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Testimony of the New York Civil Liberties Union
Before the Joint Legislative Budget Hearing on Health

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The New York Civil Liberties Union (NYCLU) is grateful for the opportunity to submit the following testimony for the Joint Legislative Budget Hearing on Health. The NYCLU, the New York state affiliate of the American Civil Liberties Union, is a not-for-profit, nonpartisan organization with eight offices across the state and over 180,000 members and supporters. The NYCLU defends and promotes the fundamental principles and values embodied in the Bill of Rights, the U.S. Constitution, and the New York Constitution through an integrated program of litigation, legislative advocacy, public education, and community organizing. As the legal arm of New York's reproductive rights movement, the NYCLU strives to ensure that New York remains a beacon for bodily autonomy and the full range of reproductive rights, from access to abortion care to birth justice. And, as class counsel in the Willowbrook case,[1] the NYCLU advocates for the rights of New Yorkers with intellectual and developmental disabilities (I/DD) to quality services provided in the least restrictive setting appropriate to their needs.

I. Access to Reproductive Health Care

In June 2022, the Supreme Court overturned *Roe v. Wade*, ending the federal constitutional right to abortion. In the wake of the *Dobbs* decision, nearly half of the states are poised to completely ban abortion[2] – and many already have.[3] Nationwide, at least 66 clinics have stopped providing abortion care since the *Dobbs* decision, and 26 have shut down

[1] The NYCLU is lead class counsel in the Willowbrook class action litigation that was filed 50 years ago in the United States District Court for the Eastern District of New York. New York State Assoc. for Retarded Children v. Cuomo, Nos. 72 Civ. 356/7 (E.D.N.Y., Hon. Raymond J. Dearie) ("Willowbrook"). The NYCLU, with others, commenced the Willowbrook lawsuit in 1972 to correct the inhumane institutional conditions suffered by the residents of the infamous Willowbrook State School; *see generally* Beth Haroules, *50 Years After A Landmark Lawsuit, How Does NY Treat People with Developmental Disabilities?*, NYCLU, Oct. 19, 2022, https://www.nyclu.org/en/news/50-years-after-landmark-lawsuit-how-does-ny-treat-people-developmental-disabilities.

[2] *State Legislation Tracker: Major Developments in Sexual & Reproductive Health*, GUTTMACHER INSTITUTE, https://www.guttmacher.org/state-legislation-tracker (last visited Feb. 27, 2023).

[3] *After Roe Fell: Abortion Laws by State*, CENTER FOR REPRODUCTIVE RIGHTS, https://reproductiverights.org/maps/abortion-laws-by-state/ (last visited Feb. 27, 2023).

completely.[4] Meanwhile, a federal lawsuit in front of a judge known for his extreme rulings threatens the availability of mifepristone, the first of two drugs used in medication abortion in the United States, in all 50 states, including New York.[5] Because medication abortion accounts for more than half of all abortions nationwide,[6] this case could provoke yet another seismic shift in access to abortion care in this country.

The impacts of being denied abortion care are profound[7] and most deeply impact those who are already multiply burdened by systemic racism and economic injustice.[8]

Against this backdrop, New York is called upon to be a beacon. In the first state budget since the fall of *Roe*, New York must codify and fund an access agenda.

A. Fund Abortion Access

In 2019, the Reproductive Health Act created statutory protections for abortion care in New York. But the right to abortion is only theoretical for many people. Many New Yorkers lack the money necessary to pay for abortion care and to cover the costs of travel, lodging, childcare, and other expenses required to obtain that care.

And, because Medicaid reimbursement rates in New York have been stagnant for a decade and are significantly below the cost of providing care, providers actually lose money every time they provide abortion care.[9] Other access states, like California, Oregon, and Illinois,[10] have increased their reimbursement rates, and New York must do the same. The legislature should maintain the Governor's proposed increases for procedural abortion care and sexual family planning services. Importantly, though, the legislature must insist on increases to reimbursement rates for medication abortion care as well. As New York providers strive to meet the current moment, it is simply untenable to ask them to operate continually at a loss.

