

Oral Public Comments

**IACC Full Committee
Meeting**

January 13, 2017

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Note: Personally Identifiable Information (PII) has been redacted in this document

Patricia Swanson

January 13, 2017



Andrew and Benjamin Swanson

My name is Pat Swanson and I would like to thank you for allowing me to testify before you today. I am the proud parent of 26 year old identical twin boys. Andrew is an adult with autism. His brother Ben is neuro typical. When Andrew was diagnosed at age 2, we embarked on a pathway of extensive therapies to help him meet the same developmental milestones as his brother. Moving through life, we started to accept that Andrew's life would have limitations and at age 12 made the decision to remove him from an academic track into a functional life skills program. This was an extremely painful decision that made us feel as if we had given up on Andrew. Despite our feelings, we somehow knew that this was best for him. In this environment, Andrew not only flourished and met kids he could finally consider friends, he became a content and happy young boy. It became clear that our choice was in reality ANDREW'S choice and that for us to continue to assist him in making correct choices we had to accept the realities of his disability.

I have parented identical twin boys. Now that they are grown, the least restrictive and most appropriate environment for these two young men is literally worlds apart. Ben lives and works in China and has mastered the language. I would give all that I own to have Andrew capable of this life. But, I have had to accept his limitations and reality: he will need help for the rest of his life. I will never give up on what my

son's potential can be. However, have to accept that there are things he will never do. I must accept that despite what I want for him, I can no more change his intellectual capabilities than a parent of a paralyzed child can ask that child to get up out of their wheelchair and walk. This is not the way I think out of fear or for ease of my own life. I am his mother. This is what I know.

There are those with autism who are not as disabled as my son and they can and should speak for themselves. In developing policies for the future of ALL individuals with autism we must hear all voices. I am Andrew's voice. Andrew still lives at home with us and has expressed in his own way his desire to be on his own. I can be seduced by the ideal of total inclusion for Andrew. But, I learned the reality of what is best for him years ago and obtaining this dream for him is dependent on the proper supports. As an almost 60 year old parent my obvious questions are: will Andrew be able to find his place before I die and when I am gone, who will know him well enough to truly speak for him?

I would urge this group to consider the wide range of abilities and interests of this population. I see though that many policies and attitudes limit the options for our adult family members with autism. Sometimes broad strokes may be needed and be what is necessary for policy. However, broad strokes can also have the opposite effect by not taking into consideration the complexity of autism. Those policies in housing, funding and research can harm our loved ones and become impediments to successful life. Please be thoughtful and recognize the vast needs of adults and target efforts of this committee to opening and not closing off solutions that form meaningful lives.

I should be and want to be excited about the future for those with autism. We are in a time of great change that holds unlimited potential for positive movement forward. But, I am extremely concerned about the future of many individuals with autism and their families. The goal of full inclusion for ALL may ultimately isolate and exclude many. The disabilities world mirrors the mainstream in requiring a range of needs and wants and the right to have a full menu of choices to meet these. People should not be shut out because they cannot express themselves. One voice in this community cannot speak for everyone. Since I am Andrew's voice, I can say with great confidence that he thanks you for listening to me today.

Pat Swanson
[PII redacted]
Wilmington, DE [PII redacted]