded, all parents will ask themselves what will happen to their grown child after they pass away. Ms. Thomson encouraged health care providers to engage families in understanding their child's disability, clarify goals for the child's treatment, and most importantly, express kindness to families taking care of children with disabilities.

Michele Shusterman, founder of the non-profit CP NOW, was awarded the Making a Difference Award and gave a presentation entitled *From Chaos to Cohesion: Making Sense of Cerebral Palsy for Caregivers*. She emphasized how parents want to be armed with information and support to support their child instead of having to uncover conditions they are not prepared to understand or address. When parents are educated about common issues associated with cerebral palsy, they can be proactive about treatment and better prepared. Ms. Shusterman outlined how her organization's CP Tool Kit provides a framework for understanding the diagnosis of cerebral palsy and helps families anticipate the effect of their child's condition on their life. The CP Tool Kit humanizes the condition of CP and shares the stories of many children and adults with CP, and by doing so, educates parents so they can engage the medical system to advocate for their children.