

Rose F. Kennedy University Center For Excellence in Developmental Disabilities (RFK UCEDD)



***“The Art of Networking, Coalition
Building, Hearing Our Voices and
Never Giving Up”***



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ADVOCACY

When the going gets tough , the tough get going...

There are no disclosures to be made by any presenter.

PRESENTATION GOALS

1. Provide a Brief History of Advocacy
2. Explore the Nature of Advocacy through Individual, Group and Community Efforts that include, grassroots efforts such as rallies, letter writing, legislative education, working with legislators, legal efforts
3. When Advocacy Is Successful, When It Fails
4. The Future: Where Does Advocacy Go From Here

NEW YORK HISTORY

- 1880-1950 from Work Farms to Large Institutions
- 1950's Anne Greenburg – Parent Places An Ad In The New York Post Seeking Support Of Other Mothers Who Were Raising Children With Intellectual Disabilities – Form AHRC
- Precursor of the Rose F Kennedy Children's Evaluation and Rehabilitation Center- starts as an Interdisciplinary Service For Children With Cerebral Palsy in Department of Rehabilitation And Pediatrics

“OUR VOICES COUNT”

Video celebrating SANYS first self-advocacy conference narrated by Geraldo Rivera

Shows scenes from Willowbrook and highlights the importance of self-advocacy through the perspective of Bernard Carabello, self-advocate who let the camera crew into Willowbrook so the world could see...

1960's

- 1961 President Kennedy authorizes Panel on “Mental Retardation” to study the clinical, institutional, education and habilitation, law and public education, biological and social research and coordination of these efforts.
- 1962 Committee report issues a Call to Action for expanded services
- 1963 Public Law 88-164 Under President Kennedy- authorizes Federal Funding To Develop “MRC” Centers under the “Mental Retardation and Facilities and Community Mental Health Center Construction Act
- 1965 Robert F Kennedy Visits Willowbrook And Pronounces It As A “Snake Pit”. New York State Given 5 Years To Improve Conditions In Willowbrook
- Bronx Parents Begin To Advocate For More Services

“LADIES IN RED”

Video Chronicles The Efforts Of 5 Mothers From The Bronx Whose Advocacy Helped Shape Integrated Community Services For Children And Adults With Intellectual And Developmental Disabilities

<http://einstein.yu.edu/centers/childrens-evaluation-rehabilitation/rose-f-kennedy-ucedd/>

1970's

- 1972 Geraldo Rivera goes into Willowbrook and tour it with Bernard Carabello. Appalling conditions remain. Parents file class action lawsuit.
- 1975 – Willowbrook Consent Decree – Court orders Willowbrook to “ready residents... for a life in the community.”
- 1975 IDEA – Individuals with Disabilities Act guarantees the right to a public education for all children through 21 years of age

1970's Continued

- 1975 Bronx Developmental Services – Headed By Herbert Cohen, MD Community Service Teams, Providing Case Management And Services In Small Store Front Locations
- 1976 Advocacy Services Begin To Develop With First Self-advocacy Group In New York State, Bronx Community Self-advocacy Group (HAND OUT) Peer to Peer Support, empowerment
- 1977 Sundheimer vs Barbara Blum and James Introne – Family Support lawsuit for equal protection for families living in the community
- 1978 - Bronx Developmental Disabilities Council Is Formed - A Coalition Of Parent/Caretakers, Voluntary Agency Providers And State And Local Governmental Organizations To Plan And Develop Services To Meet The Needs Of Persons With IDD

1970 Coalition Building

Bronx DD Council

Interagency Council of New York City

NYS Developmental Disabilities Planning
Council

NYS OPWDD

NYCDOHMH – Federation formed to plan
for services based on need

1980's

- Services Begin To Expand Tremendously Due To Deinstitutionalization
- Special Education Services Within Public Schools Begin To Develop And Expand
- Self Advocacy Movement Which Begin In The 1970's Begin To Take Hold – “Our Voices Count”

1990's

- 1990 ADA – Americans With Disabilities Act – Prohibits Discrimination Of Individuals With Disabilities In All Areas Of Life, Employment, Jobs, Schools, Transportation, Public Accommodations, And Communications
- People First Language Begins To Be Adopted

LOCAL ACTIVITIES

1990 BEGINNING OF MEDICAID CUTS

- City Hall Rally & 1994 City Council Public Testimony against cuts to NYC funding
- 1996 Durable Medical Assistance – Closure of NYS Office results in delays and cuts to DME equipment – 600 letters sent to voice outrage over cuts results in NYS Legislative Oversight Hearing-Report Issued in 2006 – “Delaying Necessities, Denying Needs”
- Annual State and Local Service Plans
- Annual Legislative Reports and Public Meetings to address Service Needs
- 2017 Rally in Albany for Direct Support Staff Salaries, Clinical & Early Intervention Services, Pre-school Program

LEGISLATIVE INVESTIGATION REPORT: DELAYING NECESSITIES, DENYING NEEDS

<http://assembly.state.ny.us/comm/Oversight/20060726/report.pdf>

DELAYING

NECESSITIES

DENYING

NEEDS

An Assembly Investigation of New York State's
Handling of Medicaid Durable Medical Equipment Claims.

[Click here to view the report as a pdf document.](#)



SAM HOYT
Chair, Committee on Oversight,
Analysis and Investigation

JAMES BRENNAN
Former Chair, Committee on Oversight,
Analysis and Investigation



JULY 2006

RICHARD N. GOTTFRIED
Chair, Committee on Health

AMY PAULIN
Chair, Task Force on People
with Disabilities

DANIELLE LANZETTA

SELF-ADVOCATE

- Battle with Board of Education for appropriate educational settings
- Problems with bullying
- Social isolation
- Petition Board of Education for a transfer to a more appropriate educational facility – Henry Viscardi (1989) – documentation to prove level competency

- 2000 Danielle graduates Henry Viscardi HS at age 21.
- Services discontinue as Danielle enters the adult service system.
- Danielle is unable to find support services such as OT, PT, dentistry and nutrition as well as physiatry. She is cut off from professionals that her understand her needs as a person with cerebral palsy.
- Adult clinical settings had no knowledge of how to treat people with chronic long-term disabilities, particularly cerebral palsy

- 2001 Petition Dr. Cohen to extend clinical services to young adults at RFK UCEDD (also Sen. Hillary Clinton)
- Public Presentations to support Durable Medical Equipment and clinical service needs
- Video – Hear Our Voices

HEAR OUR VOICES

- VIDEO - 2016 for legislators - Bronx DD Council partnership
- 12 years of slow reductions in clinical services
- Services in the home
- Early Intervention Services – staff shortage
- Adult living at home complex chronic health care needs – training in home staff

<http://einstein.yu.edu/centers/childrens-evaluation-rehabilitation/rose-f-kennedy-ucedd/>

Hear Our Voices: A Parent's Perspective

Veronica Arias

Interviewed by Diana Rodriguez, LMSW

Who
is
Veronica?



Jesus



Age

Grade

Best Characteristics

Diagnoses

Interventions

Stephanie



Age

Grade

Best Characteristics

Diagnoses

Interventions

https://youtu.be/-Yt_4qQutZg

Parenting and Advocating for Children with Special Needs

- Educational system
- Home services

What Does the Future Hold?

The Struggle Continues

QUESTIONS?

Thanks to All of Our Families For Lifting
Their Voices So That All Can Be Heard!