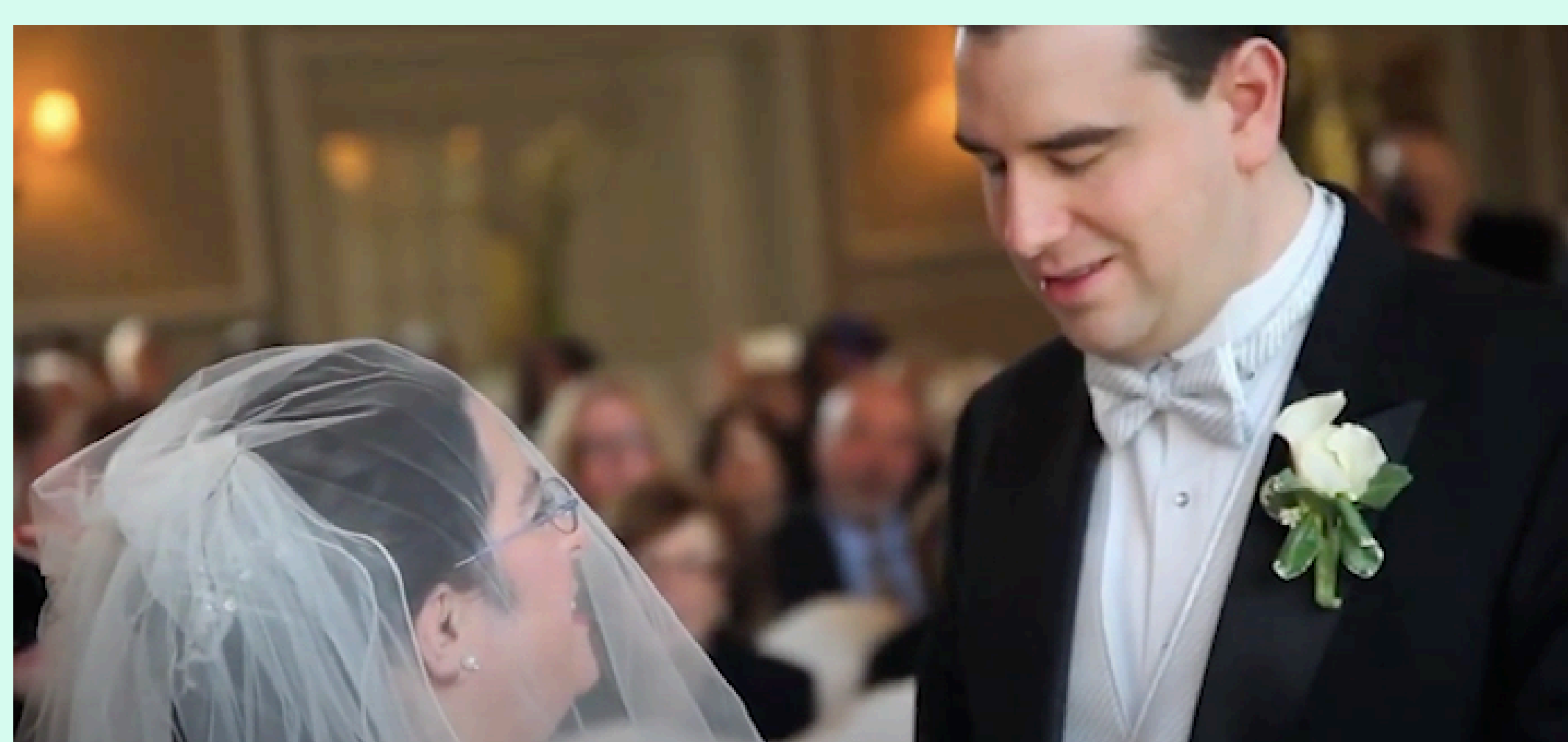


GOOD AND NOT-SO-GOOD NEWS, THREE EMAILS AND A MEETING: AN AFFIRMATION, AN OPPORTUNITY, AND A CAUSE FOR CONCERN

A while ago we attended a meeting of CUNY Disability Scholars and learned of an opportunity we thought might interest our community. Then, this week, we received three emails all from different sources, on apparently different subjects, but all, it turns out, connected. So, first, the **AFFIRMATION**.

Our initial grant came from the NYS Developmental Disabilities Planning Council (DDPC). Without DDPC (now the NYS Council on Developmental Disabilities [CDD]) none of what we have been accomplished would ever have happened. This week CDD emailed to celebrate National Disability Awareness Month. They attached a wonderful video about two people with developmental disabilities, Paul and Hava, who fell in love and wanted to marry. Assisted by their supportive parents, Paul and Hava overcame many obstacles to living together “happily ever after.” The video affirms not only their right to *decide* to marry, but to *implement* their decision by finding supported housing where they could (and still do) live together as husband and wife. That’s the affirmation–of everyone’s right to marry the person they love, and to live with them, regardless of disability. To view the video, [click here](#). Next, the **OPPORTUNITY**.



Hava and Paul at their wedding

A major obstacle to Paul and Hava’s housing problem was the unwillingness of providers to accept them unless they could demonstrate the “necessary understanding of sexuality and sexual consent” assessed by a “pass-fail test (NOT an assessment) the Socio-Sexual Knowledge and Attitudes Test (SSKAAT). They had never been taught about the subject so they couldn’t pass the “test”, highlighting the lack of adequate and appropriate education about sex and intimacy for people with I/DD.

At the Disability Scholars event we learned about a research project, STEPS2 Health Education, at the CUNY School of Public Health that is piloting and evaluating two excellent (and free) “courses”, on intimacy and sexuality, and on health more generally. We think that, for Decision-Makers who want support in either of those areas, the courses could be enormously useful. When we went to the project website, we found a video describing the project, including an enthusiastic endorsement from SDMNY Decision-Maker Oscar (Good News 1/28/22). Small world! To see the video and learn more about the project, [click here](#). And, finally the **CAUSE FOR CONCERN**.



Oscar

In this complicated time of budget cuts and government reorganization, there have been rumors about the possible closing of the Administration for Community Living (ACL) an agency within the Department of Health and Human Services (HHS) responsible for funding programs important to inclusive living including the DD Councils–our CDD– and Protection and Advocacy (P&A) agencies in every state; the P&A in New York is our partner Disability Rights New York (DRNY). Unfortunately, that rumor is true, according to an email this week ([click here](#)). An email from our friends at ASAN (the Autism Self-Advocacy Network) details the ACL dissolution and more changes to programs for people with I/DD, and, importantly, provides steps that concerned families can take to express their views ([click here](#)).

The work we have done and continue advances and affirms the rights of all people to make their own decisions, and to find and form loving relationships regardless of disability. Advancing and protecting those rights depends on support: from trusted persons in their lives, like Paul and Hava’s families, but also from government, which provides the services, from CDD grants to pilot programs; SDM facilitation; ACL; and other agencies that provide education and healthcare to people with disabilities.

AFFIRMING RIGHTS AND CREATING OPPORTUNITIES REQUIRE CONTINUING ATTENTION, CONCERN AND ACTION!