National Institute of Child Health and Human Development Scientific Colloquium

Reflections: 50 Years of Scientific Accomplishments

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Chairman & CEO
Special Olympics

December 5, 2012
The National Institutes of Health
Camp Shriver
“In the mid-1950’s, NIMH (National Institute of Mental Health) staff (at the National Institutes of Health) privately doubted if as much as $250,000 could be spent on a subject as unglamorous as mental retardation.”

-Dr. Elizabeth M. Boggs
Founder, The National Center for Retarded Children
Dr. Robert E. Cooke: When Dr. Cooke and his wife tried to adopt a child, “We were told, in writing, that we were unfit parents because we had retarded children in our home,” he recalls. “That was a blow that I’ve never forgotten.”

-Dr. Robert Cooke

• Director, Department of Pediatrics, John Hopkins Medicine, John Hopkins University, 1956 - 1973
• Director, Kennedy Program for Research into the Etiology of Mental Retardation
• First Director, Kennedy Institute for Handicapped Children
President John F. Kennedy

“This legislation will encourage imaginative research into the complex processes of human development from conception to old age.”

- President John F. Kennedy at the signing of the bill authorizing the NICHD
In The White House, President John F. Kennedy greeting a child with PKU.

- From the film Life In The Shadows: John Kennedy’s Fight for Persons With Mental Retardation
A film by Charles Guggenheim (4-time Academy Award-winner) – copyright 1999
A Call to Action
The “R” Word …
A Call to Action

What has changed, what has not changed?

“James” ... before ... and ... after!
50 years from today, where do we want to be?

- Will we be content to know so little about the quality of life of people with intellectual disability - about satisfaction, happiness, community engagement and belonging?
- Will we be content to have children with intellectual disabilities still be fifth-class citizens when it comes to research protocols?
- Will we be content when huge percentages of children with intellectual disabilities experience disproportionate rates of hearing loss, oral pain, heart disorders, loneliness, and depression?
- Will we be satisfied if there are 102 treatment trials in the U.S. for Alzheimer’s disease, yet there are no ongoing treatment trials that include adults with Down syndrome and dementia?
- Will we be satisfied if while 17% of children and adolescents in the U.S. are overweight or obese, the rates are 38% higher in children and youth with disabilities?
Conclusion

“Joyful and triumphant!”