In addition, the legislature should include the Reproductive Freedom and Equity Fund (S.348-B/A.361-A) in its one house budget proposals and ensure that the measure remains in

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[4] Marielle Kirstein, Joerg Dreweke, Rachel K. Jones, & Jesse Philbin, *100 Days Post-Roe: At Least 66 Clinics Across 15 States Have Stopped Offering Abortion Care*, GUTTMACHER INSTITUTE, Oct. 6, 2022, https://www.guttmacher.org/2022/10/100-days-post-roe-least-66-clinics-across-15-us-states-have-stopped-offering-abortion-care.
[5] *See generally* Dahlia Lithwick & Mark Joseph Stern, *Dobbs Was Always Just the Beginning*, SLATE, Feb. 6, 2023, https://slate.com/news-and-politics/2023/02/abortion-pill-outlawed-single-judge-real-possibility.html.
[6] *Id*.
[7] *The Turnaway Study*, ANSIRH, https://www.ansirh.org/research/ongoing/turnaway-study (last visited Feb. 27, 2023).
[8] Liza Fuentes, *Inequity in US Abortion Rights and Access: The End of Roe is Deepening Existing Divides*, GUTTMACHER INSTITUTE, Jan. 17, 2023, https://www.guttmacher.org/2023/01/inequity-us-abortion-rights-and-access-end-roe-deepening-existing-divides.
[9] *SEE* TESTIMONY OF PLANNED PARENTHOOD EMPIRE STATE ACTS, TESTIMONY BEFORE THE JOINT LEGISLATIVE BUDGET HEARING ON HEALTH AND MEDICAID (2023).
[10] *Id*.

the enacted budget. The Reproductive Freedom and Equity Fund will establish a comprehensive, sustainable state program that will invest in providers, abortion funds, and logistical support funds – the ecosystem that makes access to care a reality in New York. In order to seed the Reproductive Freedom and Equity Fund, we urge the legislature to maintain the Governor's proposed $25 million in grant funding for abortion providers and add an additional $1 million to support abortion funds and logistical support funds. The need is great. For example, the New York Abortion Access Fund has already pledged $421,778 in the first two months of 2023. By comparison, they pledged $1.2 million in all of 2022.[11] The $1 million for abortion and logistical support funds would match New York City's investment[12] and is a fraction of what California and Oregon have committed to abortion and logistical support funds.[13]

Finally, the legislature should continue the $1 million legislative add for the family planning grant, because a holistic investment in family planning services and family planning is essential to ensure that New York's sexual and reproductive health care providers can continue to provide comprehensive care to meet this moment.

B. Access to Medication Abortion on College Campuses

The NYCLU supports ELFA Part C, Ensure Abortion Access at Public College Campuses. As New York providers face an influx of people traveling from hostile states for abortion care and wait times for appointments tick up, expanding access on campus will better meet the needs of SUNY and CUNY students and reduce pressure on nearby providers. And, we appreciate that the Governor's proposal includes community colleges. At the same time, in order to ensure that this provision is effective, we encourage the legislature to make sure that SUNY and CUNY campuses receive funding for implementation and to create standards for referrals to community providers to account for distance, transportation, and other concerns to make sure that these referrals support students and result in access.

C. Safeguard Abortion Access through Data Privacy Protections

The NYCLU is also pleased that the Governor is focusing on the intersection of privacy and abortion in HMH Part U. As hostile states seek creative ways to prosecute people for their pregnancy outcomes, because they helped someone to seek or receive abortion care, or

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[11] E-mail from Chelsea Williams-Diggs, Interim Executive Director, NYAAF, to NYAAF's email list (Feb. 23, 2023, 16:23 EST) (on file with the author).
[12] Press Release, New York City Council, Speaker Adrienne Adams, First-Ever Women Majority New York City Council Announce Largest Commitment of Municipal Funds by Any City in U.S. to Support Increased Access to Abortion Care (Sept. 13, 2022) (https://council.nyc.gov/press/2022/09/13/2254/#:~:text=City%20Hall%2C%20NY%20%E2%80%93%20Council%20Speaker,city%20in%20the%20United%20States).
[13] S.184, 2021-2022 Reg. Sess. (C.A. 2022) (commits $20 million to the Abortion Practical Support Fund); H.5202 2022 Reg. Sess. (OR 2022) (commits $15 million to the Reproductive Health Equity Fund).

because they have provided abortion care, New York is right to center patient, provider, seeker, and helper privacy. Part U proposes a partial solution.

