

Law, Love and Money

I'm Jim Karpe, and I'm worried. I am the father of two special needs teenagers¹. I am worried about, once they get out of school, what will they do all day? I have come to learn that the answer is: Olmstead. And so I am going to talk to you today about Law, Love and Money.

Service delivery in New York State is going through a major transformation. The driving force behind that transformation is Olmstead, a Supreme Court decision. Olmstead happened because of Lois Curtis. Lois did not need to make any decisions about what she did all day-- because she was held against her will in a state mental hospital. After her doctor said that she could be released. Lois Curtis was held against her will for three years.

Her lawyer got Lois released from the mental hospital. And she went to court, and said "I don't want this to happen to me again." The Supreme Court agreed with her. Specifically, six of the justices agreed, and the result is Olmstead.

The State is not allowed to discriminate against people with disabilities. And the Supreme Court decision was, "Unjustified isolation ... is ... discrimination." Here's what you need to know about Olmstead. The court said: You have to let me live and work in the community-- but only if you say I am ready, and only if I agree.²

Olmstead is a wonderful thing. Because of Olmstead, New York State is now transforming the way services are getting delivered. The emphasis has shifted to community placement, which is great. And, there is a danger here. In the scramble to obey Olmstead, New York State has forgotten about the obligation to care for those who are not ready.

So, let's remind them. You have to let me live and work in the community-- if I am ready, and if I agree. How do I know that the State has forgotten that part? Easy: They have scheduled the shut down of **all** sheltered workshops, where eight thousand people now work. And the State itself says that half of those people are not ready for community placement. Here is what the Supreme Court had to say about that:

"We emphasize that nothing in the ADA . . . condones termination of institutional settings for persons unable to handle . . . community settings."

"ADA . . . [does not force] States to phase out institutions, placing patients in need of close care at risk. . . ."³

The Office of People With Developmental Disabilities has invited the public to comment on their transformation plan. I urge all of the parents in this room, all of the self-advocates, all of the professionals to send them an email. Remind them of what the Supreme Court said about community placement: Only if I am ready, and only if I agree. Get your comments in before the end of March. And if they do not listen to our emails, then they will have to listen to us in court.

That covers Law. Now, on to Love and Money. To move on, I need to introduce you to Eric Doughty.

Eric is blind, autistic and has Tourettes. He shouts out excerpts from "New York, New York". And Eric has someplace to go each day. He works at a nursing home, setting up the dining hall and washing dishes. Eric is blind. It took a lot of "wrap around services" for Eric to get there. By "wrap around" I mean equal parts love, and money. Eric's family advocated for him, pushed and shoved to make this

happen. Eric learned his dishwashing skills in a sheltered workshop, and practiced them there for a year before starting to work at the nursing home. And Eric gets support from paid Direct Service Professionals who help him get to the job and support him on the job.

Eric's story is amazing. And this year he celebrates 24 years of working at that nursing home. 24 years. He started in 1991. This is a tremendous success story.

We want more Eric Doughtys. To get there, we need funds. Because we already have the love. We have parents who love their adult children. We have adults with disability who would love to be productive, integrated members of their society. We need the money to help Eric find the job that fits him, money for transportation, money for people to help Eric learn, and to support him on the job. The good news for the accountants is that community placement is less expensive than institutionalization. We could lock Eric up somewhere. It actually takes less money to provide Eric with a housing subsidy and with Direct Service Professionals. But it does take money.

Eric Doughty has lived and worked in the community for 24 years, with support. Lois Curtis has now spent 17 years living in the community, with support. We need to help more people like Eric and like Lois. We already have the love, we already have the law. We need the money. Money that will allow us to meet the ordinary needs of special people. We need the money this year, and next, and next.

So, let me recap it for you. What do I want you to do today?

If you are a parent, I want you to comment on the OPWDD transformation plan. Your comment can be as simple as: **Yes, community placement. But only if I am ready, and only if I agree.**⁴

If you are a legislator, I want you to approve the increases in the current budget, which will help some of those who are ready to make the shift to community placement. \$3 million will create 1000 new opportunities for Supported Employment. And I want you to remember Eric Doughty, and provide the funding to create more Erics in 2016 and 2017 and 2018....

¹ Jim Karpe is the Parent Co-Chair of Queens Council for Developmental Disabilities. He is also a member of a recently formed advocacy group, NYC Family Advocacy and Information Resource. www.nycfamilyadvocacyinformationresource.org

² See "Opinion" under www.law.cornell.edu/supct/html/98-536.ZS.html
The anti-discrimination provision of ADA "may require" placing people with "disabilities in community settings rather than in institutions" whenever "treatment professionals have determined that community placement is appropriate" and "transfer from institutional care ... is not opposed by the ... individual".

³ Direct quotes from "Opinion" under www.law.cornell.edu/supct/html/98-536.ZS.html

⁴ The primary state agency responsible for providing and overseeing service, Office of People With Developmental Disabilities (OPWDD), has asked for public comment on the transformation plan during the month of March. www.gcddny.org/wp-content/uploads/2015/03/What-is-at-stake-in-OPWDD-Transformation.pdf

You can submit your comments at any time before April 1, 2015.

quality@opwdd.ny.gov

With subject line: HCBS Settings Transition Plan comments

-or-

OPWDD Attention: DQI HCBS Settings

44 Holland Avenue, 4th Floor

Albany, New York 12229