

CITY COUNCIL
CITY OF NEW YORK

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TRANSCRIPT OF THE MINUTES

Of the

COMMITTEE ON MENTAL HEALTH, DEVELOPMENTAL DISABILITY,
ALCOHOLISM, DRUG ABUSE AND DISABILITY SERVICES

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September 17, 2013

Start: 1:13 p.m.

Recess: 1:25 p.m.

HELD AT: 250 Broadway - Committee Rm.
14th Fl.

B E F O R E: G. Oliver Koppell
Chairperson

COUNCIL MEMBERS:
G. Oliver Koppell
Ruben Wills
David G. Greenfield

A P P E A R A N C E S (CONTINUED)

Julie Savaois:

National Down Syndrome Society

1	COMMITTEE ON MENTAL HEALTH	3
2	COUNCIL MEMBER KOPPELL: I'm Council	
3	Member Oliver Koppell. I'm Chair of the Committee on	
4	Mental Health, Developmental Disabilities,	
5	Alcoholism, Drug Abuse and Disability Services.	
6	We're here this afternoon because the requirements	
7	are that we hold a hearing on every bill and every	
8	resolution. This is a resolution calling on the	
9	Congress to enact and the President to sign Senate	
10	313, House 647, The Achieving a Better Life	
11	Experience Able Act of 2013, which amends the	
12	internal revenue code to provide for the tax	
13	treatment of able accounts established under state	
14	programs for the care of family members with	
15	disabilities and other purposes. These accounts	
16	would be similar to the Supplemental Needs Trust,	
17	which can be established under current law, but this	
18	is a simplified procedure that doesn't require the	
19	setting up of a special trust account. We have some	
20	numbers that I'll put in the record. In New York	
21	City there are approximately 887,219 individuals with	
22	disabilities, as much as 11 percent of the	
23	population. 183,000 individuals have serious hearing	
24	difficulties. 210,000 have vision difficulties.	
25	535,000 have difficulty walking or climbing stairs,	

and there's an estimate that we have 60,000 wheel chair users in the City. Unfortunately those with disabilities are much more likely to live in poverty, and the results from a 2006 American Community survey revealed significant disparities in the median income of those with and without disabilities. Median earnings for people with no disability were over 28,000 compared to 17,000 median income for individuals with a disability. The Able Act would assist individuals with disabilities by establishing tax advantaged accounts into which contributions could be made to pay for qualified expenses of the accounts beneficiary. Such expenses could include tuition, housing, transportation, technology or other needs related to the individual's disability. I believe that the passage of the Able Act would benefit people with disabilities and their families by giving them a way of paying for these expenses without effecting their eligibility for government benefits and also establishing accounts that would not result in taxation. I'm delighted to have been joined by Ruben Wills, to my right, and we might expect two other members of 'mittee to join us. I want to thank Jennifer Wilcox to my left, and Michael

Benjamin for their work on this and also Drew Gabriel who is on my staff and now is working on Committee matters since we've lost our previous Counsel for reasons that are fairly clear. So the--I got a copy of the House Bill, and I might note it has many sponsors, and I'm hopeful that the Congress will Act, although, expecting the Congress to act on anything I think is optimistic. But this seems to be something that really ought to go through. It's to benefit of many many families. While it may cost a little bit of revenue, it certainly seems to me it's worthwhile. So, we have one person so far to testify, Julie Savaivos [phonetic] who's from the National Down Syndrome Society. Could you come forward and sit over here please. Okay, can we start? Okay. Please.

JULIE SAVAIOS: Hi, I'm Julie Savaivos. I'm from the National Down Syndrome Society, and I'm here to testify as the proud mother of my daughter Nina Savaivos. She is four years old and happens to have Down Syndrome. Our organization commends the Committee, the New York City Council Committee on Mental Health, Developmental Disability, Alcoholism, Drug Abuse and Disability Services for holding today's hearing and joining along side the NDSS in

efforts to call upon the United States Congress to enact and the President to sign the Achieving a Better Life Experience Act of 2013. My dream for my daughter Nina is that when she transitions from school to working, she will do something she excels at and give back to the community and that she's paid for her work, that she can go to the bank and deposit her check into her account without fearing that she'll lose much needed benefits that support her health and well-being. Everyone wants to earn a living and be independent, and every parents wants to help his child do so. While Nina is only in Kindergarten today, I have absolutely no doubt that she'll graduate from high school with a typical diploma and attend some sort of post-secondary program to help her learn more and get a job, but because she can lose necessary and valuable Medicaid and Social Security support she'll need at various stages of her life for several reasons, I'm scared to even open a bank account with birthday money in it. She can't have more than 2,000 dollars to her name or she'll lose those benefits. Our family can't save in her name, which is demeaning and heartbreaking, not to mention bad financial policy. We have no tax-free

method of saving for her education or her other expenses including housing, transportation, and health expenses, even though we have a 520 for her brother. If I have to choose, I would rather have it for her. It's a strange situation because she's very healthy and she's included in school and she's doing well, but she still needs support and special programs, and we'll need those throughout her life. It doesn't mean she can't do things, but she needs help and help costs money. It's only fair that as a family we can save for her in her name for her expenses and have the same tax advantages that other families have for more typical children. She might well be fine health-wise all the way until adulthood, but 80 percent of adults with Down Syndrome get dementia along with other health issues, so I would not be comfortable not having Medicaid and Social Security to help me, and it shouldn't be a choice between being totally reliant on government benefits and being totally independent and paying the whole way for very costly assistance needed during her life span. As a family, we need a way to save for her under her name without losing benefits, and we need and have the right to be as independent as possible