The first part of Part U prohibits any entity headquartered or incorporated in New York from responding to a warrant from another state when the entity knows or should know that the warrant relates to reproductive health care unless the warrant is accompanied by an attestation that it does not relate to investigating or prosecuting that care. This provision is likely to help around the margins – for entities that want to do the right thing or for entities that are only located in New York. For multi-state companies, it will be easy for the hostile state to bypass New York's protections by simply serving the warrant in another state. Although Part U gives the Attorney General enforcement authority, were she to sue in this circumstance, it may have the unintended consequence of provoking an entity to move their headquarters and incorporation elsewhere. While this provision is likely worth maintaining for its limited use cases, it is no substitute for the sort of health information privacy bill that has been proposed in both chambers and that is still being workshopped.

The second part of Part U prohibits geofence advertising around health care facilities. This prohibition is valuable.[14] At the same time, as currently drafted, it is unlikely to be effective and may have unintended consequences. This is because as drafted, it only reaches first party advertisers – where the advertiser makes the geofence and serves the ad themself. The vast majority of geofence advertising, by contrast, is third party advertising – where an advertiser contracts with an intermediary to make the geofence and serve the ad. Both types of geofence advertising should be covered in Part U. Second, the proposal does not carve out the health care facilities themselves and has no geographic boundaries. This would have the effect of preventing a health care facility from advertising within its own community and, moreover, might have the unintended consequence of preventing all location-based advertising in a health care facility dense area like Manhattan, because any geographic boundary is likely to include a health care facility. The language should be amended to include a vicinity requirement articulating the distance a geofence must be from a clinic to qualify for Part U's prohibition.[15]

D. Temporary Permits for Out-of-State Medical Professionals

The NYCLU supports HMH Part W's proposal to allow "high need" medical professionals licensed in another state to practice under the supervision of a New York-licensed provider while their New York licensure application is pending. We encourage the legislature to ensure that this provision includes abortion providers. As clinics in hostile states go offline,

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[14] *E.g.* Christina Cauterucci, *Anti-Abortion Groups Are Now Sending Targeted Smartphone Ads to Women in Abortion Clinics*, SLATE, May 26, 2016, https://slate.com/human-interest/2016/05/anti-abortion-groups-are-sending-targeted-smartphone-ads-to-women-in-abortion-clinics.html.

[15] *See*, *e.g.* Assurance of Discontinuance Pursuant to G.L. 93A, §5, *In the Matter of Copley Advertising, LLC, & John F. Flynn* (Mass. Supp. April 4, 2017), *available at* https://www.huntonprivacyblog.com/wp-content/uploads/sites/28/2017/04/nDP.pdf.

there may be abortion providers in those states who would come to New York to provide care. Allowing provisional licensure for these providers will help to ameliorate a provider shortage and respond to the acute need to meet the current moment.

Fifty years ago, New York first opened its doors to people from across the U.S. who needed abortion care. New York first legalized abortion in 1970, three years before *Roe v. Wade*, and posted billboards at our state borders advertising that abortion was legal and accessible here. Now, eight months after the *Dobbs* decision and as we await a court decision that could end the new supply of mifepristone in the United States, New York is again called to be a beacon of access. By creating sustainable and adequate funding for abortion providers, abortion funds, and logistical support funds, and by strengthening and passing the aforementioned policy proposals in the FY2024 budget, New York can continue to meet the moment.

II. OPWDD Should Not Be Permitted to Spend Another Five Years "Studying and Exploring" Whether New Yorkers with I/DD Should Receive Services in a Risk-based Long-Term Managed Care Service Delivery System: HMH EE. "OPWDD Managed Care Statute Extender."

The NYCLU does not support HMH Part EE's proposal to grant a further five-year extension of OPWDD's authorization to move the system of services for people with I/DD to a risk-based Medicaid managed care funding system.

One of former-Governor Andrew Cuomo's first acts when elected governor was to establish a Medicaid redesign team that recommended, among other proposals, the adoption of a managed-care model for delivery of long-term services to all New York State Medicaid beneficiaries with disabilities. This service delivery model is intended to replace the traditional fee-for-service model that has long been used for delivery of services to individuals receiving Medicaid-funded services.[16]

Two principal factors motivated New York's movement into risk-based managed care for Medicaid beneficiaries with disabilities. First, New York sought both to reduce Medicaid spending and to make such expenditures more predictable. Second, the state claimed risk-based managed care would improve the delivery and quality of care, particularly for individuals who require complex and costly services. New Yorkers with I/DD have been exempted from this managed care – in recognition that managed care for long term supports and services has not been well understood and required significant study. But for over a decade, the state has made significant changes to managed care under the guise of reform

[16] *See DOH: About the Medicaid Redesign Team*, available at https://health.ny.gov/health_care/medicaid/redesign/aboutmrt.htm.

and terminated, reduced, or eliminated critical services for an untold number of New Yorkers with other disabilities.[17]

Risk-based managed care for New Yorkers with I/DD is inappropriate for a number of reasons. First, when delegating functions to a managed care organization, New York cannot cede its obligations under the state constitution to vulnerable individuals with I/DD who require long-term services. The State must ensure that constitutionally mandated services and care is provided. What's more, New York is required under federal Constitutional law, and Medicaid standards, to ensure that services provided to Medicaid beneficiaries with disabilities are responsive to the individual choice of these individuals and that these services are based upon a "person-centered" plan an delivered in the least restrictive setting appropriate to an individual's needs. Cost-containment standards may lead to the institutionalization of persons for whom community-based services is the appropriate setting.

Second, New York has been exploring the possibility of managed care for people with I/DD for over ten years. While New York State may consider that moving the I/DD population into a managed care system will control costs and even effectuate cost savings, there is very limited data to demonstrate that implementing managed care for the I/DD population will actually produce any savings.

For example, in 2019, the Texas Health and Human Services Commission engaged Deloitte Consulting LLP ("Deloitte") to evaluate the cost-effectiveness of transitioning the Texas fee for service programs for I/DD LTSS to managed care.[18] Deloitte conducted extensive research and collection of publicly available data from other states that have experience with I/DD MLTSS to inform their assessment of the potential fiscal impacts in Texas. Deloitte concluded, amongst other things, as follows:

> While general increased access to care could decrease expenditures through improved health outcomes for members, it is not apparent that the increase in access is consistent across all populations and managed care programs. Similar to the findings on access to care, cost data on quality outcomes are not readily available and have varied results. Over the past several years, some small case studies have indicated

[17] It has long been recognized that shifting service delivery systems into long term managed care to effect cost savings harms both the people who depend on services, as well as the direct support providers, or staff, who provide those services. The commentary, and testimony on this topic before this Legislative body, has been extensive over the years. As but a few examples, s*ee e.g., Mis-Managed Care: Fair Hearing Decisions on Medicaid Home Care Reductions by Managed Long Term Care Plans*, Medicaid Matters New York and New York Chapter National Academy of Elder Law Attorneys, Inc., July 2016, available at https://ilny.us/phocadownload/Report-on-Medicaid-Home-Care-Reductions-in-New.pdf; *Wage Parity for Home Care Aides*, PHI Medicaid Redesign Watch, available at https://www.phinational.org/wp-content/uploads/legacy/research-report/medicaid-redesign-watch-1.pdf.

[18] As OPWDD and DOH are aware, Deloitte is intimately involved with New York State as a contracted health actuarial services consulting partner.