1 saving and paying for things we need while still
2 having support. The Able Act makes it fair that like
3 I do for my son, I can save for her expenses tax-free
4 without being penalized by losing support. There's
5 no reason she has to be poverty stricken to have
6 support. While this is my story, we have stories
7 from all over the country with individuals with
8 disabilities and their families that could secure
9 more financial independence and individuals with
10 disabilities who could have more options for
11 employment. There's no other piece of legislation
12 before the US Congress today that has this much
13 bipartisan and bicameral support. As you likely
14 know, the Able Act has 256 co-sponsors in the House,
15 44 co-sponsors in the Senate, and these amount to
16 over 50 percent of the entire US Congress. Able Act
17 is a sound piece of policy that will positively
18 impact all people with disabilities in the United
19 States, and our organization is committed to seeing
20 the Able Act enacted into law this year. We've been
21 at it for seven years. So, hoping this is the one.
22 Again, thank you for convening today's hearing, and
23 we praise the Committee for its leadership on behalf
24 of people with Down Syndrome and other disabilities.
25

COUNCIL MEMBER KOPPELL: Thank you.

We've been joined by David Greenfield; welcome. And I know I--are you a lawyer or a tax expert?

JULIE SAVAIOS: No, I am not.

COUNCIL MEMBER KOPPELL: Okay, so I don't want to--I want to belabor the point, but I was wondering if you could contrast these Able accounts with the Supplemental Needs Trust that many people have established now. Do you know the differences?

JULIE SAVAIOS: What I do know from personal experience for looking into establishing a trust is that they're very expensive. So there's I think I've heard quote around 5,000 dollars. They're definitely several thousand dollars to get an expert lawyer--

COUNCIL MEMBER KOPPELL: [interposing]
Right.

JULIE SAVAIOS: who knows the very fine ins and outs of Special Needs Trust, very specific trust that has to be written up the right way, and that way then you can save, but that's a hefty price--
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COUNCIL MEMBER KOPPELL: [interposing]
Yeah.

JULIE SAVAIOS: of something even though I do earn a living and everything I'm putting that off because it's a large expense.

COUNCIL MEMBER KOPPELL: You'd also have to have a trustee and some other--

JULIE SAVAIOS: [interposing] Yeah, it's a bit complicated, right.

COUNCIL MEMBER KOPPELL: Although, I think I was just--I guess as a lawyer I was curious as how--this seems like a good idea. It's very simple and as you point out, I think it is very important we now have these college savings accounts that allow you to put money away for children's college education on a, you know, with a tax benefit that you don't pay tax on it.

JULIE SAVAIOS: Right.

COUNCIL MEMBER KOPPELL: And there's no reason why this kind of account shouldn't be also available to those who may be not able to go to college or who have obviously additional special needs. Well, I hope you get the Congress to act. We'll send--I think it's our practice in the Council to send copies of these resolutions to all members of Congress from New York, the Senators--

JULIE SAVAIOIS: [interposing] Oh, great.

COUNCIL MEMBER KOPPELL: And I am
confident that it'll pass. Does anyone else have any
questions?

COUNCIL MEMBER WILLS: Yes, I just--I
don't have a question. I just have a comment. I
think that you showed a lot of courage coming to
testify for something that is not as an attractive
issue to most people, and you've highlighted the
actual pains that this, the barriers that you've had
to undergo, and this is underscored by I'm sure
hundreds of thousands of people in the US. So I want
to thank you for that, and I wanted to ask the Chair
to make sure that my name is added to this
resolution.

COUNCIL MEMBER KOPPELL: Oh, absolutely,
sure.

JULIE SAVAIOIS: Thank you very much.

COUNCIL MEMBER KOPPELL: Sure.

COUNCIL MEMBER GREENFIELD: I too, Mr.
Chairman, will add my name. I want to thank Julie
for coming out here, and I'm hopeful that we can get
this signed into law before she starts elementary
school.

COUNCIL MEMBER KOPPELL: We also have several statements that were submitted, and I want to ask that those statements be added to the record. Is anybody else here to testify? If there isn't, we want to thank you for coming again. I appreciate; it's always, I think, hard for people to come and talk about the difficulties that their family has faced, but it's very important for us to have a persona perspective on these things. And we'll move the resolution right along.

JULIE SAVAOIS: Thank you. Thank you.

COUNCIL MEMBER KOPPELL: So with that--

JULIE SAVAOIS: [interposing] It's nice to see this in process of how things work.

COUNCIL MEMBER KOPPELL: We'll move it along.

JULIE SAVAIOS: Thank you.

COUNCIL MEMBER KOPPELL: And there being no one else to testify, the hearing's adjourned.

[gavel]

C E R T I F I C A T E

World Wide Dictation certifies that the foregoing transcript is a true and accurate record of the proceedings. We further certify that there is no relation to any of the parties to this action by blood or marriage, and that there is interest in the outcome of this matter.



Date 09/24/2013