> improved quality and outcomes in managed care with care management techniques by plans. Research conducted in five states that have implemented managed care programs indicated that "anecdotal evidence suggests" savings could be realized through implementation of effective care management techniques. Limited research has been conducted with people with more complex needs, however, such as individuals with I/DD and older persons. [19]

The OPWDD service delivery system is confronting a critical shortage of staff; an inability to serve those with complex needs; a shortage of residential opportunities; a growing population of unserved and underserved; and an aging population requiring more services. The transition to managed care for people with I/DD certainly does not appear to address any of these critical systemic challenges and, indeed, may exacerbate these issues.

As both OPWDD, and DOH, are aware, the ongoing uncertain rollout of the Medicaid managed care and the "rate rationalization" system, which DOH and OPWDD negotiated with CMS have resulted in increasing uncertainty in the OPWDD service system and significant changes to the quality and range of services afforded people who require OPWDD's services. The COVID-19 pandemic only led to further deterioration in the residential providers' fiscal circumstances and ongoing destabilization of the service delivery system.

Although OPWDD has indicated it intends to invest additional ARPA funding to "studying and exploring the potential effectiveness and sustainability of our current and other delivery models, like managed care,"[20] their studies have been ongoing for over a decade. Extending OPWDD's authorization to continue to "study and explore" long term managed care will only

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[19] *See, e.g.*, IDD LTSS Carve-In Cost-Effectiveness Evaluation – Final Report Prepared for: Texas – Health and Human Services Commission (HHSC) HHSC Contract No. 529-15-0009-00001 | Request Number: 00021-R3
Version Dated: January 11, 2019, available at https://hhs.texas.gov/sites/default/files/documents/about-hhs/communications-events/meetings-events/idd-srac/feb-2019-idd-srac-agenda-item-2.pdf, at pg. 16.
The Medicaid and Chip Payment and Access Commission ("MACPAC"), a non-partisan group of experts, convened pursuant to the Social Security Act (42 USC §1396), also concluded in 2021: "While much research has been conducted on whether Managed Care delivery systems result in better outcomes than fee for service (FFS), there is no definitive conclusion as to whether managed care improves or worsens access to or quality of care for beneficiaries." *See Managed Care's Effect on Outcomes,* MACPAC, available at www.macpac.gov/subtopic/managed-cares-effect-onoutcomes.

[20] *See OPWDD 2023-2027 Strategic Plan Document,* available at https://opwdd.ny.gov/system/files/documents/2022/11/opwdd-2023-2027-strategic-plan-final-with-links.pdf. See also *New York State Office for People With Developmental Disabilities (OPWDD) Managed Care Assessment Initial Report*, Guidehouse December 28, 2022, available at https://opwdd.ny.gov/system/files/documents/2023/01/nys-opwdd-managed-care-assessment.pdf. The Guidehouse report offers nothing in terms of recommendations, merely providing a historical summation of the uncertain trajectory of OPWDD towards a long-term managed care service delivery system. Guidehouse does promise a final report, to issue in Spring 2024, which will include very rudimentary information, including an overview of other locales' experiences with managed care,

result in delaying any effort to implement other changes to the service system in order to ensure the needs of people with I/DD and the workforce supporting them will be met.

III. 340B

Finally, we understand that Governor Cuomo's carve-out of the Medicaid pharmacy benefit program from managed care to fee-for-service is scheduled to go into effect on April 1. If the 340B changes go forward, safety-net providers statewide stand to lose $240 million per year. This will undermine their ability to provide care for uninsured and underinsured people, including undocumented people. It will undermine access to care and services that are not reimbursable through Medicaid, including care coordination for people living with HIV, food banks, and transportation to appointments for people who are not eligible for transportation through Medicaid. In fact, nearly every community health center that provides COVID vaccines does so through 340B funding, and their ability to continue to provide vaccines might be threatened. For these reasons, the NYCLU urges the legislature to either permanently repeal the Medicaid pharmacy benefit carve-out or include in the one house budget proposals the alternative advanced by Health Committee Chairs Rivera and Paulin.

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The NYCLU thanks the Legislature for the opportunity to provide testimony and for your work on the budget.

OPWDD's programmatic goals, and recommended next steps for selection and implementation of a service delivery model.